**NeuroRecovery Network Translates Activity-based and Fitness/Wellness Interventions to the Community**

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**Abstract**

The Christopher and Dana Reeve Foundation created the NeuroRecovery Network (NRN) as a means of aiding the translation of evidence-based interventions for individuals living with a spinal cord injury (SCI) from the lab to the clinic.  Care needed after discharge from traditional therapy identified the need for and creation of the Community Fitness and Wellness (CFW) branch of the NRN.  CFW facilities offer the same activity-based interventions offered in NRN rehabilitation clinics, in addition to other fitness and wellness opportunities, filling a gap in care for individuals living with SCI.  CFW facilities provide standardized evidence-based interventions that promote functional gains and administer standardized assessments to evaluate functional, health, and quality of life gains made as a result of these interventions. Standardization procedures and a national database gathering information on interventions and outcomes helps to evaluate the interventions being conducted across all sites, adding to the evidence-base of benefits in a community setting.  CFW facilities are staffed by professionals with training on the specialized needs of individuals living with SCI or other neurological disorders.  The establishment of CFW facilities allows for the quick translation of novel, effective approaches from the lab to individuals in the community, providing a much needed service for individuals to live long healthy lives despite a disability.

Keywords: NeuroRecovery Network, spinal cord injury, activity-based intervention, accessibility, fitness

## Introduction

The NeuroRecovery Network (NRN) was originally conceived by Christopher Reeve who wanted to give everyone with a spinal cord injury (SCI) access to the same cutting edge evidence-based interventions that his celebrity status afforded him.  It was Reeve’s vision to have an NRN program offering evidence-based interventions in every major city.  The cutting edge intervention, part of a paradigm shift in rehabilitation (1) was an activity-based intervention, which is a task-specific activity focusing on activating the nervous system below the level of injury (2).  The Christopher and Dana Reeve Foundation (CDRF) established the NRN with the main purpose of supporting the development of a network of specialized sites delivering standardized activity-based interventions for individuals with SCI or other neurological disorders.  In 2004 the NRN launched with a partnership of clinical outpatient rehabilitative care centers to provide activity-based interventions as part of their standard of care in physical therapy (3).

  The NRN quickly realized that participants who discharged from a therapy based NRN program could still benefit from the health and quality of life benefits of participation in a community evidence-based program incorporating activity-based interventions.  In 2009 the NRN opened the first of its Community Fitness and Wellness (CFW) facilities with the intent of delivering activity-based interventions in the context of a more holistic fitness and wellness program.  In recent years individuals who have experienced SCI or other traumatic neurological events have increasingly shorter lengths of stay in traditional inpatient and outpatient therapy programs (4). Rimmer and Henley (4) proposed a rehab continuum model that would more closely tie traditional therapy based programs to community based programs.  This model closely resembles the structure of the NRN and brings light to a paradigm shift within the neurological rehab continuum.

The NRN CFW program has six main goals: 1) Maximize the availability and quality of activity-based fitness and wellness programs within a continuum of care provided to individuals with SCI and other physical disabilities. 2) Provide quantitative measures of the response to the activity-based fitness and wellness programs. 3) Maintain a comprehensive database that will include measurements of functional presentations, health, quality of life measures, and cost and revenues associated with the activity-based community fitness and wellness programs. 4) Identify the optimal activity-based fitness and wellness program for specific populations with SCI and other physical disabilities. 5) Provide training and support for personnel and technical resources needed to provide activity-based fitness and wellness programs on a routine basis to a maximum number of people in a community setting. 6) Maintain a network of community facilities that provide standardized activity-based fitness and wellness programs to specific populations through the training and monitoring of personnel

CFW has enrolled 388 total clients, who are on average 18 months post-injury. Table 1 gives basic demographic information for the CFW population, which falls roughly in line with demographics of those living with an SCI in the United States (5).  Ongoing assessments of functional and fitness changes are collected in a standardized manner and have just begun to be evaluated.

## CFW Facilities Provide a Continuum of Care

An abundance of literature has been amassed showing the benefits of physical activity on health, psychological well-being, and quality of life for everyone (for a review see Peterson (6).  Individuals with an SCI face difficulty in being active and maintaining suggested levels of exercise.  Temporary or permanent paralysis means that those with an SCI are often inherently forced into a sedentary lifestyle, often using a power or manual wheelchair as the primary mode of mobility and spend the entirety of their day in a seated or supine position.  Sitting for prolonged periods of time has shown to increase the risk of mortality, diabetes, cardiovascular disease, and cancer (7).  The American Physical Therapy Association (8) recommends routine cardiovascular and resistance training for individuals living with SCI to help combat the negative health consequences of a sedentary lifestyle.  Those with a disability experience a decrease in health and function after discharge from rehabilitation, however the gains made in rehab can be maintained with exercise (4).

Individuals living with an SCI can see the same benefits from exercise as non-disabled individuals, but additionally exercise has been found to reduce the secondary health complications of living with a spinal cord injury such as pain, depression, stress, and pressure ulcers (9-12). Quality of life and subjective well-being are also concerns for those with an SCI, and numerous studies have found improvements in these factors after exercise regiments (13-17).

In light of the benefits of exercise for those with an SCI, it’s important to understand the unique barriers to their participation in fitness programs.  Individuals with a disability report feelings of apprehension about using traditional gym facilities due to embarrassment about their condition, a lack of knowledgeable staff to help with exercise plans, and concerns about the impact of help from personnel uninformed about their disability (18).  Concerns about fitness facility personnel lacking knowledge of fitness information for individuals with disabilities was also raised in examinations of accessibility and ADA compliance of these facilities (19-21).  A survey of fitness personnel found that they agree that working with an individual with a neurological disorder would be beneficial for the individual, other gym members, and the gym personnel, but only those with more training and education working with such a population had perceived competence in the task (22).  Professionals in the fitness industry feel that the main barrier for providing fitness opportunities for this specialized population is a lack of specifically trained staff (23).

The benefits of physical exercise for someone living with an SCI goes beyond the benefits for an able-bodied individual as paralysis limitations increase the risk of a sedentary lifestyle, and secondary syndromes from the SCI can be improved with increased exercise (9-12).  However traditional gym facilities often do not comply with ADA regulations for accessibility and trained staff in assisting individuals living with a disability (19-21).  Due to potential paralysis and mobility limitations, access to physical activity and opportunities for exercise is greatly diminished in comparison to the able bodied general population.  The consequences of a sedentary lifestyle, prolonged seated time, and barriers to accessible exercise opportunities make it necessary for specialized programs to give people living with SCI an opportunity to improve or maintain their health and quality of life through community fitness and wellness programs.  The NRN CFW facilities provide accessible, specialized equipment, and well-trained staff in order to meet the needs of individuals living with an SCI.

## Network Organization

The CFW branch of the NRN has a network structure similar to the structure of the clinical branch of the NRN.  The network is organized in order to assure standardization across the sites and easy implementation of new evidence-based techniques.  As was described by Harkema, Schmidt-Read (3), the NRN is governed by an advisory board which guides the course of the NRN.  The CDRF and advisory board oversee the operations of the NRN.  The co-network directors each oversee different realms of the NRN.

The organizational structure of the NRN is designed to encourage collaboration and cooperation across multiple disciplines. This collaboration between fitness professionals and therapists helps with standardization of outcome measures collected, interventions delivered and data collection.  Each CFW facility designates a director for the site which is responsible for the overall operation of the facility in accordance with the NRN policies and procedures.  The director is responsible for the financial documentation associated with the NRN.  CFW Administrators at each site oversee the membership process, staffing, scheduling, and financial management.  Facility supervisors are certified therapeutic recreation specialists, Physical Therapists, Occupational Therapists, Certified Athletic Trainers, or Rehabilitative Exercise Physiologists/Specialists who serves as a direct supervisor of daily functions of the CFW facility.  Facility supervisors have advanced skills in neurological disability and a minimum of three years rehabilitation or activity-based intervention experience. Additionally CFW facilities designate a database manager who is responsible for all aspects of data entry and transmission.

Along with these designated positions, CFW has established several standing committees to oversee and discuss various issues to assure adherence with the NRN mission.  CFW standing committees include the finance/business strategy committee, health committee, education committee, and Data Integrity and Dissemination Oversight/Outcomes committee.  The goals of the Finance/Business Strategy committee include identifying additional funding sources, identifing fundraising opportunities, and help all sites find financially sound business models that work for their particular setting.  The health committee addresses any health concerns that may arise in the client population as well as assuring that proper provisions are in place for assuring the health of clients. The education committee is dedicated to assuring that CFW facilities are standardized in their education and training for NRN standardized interventions and assessments.  Data integrity issues are handled by the Data Integrity and Dissemination Oversight committee which assures standardization of all data collected and facilitates dissemination of the data for analysis.

### *NRN Core Administration*

CFWs provide the most advanced activity-based programs designed to improve the fitness and health for people with SCI and other physical disabilities.  They implement the procedures and protocols recommended by the Network Directors that support the activity-based fitness and wellness programs. Outcome evaluation of the interventions performed is accomplished by collecting measures in a standardized assessment at designated times (see Assessments below).  The data collected during these evaluations are entered into a web-based data collection system which funnels into a national database housing data from all CFW facilities.  The dynamic national database can take data exported from specialized fitness equipment, minimizing human data entry errors.  Overseeing this database is a network data manager who, with support from programming staff, institutes integrity checks on the data to assure accuracy and compliance with standardized procedures.  The network data manager works with sites to assure proper coding of the data and standardization of interventions and assessments.  An NRN network administrator facilitates communication between sites within the CFW branch of the NRN, and also between the two branches of the NRN.  The administrator maintains records of committee operations and assures that committees have the necessary tools and information to meet their goals.  These NRN core administrative roles help to assure that the network runs smoothly and advances the goals of the network.

### *Selection of Facilities*

Inclusion of new sites is handled by CDRF, as is outlined by the process described by Harkema, Schmidt-Read (3).  Responses to CDRF’s request for applications to join CFW are evaluated for the site’s resources, including personnel and equipment, and the need for such a facility in the community.  The NRN advisory board makes the final selection based on priority scores assigned by external reviewers.

## Standardized Assessments

All CFW clients must be cleared by their physician to participate in activity-based interventions and fitness programs.  Physicians must sign off on a form generated by the CFW facility that includes a detailed description (with pictures) of interventions performed at CFW facilities. The form provides check boxes for each of the activity-based interventions as well as seated exercises and weight-bearing exercises to assure physician clearance for each intervention. Written informed consent, overseen by an institutional review board is collected from all clients participating in the NRN CFW program.

Upon enrollment in CFW clients are given an initial assessment to determine their level of functioning and a trainer works with the client to create fitness goals.  When a client changes membership packages and hence changes which interventions are received, a new assessment is to be performed in order to collect post-test measures from the set of interventions completed, and pre-test measures for the new set of interventions starting.  Upon continuous enrollment with the same interventions clients are assessed on the NRN standardized outcome measures assessment every 90 days for the first year, and every 90 days or 180 days after the first year, depending on the needs of the client.  Exercise plans and goals are updated as necessary based on these assessments.  Clients are also assessed on these measures upon conclusion of membership in CFW.  In addition to these fixed assessments, daily session interventions with and without assistance are documented and recorded in the web-based data collection system.

The CFW standardized assessment includes functional measures examining changes in gait, balance, and activities of daily living. Functional measures assessed include the NRS (24, 25), Berg Balance Scale (26), Modified Functional Reach (27), Six Minute Walk Test (28), and submaximal cardiovascular test. Physiological changes such as girth and strength measures are assessed, as well as additional measures such as respiratory testing and quality of life indicators. Quality of life is assessed through a battery of validated assessments including the satisfaction dimension of the Ferrans and Powers (29) Quality of Life Index v.III for SCI, the Center for Epidemiological Studies Depression (CES-D) Scale (30), Katz Index of Independence in Activities of Daily Living (31), the Craig Handicap Activity Reporting Technique-Short Form (32), and the computer adaptive SCI-QOL (33).

Data collected from assessments and interventions from each CFW facility are submitted through a HIPAA compliant web-based portal and de-identified data from all sites are merged and housed at the network data center managed by the NRN core network data manager.  Data collected during assessments is used to evaluate activity-based interventions used in the community setting.

## Standardized Fitness

CFW is not intended to take the place of inpatient or outpatient therapy. All new members of a CFW facility will receive an initial assessment by NRN trained fitness professionals prior to the initiation of activity-based interventions.  Based upon the findings of the assessment, fitness goals will be established and a specific activity-based program identified and discussed with the client.  CFW participation, as part of the NRN, does not have a standardized dose or frequency of participation.  Clients may choose to participate in any or all of the interventions as they are able based on staff recommendations, personal preferences and goals, available time, financial limitations, or scheduling restraints.  Each intervention is standardized by the NRN and has minimum requirements that must be met in order to meet NRN intervention thresholds. A description of each intervention and the standardized intervention thresholds are listed below.

### *Neuromuscular Electrical Stimulation (NMES)*

NMES is an activity-based intervention where a client performs specific motor tasks facilitated by twelve channels of alternating electrical current via percutaneous electrodes placed over specific muscles that show the most impairment from pre-injury abilities.  Task-specific activities and progression through stages of recovery are based on the NeuroMuscular Recovery Scale (NRS) (24, 25).  The NRS helps to assist trainers and clients to determine current recovery levels and provides a picture for trainers to use in determining goals for the client. The NMES intervention has clients perform tasks based on the three lowest scores of NRS.  Motor tasks are executed through facilitation by the stimulation and manually by trainers. The standardized threshold for an NMES intervention is 60 minutes of activity including performance of the motor task both with and without stimulation and manual facilitation. Pulse widths are standardized at 1000µs and frequency is standardized at 100 Hz. Amplitude during NMES varies from client to client based on tolerance and muscle response. Restorative Therapies Inc.’s RTI RT60 stimulators are used in conjunction with XCITE software to deliver the stimulation.

Additionally NMES can be performed while cycling. This intervention uses an alternating electrical current via percutaneous electrodes over the motor points eliciting muscle contractions that can be used to pedal a cycle ergometer (34).  Fitness benefits of electrical stimulation include increased aerobic health (35) and increased bone mineral density (36).  NMES cycling can be performed while upper-extremity cycling or lower-extremity cycling using the Restorative Therapies Inc.’s RT300 FES.  NRN protocols require clients to ride with twelve stimulated muscle groups at a pulse width of 1000µs and a frequency of 100Hz with a varying amplitude based on client tolerance and muscle response. The RT300 cycles deliver stimulation to the assigned muscle groups in a functional cycling pattern based on the crank angle of the ergometer.  NRN standardization threshold for an upper extremity NMES intervention is thirty minutes of active stimulation time and for a lower extremity intervention is sixty minutes of active stimulation time.

Pulse width and frequency of stimulation for NMES interventions remain constant in order to elicit an increased central contribution of torque to stimulated muscle groups. Dean and colleagues (37) showed that stimulation at these higher parameters increases the afferent volley to the spinal cord and leads to an increase in central torque, which recruits motor activity at the level of the synapse and creates a natural order of motor neuron recruitment.  Stimulation using lower parameters of 20 Hz or less recruited motor neuron activation in a more forced, artificial manner.

### *Locomotor Training*

Locomotor training in CFW facilities follows the general principles and practices of Harkema and colleagues (2).  Locomotor training is comprised of forty-five minutes of standing and walking on a body weight supported treadmill (BWST) followed by a thirty minute session of task specific training in an over ground setting. Standardized progression of the Locomotor Training model is defined by the overall score of a client based on the NRS and standardized practices defined by Harkema and colleagues (2).  The principles involved in Locomotor Training include: maximizing weight-bearing on the legs, optimizing sensory cues, optimizing kinematics, and maximizing recovery strategies (38). Along with generating larger EMG amplitudes, performing Locomotor Training can increase the endurance of a client. Harkema and colleagues (2) suggest that continuous Locomotor Training will lead to an ability to resist fatigue.

### *Other Interventions*

The NRN standardized threshold for a strength training intervention is a client completing at least two sets of three different strength training exercises. Strength exercises include all typical exercises performing in a standard strength training routine such as a bench press, back row, or leg lifts. There is no minimum number of repetitions that must be completed during the sets of each exercise.  An NRN cardiovascular training intervention is the performance of any cardiovascular activity for a minimum of 15 minutes. Vibration training is also offered by the CFW. Vibration training can be used for tone/ spasticity or as a strength training modality. In order to be considered a tone/ spasticity measure the client must perform 4 bouts of vibration for 45 seconds at a frequency of 50Hz and a low amplitude. For a strength training modality, a vibration intervention is the performance of 12-15 minutes of vibration time, a frequency of 40-50Hz, and a moderate amplitude.  Interventions are set to a minimum level in order to accommodate a wide range of functional and endurance abilities of clients.  Lessons on nutritional information can be provided to clients as an educational intervention.  Twelve lessons created by Courage Center nutritionists are given to clients over the course of several weeks.  Pre and post course tests measure the client’s knowledge of nutritional information and barriers to compliance.

CFW facilities offer a variety of membership packages to meet clients’ needs and abilities. A basic membership includes access to all equipment except Locomotor Training, and NMES.  Activity-based membership packages include Locomotor Training and NMES. A guided exercise package includes sessions with a personal trainer or other exercise specialist focusing on strength and cardiovascular fitness. Some CFWs also opt to have an alacarte option to create packages of these interventions at varying doses specific to a client’s needs. For example, a guided exercise package may be added to the activity-based membership allowing for time with a person trainer along with activity-based interventions.

## Progression

CFW clients are progressed through functional recovery based on the phases of the NRS (24, 25).  Using the NRS as an evaluation tool gives trainers and clients a progression of functional outcomes to strive for. During the evaluation the client’s functional limitations are assessed and a plan is developed to improve function based on the assessment outcomes.  While the NRS serves as a major tool for progression, clients in CFW also provide self-reported goals. Activity-based technicians work closely with clients to develop reasonable and attainable goals. Self-reported goals coincide with NRS tasks, but often allow for a specificity of training within applied interventions.

## Staffing

Each CFW facility is staffed by athletic trainers, personal trainers, exercise physiologists and some have licensed therapists.  Sites are required to maintain a staff that can properly evaluate client status, administer regular activity-based interventions, record all relevant data, and report in a web-based database. Each site maintains a supportive environment that will encourage open communication between the client, family and the facility staff to facilitate the application of potential evidence-based techniques for addressing client’s specific needs.  Staffing models vary based on the organizational model of the facility.

## Equipment

CFW facilities offer various pieces of fitness equipment necessary to deliver standardized NRN activity-based interventions.  Locomotor training requires a close-looped computer-controlled body weight support treadmill system with ergonomic seating for trainers which allow proper hand placements, along with appropriate harnessing in various sizes to meet client needs.  NMES requires Sage device tablet with XCITE software, 2 RT60 stimulators with a 12 channel stimulation capacity.  NMES cycling is conducted using both lower extremity and upper extremity FES cycles with stimulator tablets and dual RT 60’s.

Additional equipment necessary at CFW facilities includes a height adjustable mat, front and side mirrors to provide visual feedback, cardiovascular/aerobic conditioning equipment, strength and muscle development equipment, specialized grip equipment such as gloves, cuffs and hooks for clients lacking fine motor skills, and dynamic exercise equipment such as exercise balls, wedges, therabands, and free weights.  A vibration plate, either the Wave or Power Plate Pro 6, is used for strength training and tone or spasticity management.

Standardized outcome measures during assessments require the following pieces of equipment. Automatic blood pressure monitoring equipment, including a cardiac chair or mat that can quickly change position to a 90 degree hip/90 degree knee position for measuring orthostatic hypotension. A digital video camera for monitoring client progression and facilitate training and standardization among facilities.  A wheelchair scale is utilized for measuring client’s body weight. Strength is measured with a Lafayette dynamometer.  Pulmonary function and respiratory testing is completed using Breeze Suite System Medgraphic spirometers, Boehringer (Model 4103) peak flow manometer and the Philips Respironics peak flow meters, both low range 30-390 L/min and standard range with replacement disposable mouthpieces.

## Financial Aspects

All CFW facilities have payment and membership structures that meet their site specific needs. For example, a CFW that is within a hospital system may have access to billing systems and contracts while a freestanding fitness center may not. CFWs are mainly privately paid for their services and gym memberships. Some CFWs have contracted with insurance companies to bill for fitness services. Most have scholarship options for clients who do not have the funds or insurance coverage to pay for their program.

## Education and Training

Standardization is integral to the overall mission of the NRN. In order to provide the best interventions for clients, staff at each facility must be trained in the standardized assessment outcome measures and interventions. This standardization is implemented through regional trainings, an annual national summit, conference calls, and regular site reviews.

The NRN partners with the NeuroRecovery Training Institute (NeuroRTI) to host regional training events at NRN sites around the country.  Not only do these hands-on training seminars provide standardized instruction on activity-based interventions for NRN staff, it also allows for the dissemination of the evidence-based interventions to other professionals in the community.  National Summit, a joint venture with the Community Fitness and Wellness facilities and the clinical rehabilitation centers, is an event hosted annually by the NRN to advance instruction and standardization throughout the network. The multi-day training welcomes participants from all NRN sites to foster communication and standardization. Sessions on network procedure are led by senior team members from the network.

On a monthly basis, designated members of each facility participate in conference calls to review standardized procedures and identify areas for improvement in the network. Included in this process is a monthly video review in which facilities present successful or challenging client presentations.  Other network members involved in the video review learn from and suggest additional approaches within the scope of NRN standardized interventions.  Through the use of these regularly scheduled conference calls, the NRN promotes an atmosphere of collaboration and standardization.  Annually in order to ensure compliance with the CFW model, the NRN completes reviews of each facility to assess the staff’s technical skills and overall standardization procedures and data collection. Annual reviews are conducted by members of network leadership.

## CFW Role in Expanding Services for SCI

There is an expanding collective realization within the fitness community for the need to become more inclusive to individuals with disabilities (4, 39).  In conjunction with this heightened awareness of need, an increasing number of resources are becoming available to provide guidance for fitness facilities to become accessible to individuals with a disability (40). Professional organizations such as the American College of Sports Medicine (ACSM) in collaboration with the National Center on Health, Physical Activity, and Disability (NCHPAD) and the National Strength and Conditioning Association (NSCA) offer certification as Inclusive Fitness Trainers and Special Population Specialists, respectively, to increase the knowledge base and skillset of fitness professionals (see acsm.org and nsca.com for more information).

A small but growing number of fitness facilities are being constructed that not only meet, but exceed ADA requirements for accessibility and offer adaptive equipment that can be used from a wheelchair (41).  NextStep is a non-profit organization whose goal is to make life-changing rehabilitation and fitness accessible and affordable to those living with paralysis (see www.nextstepfitness.org for more information).  Nextstep offers state-of-the-art equipment, NRTI certified trainers, cutting-edge therapies, and comprehensive activity based training programs.  Their flagship facility in Los Angeles was the first community based facility in the US to be a member of the NRN and is furthering the goals of CDRF and the NRN by expanding to facilities in other cities, recently Atlanta, Orlando, and Kansas City.

Additionally, various franchising models with standardized intervention methods to promote opportunities for individuals living with paralysis have begun to spring up in various locations around the world.  These stand alone and franchised facilities, along with a growing number of certified professionals, have improved access to fitness opportunities for the SCI community.  The unique contribution of NRN CFW facilities is the opportunity for ongoing development of evidence-based interventions through the dissemination of data collected across multiple sites housed in a national database. NRN CFW facilities not only provide individuals with SCI and other neurological diagnoses accessible fitness opportunities, standardized research-supported activity-based interventions, and highly trained staff, but also have a network of facilities contributing to a database collecting quantitative data on daily session interventions and 90-day assessments capturing a wide breadth of functional, health, and quality of life outcome measures. As a network, the NRN strives to help individuals living with an SCI or other neurological disorders receive the best possible care through evidence-based practices.

## Conclusions

The CFW branch of the NRN works to meet the needs of individuals living with an SCI in the community by offering specialized fitness equipment, specially trained staff, and evidence-based activity-based interventions.  The standardization of interventions and outcomes across multiple sites and a national database allows for the evaluation of interventions and quick implementation of new evidence-based interventions.  The health benefits of the activity-based interventions offered at CFW facilities can be easily evaluated, adding to the knowledge base of functional recovery.  CFW facilities help further CDRF’s mission to improve the accessibility of evidence-based interventions for those living with SCI and other neurological disorders. CFW facilities provide a valuable service to those living with a disability, translating clinical evidence-based techniques to the community.

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Table 1 CFW enrollment demographics (values expressed as median (min-max) unless otherwise stated)

Figure 1 CFW organizational chart