

**Rehabilitation Institute of Chicago  
d/b/a Shirley Ryan AbilityLab**

**2019 Community Health Needs Assessment  
Implementation Strategy for Fiscal Years 2020-2022**

Shirley Ryan AbilityLab (“SRALab”) completed its most recent three-year Community Health Needs Assessment (“Assessment”) during Fiscal Year 2019. As a result of the input it received from various sources, five (5) areas of community health needs (“Priority Areas”) were identified. This Implementation Strategy (“Implementation Strategy”) addresses each Priority Area and: (i) details how SRALab plans to meet the needs identified, including the programs and resources that will be committed; (ii) describes the anticipated impact of its programs and resources on the need; and, (iii) where appropriate, describes planned collaborations with related organizations to meet the need.

Four of the five Priority Areas from the 2016 assessment continue as Priority Areas in 2019; specifically, Rehabilitation Health, Research, Improved Access to Information about Existing Resources, and Support Programs. The fifth 2016 Priority Area, Education and Training, has been replaced with a focus on Business Relationships.

- **Rehabilitation Health Needs** – SRALab’s clinical expertise in multiple programs and resources will continue to provide for the needs of SRALab patients in the areas of stroke, spinal cord injury, brain injury, neuromusculoskeletal conditions, pediatric care, and cancer. Additionally our ongoing focus on social determinants of health, quality of life, review of ethics issues our patients face, and patient advocacy also contribute to maximizing patient outcomes and recovery.
- **Research** – SRALab’s innovative design integrates all aspects of human subject research and rehabilitation medicine. Clinical and research staff work together in real time to improve patient outcomes. Focus areas for the next three years shall include the use of portable sensors to monitor patient activity and response to therapy, measurement of brain network activity in chronic pain patients, and measurement of neuromuscular tissue properties in neuromuscular disease.
- **Improved Access to Information about Existing Resources** – SRALab’s LIFE Center, a virtual and multimedia education center, has been integrated into the Shirley Ryan AbilityLab website. SRALab will continue sharing information about the LIFE Center with partners and through social media to expand the community, national, and international reach of our educational offerings.
- **Support Programs** – SRALab will continue to provide high-quality support programs to the community including, but not limited to, adolescent support

programs, family support programs, peer mentoring programs, accessible physical fitness, and programs for service members, veterans, and individuals with aphasia.

- **Business Relationships** – SRALab will continue to continue to focus on increased hiring of persons with disabilities and connecting people with disabilities to potential employment opportunities.

The Implementation Strategy was reviewed and approved by SRALab’s Board of Directors.

## 1. Rehabilitation Health



*The north facade of the new Shirley Ryan AbilityLab®, which opened in March 2017.*

As conditions resulting in disability become increasingly prevalent, Shirley Ryan AbilityLab’s Assessment identified the continued need to expand access for patients in various rehabilitation settings in the areas of stroke, spinal cord injury, neuro-musculoskeletal conditions, brain injury, pediatric care, and cancer.

Between December 2017 and October 2019, we have continued to expand our DayRehab programs to serve greater numbers of patients. In December 2017, we combined our River North and Ravenswood DayRehab clinics to form the Streeterville DayRehab, which serves approximately 20% more patients than the previous two clinics combined. In April 2018, we relocated our Willowbrook clinic to Burr Ridge, opening the Burr Ridge Outpatient and DayRehab Center, which serves

approximately 30% more patients than the Willowbrook clinic. In October 2019, we relocated our Homewood DayRehab clinic. To date, our patient volume has increased by approximately 8%. We have also relocated the Pain Management Center to a location closer to other SRALab services, and relocated the Northbrook DayRehab Clinic to accommodate a greater range of services in a facility that can support the therapy equipment our patients need.

Additional service expansions and relocations are planned for the next three years, including an additional 20 inpatient beds at the flagship and relocation and expansion of our Wheeling DayRehab to Arlington Heights, so that we can continue to enhance care and support the rehabilitation needs of our patients. In addition, the Assessment revealed

the need to address social determinants of health, as well as social-science issues such as depression, quality of life, and advocacy for patients who will always depend on a wheelchair for mobility.

### Social Determinants of Health

Appropriately supporting our patients and maximizing healthy outcomes for our community necessitates actively addressing not only the physical needs of our patients, but also the emotional, social, and psychological needs of our patients and their support networks. To achieve this, we focus on addressing their adjustment to disability and the impact of their disability on their self-perception and relationships. As such, all patients admitted to our flagship hospital are seen by our psychology and patient family counseling staff, who assess the patient's emotional needs and determine an active treatment plan as part of their rehabilitation services. These needs continue to be identified and addressed at all levels of care. Our staff actively works with community partners to facilitate outpatient referrals as our patients continue in their rehabilitation journey.

Healthy community reintegration after sustaining a disability is a key determinant of maintaining social health. To address this, SRALab provides support to facilitate a patient's return to their avocations and employment, when appropriate. Our Therapeutic Recreation Team actively works with our patients to reengage in their hobbies and share opportunities to engage in athletics within in the disability community. Additionally, our Vocational Counselors work with patients and their employers to facilitate their return to work with appropriate accommodations, as indicated.

Additionally, because a disability population is known to be at higher risk for suicide than the general population, SRALab has an active protocol in place to screen patients in all levels of care for suicidal ideation and then provide treatment and/or referrals, as needed. We also have a plan in place for patients in our DayRehab and Outpatient levels of care, who may present with suicidal ideation, so that they can be appropriately treated.

In addressing the emotional and psychological needs of our patient's families and social networks, there is a strong focus on family support, which includes actively managing and addressing caregiver burden. Emotional support services, including family education and support services, are provided by the SRALab LIFE Center. We also provide pastoral counseling and spiritual care and support to both patients and their families, and psychology and social work services at our DayRehab sites.

By actively addressing the psychological needs of our patients and families, preventing suicide in a higher-risk population, identifying and addressing caregiver burden, and facilitating community reintegration, the Shirley Ryan Ability Lab maintains an ongoing focus on the social determinants of health of our community, thereby maximizing patient and family outcomes.

## Patient Advocacy and Quality of Life

SRAlab's Donnelley Ethics Program is committed to looking at ethical issues related to quality of life that our patients with disabilities and community populations (including those with disabilities) are facing. To address this, all patients admitted to our flagship hospital and outpatient sites are able to request ethics consultations while in the hospital or while receiving services to address queries related to issues including, but not limited to, quality of life. Additionally, we routinely survey ethics literature to design and provide educational offerings in various formats and forums to educate our clinicians about quality of life concerns of patients/families and disability rights groups. Of note, some of these forums are inclusive of broader communities (such as support groups, secondary school groups, campus partners, and trainees). During Fiscal Year 2019, we met with a Multiple Sclerosis (MS) support group and presented on "A Day in the Life of a Bioethicist." Last year, we met with this same support group and discussed "Advance Care Planning: Basics and Beyond." In March 2018, we hosted a joint ethics grand rounds that highlighted a presentation by David Ansell, MD, MPH the author of "The Death Gap: How Inequality Kills" framed around the themes of his book.

The Donnelley Ethics Program has also regularly connected with or presented to various community groups, such as the Brain Injury Association of Illinois and Access Living, both in our hospital setting and offsite. We have also co-hosted programming with other departments at SRAlab, including the LIFE Center – a resource center that offers patient education and community links and information for people living with disabilities.

Over the next several years, we will continue to offer education that relates to quality of life issues through a variety of inclusive forums.

## **2. Research**

Shirley Ryan AbilityLab's Assessment identified the continued need for rehabilitation research into new and more promising treatments to improve and eliminate the effects of injury, diseases, and debilitating health conditions in the community we serve.

The research program at SRAlab has been in existence for decades and today has a portfolio of over One Hundred (\$100,000,000.00) Million Dollars in funding. SRAlab's research programs have international impact, continuously building on the organization's mission of helping people with disabilities to achieve as independent and fulfilling a life as possible.

SRAlab collaborates with, and will continue to collaborate with, public and private entities worldwide in conducting rehabilitation research. SRAlab is the sole academic and clinical partner of the Department of Physical Medicine & Rehabilitation at Northwestern University Feinberg School of Medicine. This relationship provides an academic framework that supports SRAlab's ongoing research efforts. A range of researchers are

supported through this partnership, including post-doctoral researchers, pre-doctoral research graduates, physicians, residents, and other clinical fellows.

The organization's scientific approach – Advancing Human Ability® – was fully implemented in 2017 with the opening of our new translational research hospital, the Shirley Ryan AbilityLab.

In addition to the inpatient care and treatment provided, the facility comprises 900,000 square feet dedicated to research and clinical programs, intentionally designed to facilitate the growth and translation of research into clinical care by fostering interactions between clinicians and researchers. This is in part accomplished through five Ability Labs, designed as integrated spaces to bring doctors, scientists, and therapists together to treat patients and conduct research. Each Ability Lab includes a combination of equipment, smart devices, and cutting-edge technology that represents not only current best practices in rehabilitation care, but also new and innovative practices that hold promise for future methods of advancing patient ability. Clinical and research staff working in this space together have, through their activities, created an environment of mutual motivation and learning. Additionally, each Ability Lab represents a hub of patient activity where the majority of daytime activities, such as patient therapies and applied research activities, take place. The Ability Labs represent the bridge between research and direct patient care where solutions to real patient problems are identified and solved quickly and efficiently to improve patient outcomes. The innovative design of the new hospital integrates all aspects of human subject research and rehabilitation medicine and has facilitated the recruitment of world renowned researchers and expansion of the SRAlab research enterprise in furtherance of our search for new and more promising treatments.

Focus areas for research include the use of portable sensors to monitor patient activity and response to therapy, measurement of brain network activity in chronic pain patients, and measurement of neuromuscular tissue properties in neuromuscular disease.

The research conducted at SRAlab ranges from cognitive behavior and decision making to epigenetic modification of stem cells in muscle contractures. Of particular note is that measurement of brain activity for research purposes is accomplished using a research-grade magnetic resonance imaging (MRI) scanner with a field strength (3.0 Tesla) that is twice that of the typical MRI scanner (1.5 Tesla). In addition, our biologics lab is housed within our hospital and contains specialized facilities to perform cell culture, biochemical, biophysical, molecular and genetic studies of tissues (blood, saliva, joint fluid, muscle) obtained from our patients.

In the next three years, we will be focusing on the use of sensors to not only detect movement abnormalities but to evaluate the efficacy of treatment in real-world settings. This latter point is based on the observation that isolated and infrequent clinician visits do not always provide a reliable view of patient function or progress. We currently have a major grant submitted to become the National Center to lead this initiative.

### 3. Improved Access to Information about Existing Resources

The Assessment identified a continued need for increasing the awareness of patients, visitors, and the community regarding Shirley Ryan AbilityLab's LIFE Center, as well as additional programs and resources, such as Pathways.

SRAIab's Henry B. Betts LIFE Center, a multimedia education center and virtual web portal, provides access to patient education and consumer health information that is peer-reviewed and best-practice. The LIFE Center's mission is to provide opportunities for **L**earning, **I**nnovation, **F**amily, and **E**mpowerment for the populations we serve, their families, and the community.

In connection with opening the Shirley Ryan AbilityLab, the LIFE website<sup>1</sup> was redesigned and merged to a single platform with the new SRAIab website. The website provides a virtual education portal to access patient education and community resources with real-time updates, printing on demand, and a dashboard that allows visitors to save their favorite resources for easy access in the future. Visitors to the website are also able to see the entire breadth of the hospital's offerings, as well as learn about Pathway – now a member of the Shirley Ryan AbilityLab family – and a leading pediatric resource in early detection and intervention tools to maximize children's motor, sensory, and communication development.

In addition to the virtual resources, there is a physical location located on the 10<sup>th</sup> floor of the Shirley Ryan AbilityLab, and provides access to curated resources that span key topic areas relevant to the life-long needs of people living with a wide range of cognitive and physical impairments, chronic conditions, or diseases affecting function. Holdings also include information for family members, clinicians, and educators. Having access to this information enables individuals to make the best choices for themselves and their families.

In addition to online resources, knowledgeable, expert staff are available to help visitors and professionals find personal connections, guidance, and trusted resource information aligned with their needs through the various stages of their healthcare journeys.

The Center embraces a holistic approach that provides access to information spanning the lifetime of needs. Resources are organized according to eight topic areas:

- Medical Information & Care
- Caregiving & Equipment
- Housing & Transportation
- Education & Employment
- Support & Wellness

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<sup>1</sup> <https://www.sralab.org/lifecenter>

- Recreation & Leisure
- Finance & Law
- Inspiration & Hope

Providing resource assistance and referral information to patients, families, staff, and the community remains the cornerstone of Center service. The Center receives and responds to thousands of resource requests from across the globe, illustrating not only the community's awareness of the Center, but also the value it provides. Resource requests are submitted to the LIFE Center in-person as well as by phone, e-mail, and mail. In fiscal year 2019, there were 344,686 page views of the LIFE website with 199,629 unique users from more than 200 countries.

SRALab will continue to increase awareness of the LIFE Center by communicating with acute care hospitals, inpatient rehabilitation hospitals, and community agencies that serve persons with disabilities to make their patients and communities aware of the resources the LIFE Center offers. In addition, a video will be developed to showcase the Center's unique resources. Finally, the Center offers an annual open house that is available to the public to learn about these key resources. Scheduled events and other relevant information that will bring attention to the LIFE Center will be shared through social media outlets to expand our community, national, and international reach.

#### **4. Support Programs**

The Assessment identified a continuing need for support programming. In particular, (i) support for helping patients manage expectations upon returning home; and (ii) developing clinical community links and formalizing communication with existing community support groups.

Shirley Ryan AbilityLab has, and will continue to have, numerous programs to assist patients with transitioning back to their homes and communities. Shirley Ryan AbilityLab also has programs intended to help patients' families and other members of the community, regardless of whether they have been SRALab patients.

*Adaptive Sports & Fitness Programs.* The Shirley Ryan AbilityLab provides year-round opportunities for children, teens, and parents to build social support networks, enhance social interaction skills, expand leisure interests or participate in competitive sports. The Programs are open to youth aged 6–17 who have a physical disability and are independent in daily living skills. All Programs promote positive quality of life through physical fitness, independence, socialization, activities, and other adaptive resources. Upon reaching age 17, participants are able to transition to a wide variety of sports and recreational programs offered to adults through SRALab Adaptive Sports Programs. Free door-to-door wheelchair accessible bus transportation service to/from most programs is available for participants living within Chicago city limits.

*Accessible Fitness Programs.* In 2012, SRAlab moved its Adaptive Sports & Fitness Center (“Center”) into a newly designed and expanded, state-of-the-art accessible fitness center. The Center includes the latest designs in adapted weight training and aerobic equipment, and experts in exercise physiology and therapeutic recreation are present to lead programs and assist participants. In response to the identified needs for community-based integrated exercise programs, the Center developed a Functional Fitness program to transition patients from inpatient hospitalization to customized exercised programs, allowing them to continue building towards health and fitness goals following discharge. Additional fitness programs have been added to the Center’s offerings and have been extended to the communities at SRAlab’s suburban DayRehab locations.

To ensure ongoing support of all community members, membership is open to any person with a disability at a very low cost. In addition, the Center provides adaptive recreation and competitive sports programming at no cost to participants. The Center’s competitive sports and Paralympic programs are among the best in the United States, and are offered for both adults and children. Participation in programs held at the Center requires a written membership application that includes medical approval from a physician.

*Military Sports Camp.* SRAlab Military Sports Camp is designed for injured military personnel with a primary physical disability. Introductory level athletes are invited to learn from elite level coaches while enjoying all that Chicago has to offer. There is no cost for the program.

SRAlab offers the camp each year, usually over multiple days in the summer. All individuals who have or are currently serving in the US Armed Forces and have a primary physical disability are welcome to apply. Recent camp participants represented every military branch and came from nearly all 50 states.

*Therapeutic Recreation.* Therapeutic Recreation is a community reentry program developed to assist individuals with disabilities to adjust and learn new ways to participate in community offerings and Activities of Daily Living (“ADL”). Each week therapists lead multiple therapeutic recreation sessions with patients and their families. During these sessions, patients and their family members travel to museums, stores, restaurants, and even the airport, where patients practice boarding airplanes. All of these activities prepare patients and their families to navigate the community and continue to engage in ADL that are of interest to them.

*Car Seat Program.* The Shirley Ryan AbilityLab has a long standing car seat program to ensure that each pediatric patient is discharged with an appropriate car seat, properly fitted into the vehicle. If the family does not have a car seat, one is obtained for them free of charge. SRAlab has staff who are also trained car seat technicians to complete this process with each inpatient patient and family.

*Young Adult Transition Program.* This program provides skill training for adolescents, empowering them to become more independent by preparing them for a transition to the future. Skills taught include money management, cooking and grocery shopping,



navigating the community via public transportation, asking questions at medical appointments, identifying potential areas of career interest, and creating a resume.

*Aphasia*. SRAlab sponsors weekly programming for community members with aphasia. Participants are charged a nominal fee of \$5-10 per class per week, with alternate arrangements available if a participant cannot afford the fee. Programming is offered to about 50 community members per week and includes conversation groups, book clubs, and topic-specific sessions that focus on a variety of themes including the creative arts, health and fitness, and other recreational activities. The annual “Aphasia Day,” held in June, draws about 150 people – both people with aphasia and their family members – to SRAlab for a full day of educational programming that includes a luncheon and a keynote speaker.

*Peer Mentors*. The LIFE Center has developed a highly regarded peer mentor program to support patients in the early stages of recovery. The program’s unique model incorporates peer mentors into patient education, providing opportunities for patients and families to glean insights from someone who has “been there” and developed strategies that support goal achievement and community integration. Currently, the peer team includes 40 individuals with various conditions (cancer, multiple sclerosis, spinal cord injury, traumatic brain injury, stroke, ventricular assist device, and limb loss) who are successfully navigating life post-rehabilitation and can share the “lived” experience of disability. All peers are carefully screened and receive extensive training and ongoing talent development through quarterly in-service training. In addition, peers are coached and mentored to ensure effective development of communication skills. The peer program is directed by the LIFE Center with additional educational consultation from Access Living of Metropolitan Chicago, a non-residential independent living center. Ongoing collaboration provides helpful insights and strategies for team development and community advocacy.

*Support Group for Caregivers*. Through our chaplaincy, SRAlab offers weekly support group meetings for caregivers. The meetings, which began in November 2019, offer caregivers and other loved ones a safe space to express their emotions and concerns confidentially. Participants benefit from recognition, counseling, support, peer socializing, and the sharing of problem-solving ideas. While initially focused on our inpatients’ caregivers of inpatients, SRAlab will be expanding the program to outpatient caregivers as well.

*Family Education Days*. SRAlab offers formal training for family members and friends of patients, as well as homemakers. This education includes training with occupational therapists, physical therapists, speech therapists/speech language pathologists, and nursing staff, all in preparation for a patient’s discharge. Education days can be scheduled in single or multiple-day increments, depending upon how many people are being trained and whether additional training is required.

In addition to these programs, SRAlab will maintain a position in its Care Management department that is partially dedicated to working with post-discharge patients. This

position provides assistance to discharged patients in areas such as nursing home placement, DME follow up, management of transportation issues, medication management, homemaker referrals, outpatient appointments, DayRehab, and transitions to home health.

SRALab intends to continue these support services at little to no cost for patients and participants.

## **5. Business Relationships**

Participants in the Focus Group identified a continued need to increase hiring of persons with disabilities. Shirley Ryan AbilityLab will continue to be cognizant of, and continue to assist with, meeting these needs. This will include ensuring that the LIFE Center is aware of available resources specifically designed to help connect people with disabilities to potential employment opportunities.

As a result of the 2019 Assessment, the Shirley Ryan AbilityLab will develop a multi-year disability inclusion program for continued focus on these identified community needs. The formalized, structured program, championed by an SRALab Disability Business Resource Group (“BRG”), will be tasked with identifying and engaging internal and external community partners and supporting disability and inclusion hiring programs. The BRG will meet on a reoccurring basis with the goals of:

- Establishing and reviewing short and long term goals of the SRALab Disability Inclusion Program;
- Identifying and partnering with community businesses and organizations to that support individuals with disabilities, thereby strengthening SRALab’s network to identify and hire to the organization;
- Participating in the design and implementation of internal education programs; and
- Educating managers on the importance of hiring and supporting a workforce that is inclusive of individuals with disabilities.

Additionally, the Rehabilitation Research and Training Center (RRTC) focuses on addressing issues related to employment for those with physical disabilities to help improve overall, long-term outcomes. In September 2018, the RRTC received a five-year, \$4.3 million grant from the National Institute on Disability, Independent Living, and Rehabilitation Research, which will fund research into barriers hindering individuals with disabilities from maintaining employment. Four primary research projects will be undertaken with these grant funds: (1) reducing chronic lower back pain’s impact on work; (2) helping people with Parkinson’s stay employed; (3) strategies to successfully seek accommodations from employers; and (4) identification of employers’ best practices. Beyond carrying out these research projects, the RRTC will also (1) continue

disseminating its quarterly newsletter, which reaches approximately 4,000 people; (2) providing education to employers and the community at large on issues relating to the employment of individuals with disabilities; and (3) maintaining relevant resources and materials on the RRTC website.<sup>2</sup>

## **Conclusion**

In accord with the foregoing, Shirley Ryan AbilityLab looks forward to continued implementation of the above strategies to assist in addressing the five identified Priority Areas; Rehabilitation Health, Research, Improved Access to Information about Existing Resources, Support Programs, and Business Relationships. Specifically,

- We will continue to expand access for patients in various rehabilitation settings in the areas of stroke, spinal cord injury, neuro-musculoskeletal conditions, brain injury, pediatric care, and cancer, while also supporting the emotional, social, and psychological needs of our patients.
- We will continue our focus on translational medicine, both for our patients as well as collaborating with public and private entities worldwide related to cutting edge research.
- The LIFE Center will continue to communicate its programs and identify appropriate outreach for patients and their families through scheduled events and social media.
- We will assist patients and their families through programs relating to transitioning back to their homes and communities.
- We will continue to identify opportunities and appropriate vehicles to ensure patients have information related to hiring and employment.

Over the next three years, we will work diligently to continue implementing the strategies identified above which are designed to provide community benefits to those patients and their family members.

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<sup>2</sup> <https://www.sralab.org/research/labs/rrtc-employment-and-disability>