Integrating Wellness into Health Care and Public Health Practice for Individuals with Recently Acquired Disability and Those Accessing Healthcare Services Due to a New Secondary Health Condition

## STRATEGIC DIRECTIONS AND POLICY RECOMMENDATIONS

January 2020

Funded by the Centers for Disease Control and Prevention Grant # 6NU27DD001157



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## I. EXECUTIVE SUMMARY

One in four adults, or an estimated 61 million Americans, report living with a disability (CDC, 2019). This statistic covers between 18-20% of the US population making it the nation's largest minority group most often prone to differential treatment. This demographic group is intersectional as it cuts across racial, ethnic, age and gender lines. As a nation, we have failed to address the societal responsibilities and barriers that prevent individuals with mobility disability from leading healthy, active lives. We have not achieved health equity. Individuals with mobility disability – both recently acquired and existing for many years – are rarely directed to wellness programs by their healthcare providers, who have high patient loads and must focus their encounters on immediate medical services such as discussing new and existing health conditions, recommending additional diagnostics, and/or prescribing medications.

Society at large has failed to address the huge gap between the U.S. healthcare system and the public health community that the individual returns to after acquiring a disability, being diagnosed with a new health condition such as multiple sclerosis or Parkinson, or having a disability and reentering the healthcare system with a new secondary health condition (e.g., pain, depression, pressure ulcer). The public health community is often underprepared to support the needs of these individuals and to include them equitably in wellness programs (e.g., recreation, leisure, proper nutrition, stress management) offered to the general community. Consequently, the vast majority are unable to make the transition from "rehabilitation patient" to "wellness participant."

This strategic plan addresses the existing gap in continuity of care for patients with mobility disability as they transition through the stages of medical treatment, co-managed care, and self-managed wellness. It addresses the existing financial, cultural, social, and environmental barriers to continuous self-managed wellness for the following populations:

- Individuals who have recently acquired a disability;
- Individuals who have recently been diagnosed with a health condition that is likely to result in a disability and;
- Individuals with existing disability who have recently accessed the healthcare system with a new secondary health condition.

We offer a plan to create a **continuum of care** that will make it easier to connect these individuals to wellness activities and resources, which can help them develop and sustain their own self-managed health and well-being. In addition, we propose new strategies of community engagement to build a network of organizations and institutions committed to long term wellness for individuals with mobility disability.

# II. HOW THE PLAN WAS CREATED

This strategic plan reflects the priorities and long-term objectives of the UAB-Lakeshore Foundation Research Collaborative, created in 2009 to develop a world-class research program in health promotion and rehabilitation science. UAB is an internationally renowned research university and medical center, and Lakeshore Foundation is an international leader in enabling people with physical disability and chronic health conditions to lead healthy, active, and independent lifestyles through physical activity, sport, recreation, advocacy, policy, and research. The UAB-Lakeshore Foundation Research Collaborative conducts and promotes comprehensive health and rehabilitation science research to establish the effectiveness of current programs and services, and to seek better and more effective ways for improving the quality of life of people with disabilities.

Two separate committees of researchers and thought leaders in the fields of health administration, public health, and rehabilitation science were convened to study barriers to wellness initiatives for the target population. As noted previously, the target population consists of three subgroups, each of which is anchored by their need for healthcare services. The subgroups consist of individuals who have (a) recently acquired a disability requiring hospitalization (e.g., stroke, spinal cord injury, brain injury); (b) been diagnosed with a new health condition (e.g., multiple sclerosis, Parkinson); and (c) an existing disability and are accessing healthcare services for a recent medical event (e.g., pressure ulcer, urinary tract infection, pain).

The committees were tasked with identifying the current challenges to community-based health promotion (i.e., wellness), the unique needs of the target population, and the existing barriers that prevent them from accessing wellness initiatives. Both committees developed a personcentered continuum of care that focused on increasing access to wellness/health promotion for this underserved group. Each committee had a specific emphasis. One committee focused on removing barriers to wellness initiatives at the health provider level through analysis of the existing health care delivery system and its limitations. The other committee focused on removing barriers to wellness initiatives at the community engagement level.

Each committee created its own set of proposals that focused on enabling the target group to self-manage or co-manage their post-healthcare/post-rehabilitation wellness. Each document aimed to close the gaps in the existing continuum of care. Both were created in collaboration with experts who have a disability and are currently working in the field. The concept of "nothing about us without us" was a central theme during the planning and creation of this strategic plan. The inclusion of the lived experiences of PWD from conception to implementation enhances a program's effectiveness. Not only is it likely to increase adherence to the program, thus improving outcomes, it will also contribute to generalizability to a wide audience of PWD. Several members of the committee had a disability.

This document integrates these two proposals into one comprehensive plan to provide specific solutions to existing barriers at both the community and health service provider levels. This

integrated strategic plan seeks to create a formal network of community wellness providers, supported and guided by the National Center on Health, Physical Activity and Disability (NCHPAD), to close the existing gap in the continuum of care for patients who have recently accessed the healthcare system for care related to a new or existing disability. Founded in 1999 as a public health practice and resource center on health promotion for individuals with disability, NCHPAD's objective is to assure health equity by providing information, referral and consultation services, and training to individuals with disability, their families, policymakers, health care practitioners, public health professionals, and community members. NCHPAD is home to numerous activities that support wellness.

# **III. EXPLANATION OF PROBLEM**

Our current system for funding quality health care for those with a recently acquired disability is broken. Patients experience fragmentation of care between individual acute care providers, and they lack access to wellness initiatives that could dramatically increase engagement in their own care while improving quality of life and well-being (Bodenheimer, 2008; Shih et al., 2008).

Consider an individual with a recent spinal cord injury (SCI). This individual is likely to require care from several different providers in an acute care hospital and in an inpatient rehabilitation facility. Each provider is reimbursed separately using different methods of reimbursement. Providers are responsible for well-defined portions of a patient's care (e.g., acute care only, rehabilitation care only) but have little financial incentive to coordinate care across provider types (Ackerly & Grabowski, 2014; Mechanic, 2014). New providers frequently lack information about patients' conditions, and patients are often unaware of how their care is changing (Tulsky et al., 2017). As a result, transitions in care for patients with recently acquired disability are problematic. This fragmentation becomes even more pronounced as a patient with a mobility disability is directed (or fails to be directed) to programs and resources that can promote their overall wellness but for which reimbursement from payers is not available.

The inability of individuals with mobility disability to readily access wellness resources likely contributes to an increased prevalence of acute secondary conditions that result in higher costs for private and public health insurers. The costs of these secondary conditions are substantial. For instance, the cost of unplanned hospitalizations for persons with SCI averages \$20,583 per hospitalization, and almost a quarter of persons with SCI experience at least one hospitalization per year (DeVivo & Farris, 2011). Even relatively mild secondary conditions can have sizable cost implications. One study found that the adjusted cost of hospitalizations for ambulatory care sensitive conditions (ACS) for elderly Medicare beneficiaries was \$799 for people without a disability. This cost increased by \$5,513 for those with a disability and by \$8,557 for individuals with a severe disability (Pezzin et al., 2018).

Among individuals with mobility disability who are also obese, the annual cost of care is \$1,107 higher than individuals with similar disability who are of normal weight (Peterson & Mahmoudi, 2015). When compared to the average index cost admission for any diagnosis (\$12,500), these examples represent significant and costly increases (Bailey et al., 2019). Wellness interventions for these patients have the potential to prevent secondary conditions, improve quality of life and well-being, and reduce the cost of care. Despite this potential, private and public health insurers have shown reticence to reimburse for wellness care directly.

Wellness interventions for individuals with mobility disability have the potential to prevent secondary conditions, improve quality of life and well-being, and reduce the cost of care.

# CURRENT BARRIERS TO SELF-MANAGED WELLNESS FOR INDIVIDUALS WITH A RECENTLY ACQUIRED DISABILITY, DIAGNOSIS OR NEW SECONDARY HEALTH CONDITION

There are many internal and external barriers that inhibit individuals who have acquired or been diagnosed with a disability from engaging in wellness activities that can help them self-manage their health. This plan aims to close these gaps by eliminating certain barriers that prevent lifelong self-managed wellness. A few examples of these barriers are described below.

#### **Internal Barriers**

Studies have shown that recovery after a traumatic injury or health event is greatly improved through use of a variety of wellness activities including exercise, proper diet, mindfulness, building new relationships, and spiritual practice. Unfortunately, the current cultural mindset has been structured around a medical model focused on curing disability rather than living a fulfilling life with disability. Patients may focus only on the hope of recovery, which has been perpetuated by the medical model, rather than on the potential for maintaining health and life satisfaction while living with a disability. People with a recently acquired disability or new diagnosis may perceive their condition as a limitation in self-managing their health. They may have few role models to emulate and lack access to an active group of peers. Many patients may become socially isolated leading to a deficit of self-managed wellness skills. Socially isolated individuals present higher risks of morbidity and mortality from all causes of disease/chronic conditions.

#### **External Barriers**

Several barriers at the community/societal level prevent individuals with mobility disability from achieving self-managed wellness. Individuals may lack social support from community members, friends, or family. They may be perceived by others as unable to participate in wellness or uninterested in doing so. Health promotion and wellness initiatives developed for community members may not be adapted to fit the needs of people with disabilities. Exclusion from exercise and physical activity is the norm for most individuals, despite evidence suggesting that they have the greatest potential health benefits from such activities. Staff providing services to people with

disabilities (PWD) may be inexperienced and need resources and training on how to create a healthy community that is fully inclusive. And, many health and fitness centers have limited accessibility to individuals with mobility disability.

Physical access to such services such as transportation and sign language interpreters is also limited. Public transportation services offer, at best, unequal options for people with mobility disability.

The existing health care system is not designed to support these patients in an integrated manner as they transition through the stages of care from initial injury or diagnosis to lifelong health and wellness. Despite the general availability of resources, targeted support for PWD to maximize health and wellness is lacking. Information on wellness initiatives is not adequately integrated into the health care system. Healthcare providers routinely advise patients about the health benefits of exercise and diet but rarely offer PWD similar advice or recommend wellness programs for them. Most resources about wellness in doctor's offices do not represent many PWD. Information on wellness initiatives is rarely available when an individual acquires a disability or when an individual with an existing disability acquires a new health condition.

Information about long-term sustainable wellness for individuals with recently acquired disability, diagnosis, or an existing disability with a new health condition exiting the healthcare system is also frequently unavailable at times when patients are ready to begin engaging in wellness promotion. In the acute care setting, the emphasis is on medical management (Arcilla et al., 2019). This can be an overwhelming time for patients and their families.

Financial barriers also prevent many individuals from benefiting from wellness initiatives. Even when individuals can become connected to appropriate wellness programs, the cost to participate can be prohibitively high. For many patients, transportation costs to access wellness programs and facilities are also prohibitive. Private and public payers have been willing to reimburse for medical treatment but unwilling to reimburse for non-medical services that could contribute to the well-being of individuals with disability.

# IV. INFORMATION ACQUISITION FROM EXPERTS

A consulting firm was hired to conduct one-on-one interviews with nine key stakeholders and critical partners to inform the strategic planning process (Table 1). The group was selected based on their background in healthcare, rehabilitation, health promotion, or disability services.

Table 1. List of Experts

1	Casey Azuero, PhD, MPH	UAB School of Medicine, Dept. of Physical Medicine & Rehabilitation
2	Monica Baskin, PhD	UAB Dept. of Medicine, Division of Preventative Medicine
3	Gareth Dutton, PhD	UAB Dept. of Medicine, Division of Preventative Medicine
4	Gary Edwards, PhD	CEO, United Ability

5	Will Ferniany, PhD	CEO, UAB Health System
6	Amie McLain, MD	UAB School of Medicine, Dept. of Physical Medicine & Rehabilitation
7	Jan Troncale, RN	UAB School of Medicine, Dept. of Physical Medicine & Rehabilitation
8	Jeff Underwood	President & CEO, Lakeshore Foundation
9	Eric Wallace, MD	UAB Dept. of Medicine, Division of Nephrology, Director of Telehealth
		Medicine

Interviewees were asked to share their knowledge about the unique needs of the target population, opportunities to improve care for the target population, and challenges for implementing a healthcare-to-wellness program. The following themes emerged from the interviews:

- The healthcare system is structured upon a medical model of curing illness instead of improving well-being, and this model limits care for PWD who are not "sick" in conventional medical terms.
  - "We have to begin by telling people that they are not 'sick.' They have a disability which is quite different from the 'sick' model of health care that we have been accustomed to."
  - This group needs to understand the wellness versus sick model. We need to begin this process early on, because they have to learn how to take care of themselves."
- Individuals with mobility disability need ongoing education to understand their condition and possible limitations, and immediate caregivers need training to provide quality care and maintain their own well-being:
  - "It is critically important for patients and their families/social networks to understand their condition and any possible limitations. The other thing is to have information on the trajectory of a condition/prognosis to better help individuals see what role the diagnosis plays in their overall lifespan."
  - "Education, support, and problem solving are not unique to these populations, necessarily, but perhaps more intensive. For newly acquired disabilities, this group has a unique need in terms of understanding the resources available. Also, for those with a newly acquired disability, they have unique needs to connect with vocational rehab."
  - "Caregivers' health issues are also a burden on the health system, so they should be included in any of the offerings for health and wellness and this type of platform could be the method for including them"
- 3. Education about wellness for PWD must also target policy makers, health service providers, and the general public.
  - "Education has to be not only to the patients but also to policymakers and healthcare providers. Traditionally the doctor just says, 'you need to lose 5 pounds,' with no real follow-up or referral or resources, and we need to find a way to go beyond that somehow."

- "We need to get the message out that obesity is a major complicating factor for people with disabilities, and it needs to start sooner than adulthood."
- 4. Telehealth offers an innovative way to expand medical and wellness services for PWD.
  - "Access restrictions and financial limitations make telehealth very important for this population. This population would significantly benefit from being able to access medical care without having to physically get themselves to Birmingham."
  - "I think the greatest opportunity will be where telehealth services intersect with patient care. This could happen by introducing telehealth when a patient is in the hospital, moving to telehealth in the home which would include patient monitoring and telehealth home visits and then could eventually move to having telehealth providers (non-MDs) supporting the patient in health and wellness (nutritionist, health coaches, etc.)."
- 5. Coordinated and integrated individually-tailored wellness plans are difficult to execute but critical for improving health outcomes for PWD.
  - "Right now, everything is still pretty piecemeal. The different systems are barriers. The disabled population needs doctors and practitioners working in a team and talking about their care."
  - "They need interventions that are specific to their needs. There are a lot of variations to that. In the world of people with disability (physical, visual, cognitive, etc.) there isn't one approach that will be effective in education or intervention. Also, folks who have a disability need to be included in the development of these interventions so we can be sure interventions are as relevant as possible."
  - "Time is a challenge in creating health wellness programs. Making individualized, tailored plans for each person and having the time to really connect them with resources is a challenge."

This strategic plan addresses many of the challenges, barriers, and opportunities articulated by stakeholders in these one-on-one interviews. Our goal is to enable patients to transition out of healthcare/rehabilitation services into a sustainable healthy lifestyle that uses several domains of wellness to lower the risk of preventable health conditions, reduce healthcare utilization, and promote higher quality of life.

We propose building on existing programs and resources currently offered by NCHPAD and the UAB-Lakeshore Foundation Research Collaborative.

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## V. GUIDING FRAMEWORK TO ENSURE LONG-TERM SUSTAINABILITY

The creation of this strategic plan was based on a guiding framework that was aimed at facilitating a positive transition from healthcare to wellness for patients exiting the healthcare system. The plan emphasizes the need to build this framework into a sustainable and scalable infrastructure so that it is readily accessible to the tens of thousands of patients with disabilities who are discharged annually from hospitals and healthcare services and are in dire need of precision-based, publicly available wellness services/programs in their communities and homes.

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The committee recommended leveraging the existing infrastructure of the National Center on Health, Physical Activity and Disability (NCHPAD) rather than creating a completely new center that would have limited sustainability and scalability. NCHPAD has been in operation for 20 years and has the built-in infrastructure to ensure that recommendations of this strategic plan can be put into operation almost immediately.

In the development of this strategic plan, we consulted two theory-based frameworks—CDC's Socio-Ecological Model (SEM) and NCHPAD's N-KATS framework for knowledge transfer—to guide the development of this strategic plan. Both SEM and N-KATS have framed our approach towards enacting systems-level change to achieve inclusion of PWD in public health initiatives.

## The Socio-Ecological Model (SEM)

The SEM provides a model for understanding the multifaceted and interactive personal and environmental factors that influence and shape individual behavior across four sociological levels: individual, relationship, community, and societal. Systematic analysis of the experiences of PWD at each of these four sociological levels provided a context for developing a holistic approach to the inclusion of PWD into the existing health community. In our analysis, we identified existing barriers, challenges,

Societal Community Relationship Individual

Figure 1. The Socio-Ecological Model

unique needs, and gatekeepers at each of these four levels of the SEM that currently prevent PWD from experiencing full inclusion in community wellness and public health initiatives.

The emphasis of this strategic plan is to build infrastructure for inclusive public health initiatives at the community level of the SEM model, which is essential for the long-term sustainability of any wellness program. Many organizations are starting to promote greater levels of accessibility and inclusion but there is a still a long way to go. The buy-in and resources allocated to the community level will contribute to systems-level changes that can endure if appropriate care is taken to develop and maintain strategic partnerships with community organizations and institutions that can enable inclusive public health programs to grow. To meet identified needs at the community level, we provide a comprehensive community engagement plan to educate and train health service professionals and community-based service providers about the specific needs of the target population, the existing barriers that prevent PWD from fully participating in wellness initiatives, and the benefits of a comprehensive healthcare-to-wellness program for their long-term well-being.

## Knowledge Adaptation, Translation, and Scale-Up (N-KATS)

To operationalize this strategic plan, the committee was guided by the N-KATS (Knowledge Adaptation, Translation, and Scale-up) framework for knowledge transfer, designed to ensure that inclusive programs are successful in reaching and engaging the target group, are able to achieve intended outcomes, and have some level of sustainability. This knowledge-to-practice framework, developed by NCHPAD in association with Dr. Ian Graham, an international leader in knowledge translation, was designed to systematically build, advance and apply evidence-based knowledge to the creation of inclusive programmatic, policy, systems and environmental (PPSE) changes across each level of the SEM to reduce health inequities in PWD.

The N-KATS framework maps out a collaborative, dynamic process of knowledge acquisition and knowledge transfer, by which NCHPAD can simultaneously support and gain further knowledge acquired through various health professionals engaged in the process who function as knowledge brokers, facilitators, and users.

As the diagram below illustrates, the N-KATS framework includes four sequential phases (Figure 2). These four phases—knowledge adaptation; knowledge uptake; knowledge utilization; and knowledge evaluation, update and maintenance—provide a process for NCHPAD to translate and disseminate "customized knowledge" to health/rehabilitation professionals for application in specific programs and contexts. The successful implementation of an inclusive wellness program through the N-KATS framework—by disseminating and using customized knowledge in an applied manner—produces further customized knowledge, in the form of "best practices," which can be used in future iterations of program implementation.

Figure 2. N-KATS Knowledge-to-Practice Framework



## VI. THE APPROACH

# APPLICATION OF THE N-KATS FRAMEWORK IN PROMOTING COMMUNITY-BASED WELLNESS IN THE TARGET POPULATION

Given the challenges associated with identifying critical resources necessary for building a seamless healthcare-to-wellness network for the target population (i.e., people with recently acquired disability/diagnosis or those with an existing disability and new secondary health condition requiring medical care), the committee recommended that such a system be built upon existing resources. In particular, there was a recommendation to integrate the work proposed in this strategic plan within NCHPAD's Inclusive Health Coalition (IHC) infrastructure, which began in 2012.

The N-KATS implementation science framework has guided the development of this strategic plan, which outlines a community engagement strategy to build a coalition of partners at the community level of the SEM that can support implementation of wellness services and health coaching. Below, we summarize how each of the four N-KATS phases should guide program development and implementation and how buyin at the community level will help support patient/participant access to the new healthcare-to-wellness program.

Phase I: Knowledge Adaptation: **PPSE** Adaptation and Communication. Knowledge adaptation is the systematic process of taking evidence-based information and adapting it for use in a specific context. During this phase, NCHPAD's Expert Information **Specialists** identify and collect new evidence- and practicebased knowledge associated with programs similar in nature. The information is then customized into а set of Guidelines, **Recommendations and Adaptations Including**  Inclusive Health Coalitions (IHCs) are diverse groups of community leaders and organizations focused on promoting disability inclusion in programs and services related to physical activity, nutrition and obesity. Coalition efforts focus on the removal of barriers that prevent PWD achieving the same health transformation opportunities available to community members without disability through the creation and modification of community health programs, policies, systems, and environments.

**Disability** (referred to as **GRAIDs**) and placed on a web-based platform available to IHCs and community service providers across the U.S. The GRAIDs provide program leaders with a set of options that allow for customization to the local community and end user.

Communication resources are also created during this phase and customized to the target group and their family members, and gatekeepers who can refer patients to the program (e.g., physical

and occupational therapists, physicians, physician assistants, nurses, other healthcare practitioners). Video content is a critical feature of communication development. A growing number of companies and media outlets are using more video and less text, or some combination of both, to reach target audiences.

**Phase II: Knowledge Uptake: Dissemination and Training.** An extensive dissemination network should be created to ensure that the target group and their family members, and key stakeholders in healthcare and rehabilitation, are made aware of the program. IHCs should also guide training and education activities targeting those who might contribute to the program and those who can raise awareness for the program's need across the broader community. This work can also lay the groundwork for identifying the most effective recruitment strategies to reach the target audience.

Phase III: Knowledge Utilization: Implementation Facilitation. This phase encompasses the actual implementation of a healthcare-to-wellness program in local communities. IHCs can lead this phase of implementation starting with recruitment of new members. Members of the IHC should include stakeholders and gatekeepers with varying types of disability, caregivers and family members of PWD, organizations serving PWD, healthcare service providers, and public health professionals. Shared decision-making among these individuals makes it much more likely that the program is both applicable to the community and sustainable.

NCHPAD can assist IHCs in an intentional process of knowledge translation through training of disability and health state grantees, who subsequently can coordinate training healthcare and community-based service providers to facilitate implementation of the program. NCHPAD's inclusive Community Implementation Process (NiCIP) provides a set of four stages for supporting community adoption and implementation of the program in a structured and systematic format. Through the NiCIP, the IHC is responsible for identifying and removing barriers to the implementation of the healthcare-to-wellness program.

**Phase IV: Knowledge Evaluation, Update and Maintenance: Sustainability.** The final phase is used as a system of accountability and evaluation to monitor the program's performance and effectiveness. The program must be continuously monitored and evaluated to ensure it is meeting the needs of the target population within the community context. It is also important to document the process of implementation and impact. This information can be applied to other communities that aim to implement similar programs. As the program is evaluated and areas of improvement are identified, the findings can be added to the adaptation process in Phase I and may be defined as successful "best practices."

# VII. A NEW EVIDENCE-INFORMED HEALTHCARE-TO-WELLNESS PROGRAM FOR THE TARGET POPULATION

The strategic planning committee acknowledged that a specific wellness program tailored to the needs of the target population was necessary for the plan's goals to be achieved. Below is a description of a new program recently created by NCHPAD.



The MENTOR healthcare-to-wellness program (Mindfulness, Exercise and Nutrition To Optimize Recovery) was created to bridge the gap between healthcare and posthealthcare public health practice for individuals who have recently accessed the healthcare system for treatment

related to a new or existing disability or a condition likely to result in a disability. The program was established with CDC funding and a collaboration between Lakeshore Foundation, UAB School of Health Professions, UAB Department of Physical Medicine and Rehabilitation and the UAB Health System. In developing the MENTOR program, individuals from these institutions worked with a panel of nationally recognized healthcare and health promotion professionals to address barriers to health and wellness among individuals living with a physical disability.

MENTOR is considered a 'starter' program for patients exiting the healthcare system who are in need of a specific recovery process prior to joining a generic community-based wellness program. It offers access to home and community-based services and the opportunity to work with a health coach in promoting their own health. MENTOR's holistic approach is aimed at restoring, improving, and protecting health across the lifespan.

One of the primary outcomes of the MENTOR program is improving **resilience**, which refers to a person's ability to understand, cope, adapt and strive for a positive balance between gains and losses in health and function across their lifespan. Implementation of the MENTOR program is optimal when the individual and their support system recognize the importance of the program and there is a level of 'readiness' on the part of the individual to participate in the program. To make meaningful change in personal health and well-being, the individual is taught to understand

MENTOR's holistic approach is aimed at restoring, improving, and protecting health for individuals who have recently accessed the healthcare system for treatment related to a new or existing disability or a condition likely to result in a disability.

the importance of the required change in behavior and provided with the necessary support to change one or more health behaviors (Elliot, 2019).

The MENTOR program will be offered in two versions: (a) an 8-week onsite program for participants who live in close enough proximity to Lakeshore Foundation; and (b) an e-Health version for those who are geographically too far to travel to Lakeshore. The onsite version consists of a 2-day per week, 2-hour per

session program offered at Lakeshore and a 1-day per week 1-hour telecoaching call from a health coach. The program consists of several wellness domains (described below) including participating in various types of adapted exercise, sport and recreation activities; learning how to prepare healthy meals through various styles of cooking classes; and practicing mindfulness-based stress reduction techniques to reduce mental health issues such as anxiety and fear.

Each MENTOR participant is assigned a health coach who supports the onsite and online portions of the program. All participants receive a 'scorecard' that subdivides the MENTOR program into 11 evidenced-based wellness domains characterized under the acronym, MYSCORECARD. Each letter stands for one domain: Mindfulness, Your spiritual practice, Self-care skills, Core values, Outdoor time in nature, Relationships, Exercise, Contribution to others, Arts and Leisure, Rest and Relaxation, and Diet. Health coaches develop a customized program based on a baseline assessment and individual needs, and as the weeks progress, health coaches empower individuals to take ownership of their health and well-being. Various NCHPAD resources (text and video) are being created for each of the 11 MENTOR wellness domains. The online version will be offered in a similar 8-week framework through NCHPAD's e-Wellness platform.

# VIII. CONCLUSION

#### TRANSFORMING HEALTHCARE PATIENTS INTO WELLNESS PARTICIPANTS

The goal of this strategic plan, as well as the related NCHPAD initiatives, is to integrate individuals who have recently accessed the healthcare system with a new or existing disability into community programs and services that promote health and wellness. In the process, it aims to achieve parity and equity in access to public health initiatives. The plan proposes to build inclusive communities that enable PWD to self-manage or co-manage their health and wellness in their own communities. This can be accomplished by creating a system that supports a continuum of care for individuals transitioning from the inpatient to outpatient setting and from co-management to self-management of personal wellness.

This proposed system of care would enable the patient to transition from medically managed healthcare, to co-managed wellness (health coach-participant dyad), to self-managed wellness (participant only), with formal transitions between each of these levels using NCHPAD and MENTOR as the essential linkages.

Through these initiatives, people with disabilities will have greater access to, and inclusion in, community wellness programs and public health

We propose to create a system that supports a continuum of care for individuals transitioning from the inpatient to outpatient setting and from comanagement to self-management to personal wellness.

initiatives. Inclusion is a societal ideology that states that opportunities are intended to be equal for all people. This includes individuals with disability exiting the healthcare system who need a

community that promotes wellness in areas such as exercise, nutrition, outdoor activity in nature, and mindfulness.

# **REFERENCES**

Complete bibliography available upon request.

# **APPENDIX**

#### **DETAILED STRATEGIC PLAN**

#### TRANSFORMING HEALTHCARE PATIENTS INTO WELLNESS PARTICIPANTS

#### Expand the Mission of IHCs to Support Patient Transitions from Healthcare to Wellness

The first step in this strategic plan is to expand the role of existing Inclusive Health Coalitions (IHCs) currently served through NCHPAD. These IHCs are multi-stakeholder groups of community members working together to promote inclusion in all aspects of community life. Traditionally, IHCs have had the role of establishing partnerships between community health organizations to create accessible health programs and ensure that inclusion of PWD is a cornerstone in community health planning. IHCs have had a tremendous impact in the communities in which they operate. However, the primary area of focus for IHCs has been improving inclusion in the community at large.

IHCs offer an existing organizational structure that can support the provision of wellness services. By providing these services and engaging health care delivery organizations in the creation and dissemination of these programs, IHCs can make progress in creating a unique continuum of care that meets the needs of individuals who have recently accessed the healthcare system for treatment related to a new or existing disability.

IHCs can make progress in creating a unique continuum of care that meets the needs of individuals who have recently accessed the healthcare system for treatment related to a new or existing disability.

We propose that individual IHCs expand their missions to include a specific focus on patient transitions from healthcare to wellness, helping patients progress from medically managed care in which they receive services from health care providers, to full-fledged participation in long-term wellness. We suggest that existing IHCs, under the expanded mission, begin offering health coaching and wellness services based on the Lakeshore MENTOR model. IHCs will be tasked with making targeted outreach efforts to

individuals with recently acquired disability, new diagnoses or new health conditions requiring health care services. The goal of these new initiatives will be to engage patients earlier in their recovery process and to educate them about the new wellness services available through the IHCs.

The MENTOR program should be included as a primary focus of the IHC. MENTOR is aimed at reaching PWD in the home and community settings and targets two levels of the Socio-Ecological Model – the individual and relationships between the individual and community. IHCs will need

to engage local health care delivery organizations in the process of developing and delivering MENTOR wellness benefits.

We believe that IHCs will need to adopt a formal structure designed to ensure a seamless transition for the individual from healthcare to wellness. This new structure should have several features including the ability to connect different organizations involved in the care of individuals with disability. These groups include:

- Community-based organizations focused on wellness for PWD and the general public, such as fitness and recreation centers;
- Health care providers caring for individuals with disability;
- Community-based organizations that can provide supports for individuals with disability facilitating their participation in wellness activities (e.g., transportation—accessible ride share, taxis/cabs, buses; durable medical equipment providers; architects) and;
- Payers including commercial health insurers, government payers such as Medicare and Medicaid, state workers' compensation programs and private philanthropic organizations.

In addition, IHCs will need to have the flexibility to adapt to differences in local environments, the capacity to offer benefits that meet the unique needs of individuals with disability, and the ability to build relationships with large, national organizations that serve as thought leaders promoting and disseminating best practices in the wellness care of PWD. In order to meet this new or expanded purpose, an IHC may need to engage in activities to formalize its organizational structure such as writing a clear mission statement, receiving letters of commitment or memoranda of understanding, and documenting clear expectations of partnerships. As preliminary activities, we recommend that IHCs:

- > Identify whether existing groups share a focus on the health of PWD. If so, aim to collaborate with those that have an interest in this work.
- ➤ Identify diverse stakeholders to serve on the IHC. This should include PWD, caregivers, and gatekeepers identified at all levels of the SEM. It is critical that PWD and their family members are pivotal partners of the IHC. **PWD must be part of the coalition** and have an active voice.
- Establish and maintain commitment to the IHC and its mission. Think broadly about the mission. Groups interested in health equity, participation, increasing health of all populations, disability-specific interests, and social justice initiatives may offer unique input and serve as gatekeepers that can be engaged in this work.
- Formally partner with organizations that advocate and serve PWD to leverage their ability to encourage their members to participate in the program. IHCs should identify a specific contact within each organization and, if that individual leaves, identify another contact to serve in his or her place. IHCs will need to define objectives, outputs, or activities to be completed in collaboration with involved organizations to maintain connectedness to the program. For these partnerships to be successful, IHCs should establish a clear and regular

communication protocol for updates, needs, and successes of the program to maintain engagement with organizations.

We recognize that some IHCs may choose not to revise their mission for a variety of reasons. For instance, some may already be implementing other changes and may lack the capacity for a new initiative. For IHCs that do not pursue such an initiative, we suggest that the CDC designate a national coordinating organization like NCHPAD with the capability to deliver telehealth interventions and health coaching to IHC communities. We suggest that all IHCs initiate efforts to engage health care delivery organizations in their areas to promote wellness services to PWD as they are interacting with the healthcare system.

Ultimately, to fully address the existing barriers that currently limit the ability of PWD to participate fully in wellness initiatives, IHCs may need to further evolve into more "corporate" organizations capable of crafting agreements that would supply financial support for wellness care. While IHCs have been very successful in promoting community level change, we anticipate that the 'loose' organizational structure IHCs currently employ may be a barrier to developing close relationships with health care delivery organizations. The end goal of integrating with health care delivery organizations may require formal partnerships characterized by well-defined responsibilities that meet the needs of both health care delivery organizations and the patients that these organizations serve. These formalized relationships can help to establish permanence and accountability.

# Expand the Role of NCHPAD as a National Translation and Coordinating Center

In order to fully implement our strategic goal to expand the missions of IHCs to more effectively meet the needs of our target population, we believe it is necessary to create a national translation and coordinating center to guide and support their efforts. The coordinating center will be responsible for issuing a request for applications for start-up funding to support IHCs that wish to provide access to the MENTOR program in their own communities. We imagine NCHPAD will become this center. In this role, NCHPAD will need to

- Provide resources to assist local organizations in partnering with stakeholders and disseminating best practices;
- Assist IHCs with staff training and help with program planning;
- ➤ Directly provide MENTOR to the target population in their own homes and/or communities through telehealth programs to improve their wellness and;
- Support IHCs as they begin to explore how to achieve fiscal sustainability by identifying benefits that have proved cost saving in other settings and by approaching funders, such as private payers, in seeking funding.

Once IHCs have evolved their structure to support transitions of patients from healthcare to the MENTOR wellness program, they can begin engaging in activities to support the scaling of MENTOR according to the N-KATS framework for knowledge transfer. The success of this strategic plan requires a significant transfer of knowledge about wellness programs, specifically

about the MENTOR program which has been designed for patients transitioning out of healthcare. Many healthcare providers lack awareness of what is required to ensure individuals with disability accessing healthcare services are able to transition into a wellness program in their home and communities. Likewise, community service providers may lack the knowledge and skills needed to facilitate the inclusion of PWD in their programs and facilities. Therefore, the long-term goals of this strategic plan use the N-KATS framework to develop a systematic way of educating and training community partners, specifically health service providers and community-based service providers, who will work closely with IHCs to engage patients in wellness initiatives.

# DETAILED STRATEGIC PLAN USING NCHPAD'S KNOWLEDGE ADAPTATION, TRANSLATION AND SCALE UP (N-KATS) FRAMEWORK TO IMPLEMENT MENTOR PROGRAM

## **N-KATS PHASE I: KNOWLEDGE ADAPTATION**

During Phase I, our objective is to support health care providers in developing the necessary knowledge and skill to support the transition of these patients into post-rehabilitation, community-based wellness programs structured around the MENTOR paradigm. We aim to increase their knowledge of a) the health and wellness needs of the target group, and b) factors that facilitate or restrict their access to new or existing community health and wellness programs.

## IHCs Assess Community Partners' Knowledge and Awareness of MENTOR

Initially, we propose that IHCs perform an assessment to identify what health and community-based service providers do and do not know about the following domains:

- Health and wellness needs of the target group;
- Factors that facilitate or restrict their access to community health and wellness programs;
- > Capacity of the target group to participate in and benefit from community-based health and wellness programs;
- Existing community-based health and wellness programs that the target group can join/attend;
- Existing community services that could attenuate factors that restrict access and;
- ➤ Local, regional, state, and federal policy, regulations, and laws related to factors that facilitate or restrict the target group's access to community-based health and wellness programs.

#### **IHCs Engage Stakeholders and Increase Participation in MENTOR**

Continuous effort will be required to achieve the desired level of participation in the geographic catchment area of interest and achieve a critical mass of participant pipelines enough to achieve sustainability. We recommend that NCHPAD and IHCs create partnerships with local service providers to recruit patients for MENTOR-based wellness programs. The following goals,

objectives, and activities are designed to facilitate the development of sustainable engagement in the MENTOR program.

For each IHC, a 'boots on the ground' committee will be necessary for identifying and engaging with stakeholders, including community members with disability and their caregivers, family members, and service providers. This committee should ensure that individuals who have recently accessed the healthcare system for care related to a new or existing disability are involved in the planning and execution of the transitional healthcare-to-wellness program (i.e., MENTOR). It should also ensure that caregivers and families are involved in the planning and execution of the transitional healthcare-to-wellness program. In the planning stages, we recommend that the IHCs

- ➤ Identify and engage individuals who have recently accessed the healthcare system for care related to a new or existing disability and their caregivers and families;
- Conduct focus groups and/or interviews of people who have recently accessed the healthcare system for care related to a new or existing disability and their caregivers and families;
- Create a stakeholder committee of individuals who have recently accessed the healthcare system for care related to a new or existing disability, their caregivers and family members, and local service providers;
- ➤ Engage the individual's support network through events and activities to include family and friends and;
- Compile resources to support the involvement of family and friends.

Further, we recommend that the IHC engage in recruitment, marketing, and communications activities to expand knowledge about and facilitate successful transitions of patients into the transitional healthcare-to-wellness program. For example, IHCs can

- ➤ Identify and meet with gatekeepers of CBSP in the area, invest in understanding the needs of CBSP through relationship building, and create partnerships with local HSP and CBSP to gain access to patient populations;
- ➤ Identify the communication needs and resources in the community that have the potential to reach those who are isolated and develop a marketing plan including messaging, materials, and a list of potential channels of advertising;
- ➤ Develop a comprehensive recruitment plan that targets isolated groups who have traditionally been unable to access health promotion and wellness services in their community and;
- Establish incentives for community fitness and recreation centers to offer the MENTOR wellness program to the target group.

The IHC will also need to facilitate patient access to telehealth technology that can provide a version of MENTOR to patients in their homes at different points in the recovery process. To do so, IHCs should

- Review the NCHPAD website to learn about potential resources;
- Speak with an expert information specialist to gather information about resources in the making;
- Compile a list of currently available telehealth and mobile technologies (i.e., Zoom, iBuild app, Wordpress) and identify those that are useful and;
- ➤ Gather and/or develop resources to be shared through telehealth and mobile technology apps.

#### N-KATS PHASE II: KNOWLEDGE UPTAKE

# IHCs Educate Community Partners, Specifically Health Service Providers (HSP) and Community-Based Service Providers (CBSP), about MENTOR

Based upon knowledge gained through initial assessments, we propose that NCHPAD work with IHCs to develop communication and training plans tailored to the needs of health service providers in the region they work in. These communication and training plans should be designed to enhance knowledge among health service professionals of the above domains. We recommend that these plans include the following steps to achieve adequate knowledge and uptake about MENTOR:

- ➤ Develop print, video, and audio forms of education materials to support the communication and training plan.
- ➤ Identify HSP concerns about their patients' potential participation in the MENTOR program and what they would like to know.
- ➤ Develop a training plan to enhance HSP knowledge about the MENTOR healthcare-to-wellness program.
- > Deploy HSP communication and training plan.
- Deploy evaluation plan for this objective and supporting activities.
- ➤ Based on the report from the evaluation plan, implement the previous activities as needed to achieve the desired awareness and knowledge.

We also propose that individual IHCs develop an education and training plan specifically designed to support community-based service providers (CBSP). Our goal is to help CBSPs develop the necessary knowledge and skills to support transition of the target population into a post-rehabilitation, community-based wellness program. The strategic objective of this plan is to increase CBSP knowledge of a) the health and wellness needs of the target group and b) factors that facilitate or restrict their access to new or existing community wellness programs. The plan should include the following activities:

- ➤ Determine CBSP comfort with and interest in participation in a formal process to transition PWD from a HSP directed care program to a comprehensive community-based wellness program.
- ➤ Identify CBSP concerns about participation of PWD in wellness initiatives and what knowledge or training would increase their comfort.

- Increase CBSP knowledge of disability etiquette, universal design principles, and local, regional, and national accessibility policies. Include both general knowledge and information that addresses specific concerns.
- ➤ Lead HSP and CBSP partners through a process to define a procedure for formal transition or referral of PWD to community wellness programs. (Further explanation of this process below.)
- Support HSP and CBSP in implementing the pathway or process defined above.
- ➤ Deploy an evaluation plan designed to assess CBSP and HSP buy-in and concerns and to identify gaps in the training plan.
- ➤ Based on the report that results from the evaluation plan, revise and implement the previous activities as needed to achieve desired outcomes.

# IHCs Offer Health Promotion/Wellness Programming and Training for Target Population and Stakeholders

The goal of this element of the strategic plan is to provide training and/or collaborate with community partners to increase wellness training opportunities specifically designed for the target population and their family members, caregivers, and related stakeholders. These trainings should focus on the health and wellness of the total individual, rather than disability-related issues only. As needed based on local resources and interests, programming can be adapted from existing programs or developed from the ground up. The activities listed under this goal are general enough to support adaptation or development.

- ➤ Identify a pool of potential community partners, including organizations' names, leaders, contact information, and current programs offered.
- Identify which training areas should be addressed in a comprehensive program.
- Engage PWD to determine what they need and consult with them.
- Identify gaps in current training programs.
- > Engage existing programs to determine openness to expansion.
- Draft content for each training.
- Determine schedule of offerings (e.g., all at once, sequentially, and/or in rotation).

#### **IHCs Execute Comprehensive Communication Plan to Raise MENTOR Program Awareness**

We recommend that each individual IHC, with the help of NCHPAD, develop a communication plan to increase awareness of MENTOR and its impact on candidate participants, healthcare service providers, and community-based service providers. We recommend that IHCs engage in a variety of marketing, social media and mass media activities to increase public awareness about the need for healthcare-to-wellness programs like MENTOR to serve individuals who have recently accessed the health care system for care related to a recently acquired or existing disability.

First, we recommend that IHCs work closely with hospitals and rehabilitation facilities to raise awareness about the MENTOR healthcare-to-wellness program:

- ➤ Identify hospital and rehabilitation facilities in their immediate area that can develop a transitional wellness program or refer patients to an existing one.
- Share with these hospitals and rehabilitation facilities examples of transitional healthcare-to-wellness programs. If none exist in the local community, encourage use of the MENTOR program.
- ➤ Identify the best way to facilitate public awareness and social marketing with the help of these healthcare facilities (e.g., meet with leadership, use flyers, tap into social media, capitalize on marketing strategies that are important to the specific target group).

Next, we recommend that IHCs use mass media and online marketing tools in a multi-level statewide campaign to increase enrollment in MENTOR. This will require assessment of best marketing strategies and the development of recruitment materials. We anticipate IHCs will engage in the following activities:

- Identify a change agent within a target community who can help with advertising.
- > Engage community members in the process of developing messaging for outreach.
- ➤ Use previous examples from current programs (e.g., testimonials, qualitative data) to promote enrollment in MENTOR.

Finally, we recommend that IHCs ensure comprehensive media coverage for local and regional news and events associated with the MENTOR program through the following activities:

- Identify potential local and regional news agencies and provide an overview of the program to build interest.
- > Develop a timeline for implementation and identify which phases in program implementation will leverage the most benefit from media coverage.
- ➤ Reach out to local and regional news agencies for coverage of the most important components of the program to boost enrollment.

This communication plan should include the creation of a dissemination network that reaches all service providers and stakeholders.

# IHCs Assist HSP and CBSP to Formalize Process for Patient Referral to MENTOR Wellness Programs

One of the biggest challenges in the development of any post-rehabilitation/post-healthcare wellness program is to address the lack of active, strong relationships between HSP and CBSP. These relationships must be developed if they do not already exist. If they exist, then they may require reinforcement to support the objectives of this effort.

One of the first goals of the expanded NCHPAD and participating IHCs will be to support HSP and CBSP in enacting a formal procedure to transition patients from rehabilitation to post-rehabilitation wellness programs. We recommend that IHCs work closely with HSP and CBSP to

create a joint vision for the transition for PWD. Multiple processes may be envisioned. All processes should identify potential barriers and provide solutions and strategies to overcome those barriers. These barriers may involve HSP and CBSP, which will require both to be involved in creating a solution.

It will be the job of NCHPAD and IHCs to lead HSP and CBSP in developing and training partners in a procedure for formal referral to MENTOR. This plan should be concrete, actionable, and documented for accountability. We recommend pilot testing the transition plan on a small scale to identify additional barriers to actual implementation. Initial pilot implementation can begin with a single individual or a single health service provider. Each individual can represent a new iteration. IHCs will be tasked with documenting all challenges encountered during initial implementation and solutions found. The next step will be to support HSP and CBSP to implement a full transition plan based upon the pathway/processes developed during the pilot testing. An evaluation plan will enable all parties to continue assessing the success of the transition plan and modifying these processes as needed.

#### N-KATS PHASE III: KNOWLEDGE UTILIZATION

## Create IHC Healthcare-to-Wellness (H2W) Committees to Assist in Implementation of MENTOR

We propose that the national coordinating center (i.e., NCHPAD) facilitate the launch of a new Healthcare-to-Wellness initiative by arranging a request for applications to develop Healthcare-to-Wellness (H2W) committees (as part of an existing IHC or as a new IHC) specifically responsible for meeting local needs, implementing the MENTOR wellness program, evaluating and refining the approaches as needed, assuring that appropriate management and administrative practices are adopted, and creating a plan for fiscal sustainability through reimbursement mechanisms. To begin, each H2W Committee, subsumed under the IHC, would be responsible for the following:

1. Design a unique program based on the needs of the individual and the available resources in the community.

To enable greater access to the MENTOR program, we propose that the H2W Committee perform the following activities as part its role in the IHC:

Increase universal design in the built environment and among institutions/organizations that have the facilities necessary for participating in a transitional healthcare-to-wellness program in their community. The IHC H2W Committee should begin with an assessment of the built environment around institutions/organizations that promote wellness to identify key areas lacking universal design. Next, we recommend that they identify resources to support conducting assessments of the built environment. These might include students, tools, interns, staff, volunteers or organizations in the community interested in health and wellness or disability advocacy. The H2W Committee should recruit individuals with disability to participate in assessment of the built environment to help identify existing barriers. The H2W Committee may include the Community Health Inclusion Index (CHII) or other accessibility assessment tools to assess the built

environment in and around any facility involved in program implementation. Along with identified stakeholders, they will need to prioritize built environment barriers to address.

- Increase awareness of universal design principles and adaptations to the environment to increase support for universal design throughout the community. We anticipate that the IHC H2W Committee will provide training and resources on universal design and adaptations for HSP, CBSP, and the larger community; identify resources or supplemental funding to complete projects that reinforce universal design; and review policies and laws within the community and within the organizations (i.e. ADA, staff training policies). In addition, the IHC H2W Committee may need to work to work more broadly to enforce policies that create an inclusive environment for individuals with disability to participate or create policies that enforce universal design where none exist.
- ➤ Improve transportation services to local health and wellness facilities, especially facilities offering MENTOR. The IHC H2W Committee should coordinate with local organizations to identify potential solutions to assist with transportation needs. For example, they may meet with public transportation or para transit providers to discuss routes to facilities or identify if there are ride shares or company-owned vans that can be used. More generally, the IHC H2W Committee can work to increase awareness of transportation needs among transportation providers in the community through resources and training.
- ➤ Improve access to healthcare-to-wellness services (i.e., MENTOR) for those who cannot afford to pay for these services. IHCs should include the MENTOR program as a line item in the annual budget to allocate resources to program implementation. In addition, we recommend that the IHC H2W Committee identify supplemental funding to support the program through local and national funding opportunities and resources.
- 2. Actively engage in outreach to enroll clients and expand access to the MENTOR program.

When an individual with a disability enters the healthcare system, there is a unique opportunity to inform the healthcare provider, individual and/or caregiver of resources that could assist in making the transition from rehabilitation patient to wellness participant. The H2W Committee should work jointly with healthcare providers to identify individuals who would enroll in the program and receive appropriate support from the IHC. The H2W Committee might also work with insurance companies, including workers' compensation

When an individual with a disability enters the healthcare system, there is a unique opportunity to inform the healthcare provider, individual and/or caregiver of resources that could assist in making the transition from rehabilitation patient to wellness participant.

programs, to identify beneficiaries who might benefit from participation in the MENTOR program. Upon intake, a social worker would refer patients to the program.

This task involves **active** outreach to acute care and rehabilitative care providers, including social workers, physical and occupational therapists, and others involved in care transitions. Much of this effort would come through the IHC's close relationships to health care provider organizations within the community. Health care providers—like acute care hospitals, therapists, rehabilitation facilities and physicians—encounter individuals with disability during the time period in which they are adapting to a new disability or when they are accessing healthcare services for a new secondary health condition (e.g., urinary tract infection, pain, relapse associated with multiple sclerosis).

#### 3. Eliminate Barriers to Participation

Individual level barriers to participation are perhaps the most widely acknowledged and documented. Despite this knowledge, they persist and represent significant challenges to program implementation and sustainability. The H2W Committee will need to determine how to reduce the impact of the built environment, transportation, and other specific barriers to candidate participation in health promotion and wellness programs.

As stated above, transportation has been shown to be a major barrier that individuals with disability face when attempting to engage in physical activity (Martin Ginis et al., 2016). To address this barrier, H2W committees in some localities may provide funding for initiatives that help individuals with disability learn to navigate the public transportation system. In other localities without public transportation options, they may identify different solutions such as the use of ride-share apps to address transportation needs.

Another barrier is a lack of fitness facilities that are accessible to people with mobility disability (Rimmer et al., 2017) and the costs associated with membership at these facilities (Martin Ginis et al., 2016). The H2W Committee may choose to work with local fitness facilities to develop suitable accommodations for individuals with disability and to offer free, health plan subsidized, or discounted membership to these facilities. The benefits offered by the IHC H2W Committee could vary widely based on differing needs and resources within the collaborative organization's local area.

#### **IHC H2W Committees Establish and Maintain Local Volunteer Networks**

In the current healthcare climate and model of service delivery, we anticipate that the budget will be insufficient to fully fund all objectives and activities needed to support the development of MENTOR programs on a large scale. Success, therefore, may depend on the ability of the H2W Committee to develop and manage volunteer efforts. At least in the short term, we recommend that the H2W Committee create and train a volunteer network that can participate as needed to support development, implementation, and sustainability of MENTOR-based wellness programs.

Our strategic objective is for the IHC H2W Committee to develop clear procedures and processes for identifying and training a sustainable and informed volunteer network. IHCs will need to identify and clarify the services and activities that the volunteer network can provide and define the benefits of this network to the organization, the volunteers, and PWD. This is important to

help all stay motivated and involved. IHCs will need to develop a volunteer manual that defines volunteer job descriptions, policies and grievance processes, roles and responsibilities, expectations, and what makes a person eligible/ineligible to volunteer (e.g., age, conflicts, availability, background checks). There should be a clear division between the roles and responsibility of lead organization staff and volunteers. IHCs will also need to clearly define who will be responsible for recruitment and management of volunteers. This person will update the volunteer manual as needed (and may draft the initial version). This person will also develop a training/orientation/onboarding program that provides information about the organization, how the volunteer impacts the target group and organization, how to interact with a member of the target group, and the activities they should engage in with the participant.

Next, we recommend that IHCs identify an initial group of individuals who will participate in the activities below to support development and launch of the volunteer network. This should be a group of people who are invested in or excited about the development and implementation of the comprehensive community-based health and wellness program. IHCs should identify candidate volunteer pools and query other local groups about the pros/cons of each candidate group before recruiting. For example, college students are often interested in volunteering, but they may have occasional conflicts (e.g., need to miss the same days due to exams and university holidays). Therefore, multiple candidate pools may be needed.

IHCs will need to engage in systematic record keeping. We recommend that they develop and maintain a volunteer database that includes names, addresses, telephone numbers, email addresses, social media user names, availability, completed hours, and any other pertinent information. We further recommend that they develop a process to identify how each volunteer prefers to be recognized for their contribution and to provide recognition via the preferred pathway.

Finally, IHCs should identify how to quantify the numbers (e.g., number of volunteers, hours served) and impact of volunteers (e.g., dollars raised, people served) and develop a process for communicating the impact to volunteers, staff, participants, HSP, and other members of the local community.

#### N-KATS PHASE IV: KNOWLEDGE EVALUATION, UPDATE AND MAINTENANCE

## Track and Incentivize Patient Participation in MENTOR

The IHC H2W Committee will need to assess participant engagement in the transitional healthcare-to-wellness program and plan innovative ways to maintain participant engagement. We recommend that the IHC H2W Committee develop reinforcement tools (e.g., technology apps and text messaging) that will motivate people to join MENTOR and maintain regular involvement. The IHC H2W Committee will need to identify incentives desired by the target group and create a distribution plan (e.g., receive a \$25 gift card when joining the program). In addition, the IHC H2W Committee can identify core components of the program that can be tracked, implement a

check-in system, and develop a protocol to reward high level participation and encourage improvement among lower level participants. The IHC H2W Committee can develop a system to monitor and track participant's adherence to the program and levels of engagement.

## **Create a Care Management Informatics Platform to Support Mentor**

Delivery of wellness benefits across the 11 MENTOR domains requires a sophisticated informatics system to serve as a content and participant management system that will enable the delivery of individualized content and services. NCHPAD should expand its current content management system to include a care management platform that should serve as a historical repository of participation and allow health coaches to focus on behavior change strategies, personalized coaching, and tracking of participant progress. This platform will include live dashboards and drill downs that display the current health and wellness status of all clients. The platform will include regular monitoring of patients' wellness using a questionnaire that provides the health coach with information on which of the 11 wellness domains needs the most attention. Health coaches can use this information to prepare for weekly coaching calls and other asynchronous communication with participants. The weekly calls will use motivational interviewing techniques to develop a person-centered action plan (P-CAP). The health coach will then use the platform to find appropriate support materials for the MENTOR P-CAP and deliver the materials to the participants through asynchronous methods. We also propose this platform include gamification features to motivate and incentivize participation similar to the Starbucks app which provides points and rewards (bonus stars) to members for "positive behaviors" (i.e., purchasing their products). Such uses of technology have been shown to increase health, wellness, and socialization (Jimison et al., 2013; Willey & Walsh, 2016).

#### **Develop System for Accountability and Sustainability**

The success of our proposed plan to leverage and expand NCHPAD and the IHC initiative to facilitate patient access to MENTOR-based programs will depend on adequate monitoring of program performance and effectiveness. We recommend the development of a data collection strategy (e.g., a survey) to monitor rates of participation in the MENTOR program.

We also recommend the identification of an established evaluation model to guide evaluation of the training and communications plans and to assist in their improvement as they are being implemented. This model will enable us to identify effectiveness indicators as well as to develop tools and processes to measure those indicators. For example, the Kirkpatrick evaluation model has four levels to assess participant engagement: reaction, learning, behavior, and results. The reaction level seeks to quantify how participants felt about the training. The learning level quantifies participants' increase in knowledge. The behavior level quantifies the degree to which learning changed their behavior. And, the results level quantifies changes in the outcome of interest.

This evaluation plan should monitor the effectiveness of each step of the strategic plan, explicitly stating the effectiveness indicators for each objective/activity and the tool or approach used to

quantify each indicator. A timeline should be created for generating a brief report regarding the effectiveness of each activity. These reports should be submitted to a governing/regulatory body, like NCHPAD, quarterly. Activities or objectives judged as minimally effective can be revised with a plan for improvement.