

PROGRAM EVALUATION OF ACCESSURF HAWAI'I,  
AN ADAPTIVE SURF, SWIM AND CANOE PROGRAM FOR PEOPLE  
WITH DISABILITIES

DISSERTATION FOR THE DEGREE OF  
PhD in PUBLIC HEALTH  
AT THE UNIVERSITY OF HAWAI'I AT MĀNOA

March 2021

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## **ACKNOWLEDGEMENTS**

### **Acknowledgement of academic support**

I would like to thank all five members of my PhD committee, and especially Dr. Kathryn Braun, the chair, for her support throughout the years.

I would also like to thank all AccesSurf Hawai'i community members who helped with designing and facilitating the studies and all study participants. It was a pleasure to read their input on the surveys, talk to and learn from those interviewed.

### **Acknowledgement of other support**

I would like to use the opportunity to thank the Craig H. Neilsen Foundation, which supported the development of Study 1's Skills Tool.

My heartfelt thanks to my family, especially my husband, Dan Prellberg, and my daughter's home health nurse, Angela Tilden, within that past year.

I thank Caitlin McOmish and Julia Mortimer for editing support.

## **ABSTRACT**

Approximately 15% of the global population lives with disability (1). The proportion is even greater in the United States, where 1 in every 4 adults experienced disability in 2017 (2). People with disabilities have three times greater risk of developing non-communicable diseases than people without disabilities (3), in part because they are less active than their peers without disabilities (4). People with disabilities also are likely to experience social isolation and loneliness, which can lead to negative health consequences and even lower physical activity levels (5–8).

One approach to combating these health disparities is through community programming in adaptive sports. AccesSurf Hawai'i provides people with disabilities the opportunity to participate in adaptive swimming, surfing, and canoeing. The purpose of my three-study dissertation was to evaluate AccesSurf's impact on participants' benefits, ability to assess community need during COVID-19, and program sustainability.

Study 1 identified the benefits of aquatic physical activity and participation in AccesSurf programs for people with disabilities through a secondary data analysis of participant surveys (called "Fun Wall") (n=442) and a Skills Tool (n=8). Results showed that participants improved in levels of aquatic physical activity, skills, independence, confidence, and community integration.

Study 2 identified AccesSurf community's need for programming during the COVID-19 pandemic through a mixed-method approach, first soliciting answers from open-ended questions (n=89), followed by a closed-ended questionnaire (n=149). There was high awareness and satisfaction across all programs, including the newly added virtual programs. The results provided insight into community needs, and showed differences between sub-groups, such as in feeling the effects of COVID-19 pandemic.

Study 3 explored the contributing factors of AccesSurf's sustainability, as well as opportunities for improvement, using a mixed-method approach. The closed-ended Program Sustainability Assessment Tool (PSAT) (n=15) was administered to governing members, followed by in-depth interviews (n=5). This study highlighted areas of strength, including AccesSurf's adaptability, champions, and communications. Areas for improvement are strategic planning, stable funding, and partnerships with other community organizations and leaders.

Taken together, findings confirm that the program was beneficial to participants, has high program satisfaction, and many characteristics supporting its sustainability, with some room for improvements, all of which benefit the AccesSurf community. Findings can inform

similar organizations that are providing innovative, recreational physical activity options for people with disabilities and future research.

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## LIST OF ACRONYMS

|           |                                                                                                       |
|-----------|-------------------------------------------------------------------------------------------------------|
| ASD       | Autism spectrum syndrome                                                                              |
| BOD       | Board of Directors [AccesSurf Hawai'i]                                                                |
| CBPR      | Community-based participatory research                                                                |
| CDC       | Centers for Disease Control and Prevention                                                            |
| CDC-FPEPH | The Centers for Disease Control and Prevention's Framework<br>for Program Evaluation in Public Health |
| COVID-19  | 'CO' stands for 'corona,' 'VI' for 'virus,' and 'D' for disease (discovered in 2019)                  |
| DATB      | Day-at-the-Beach [main program of AccesSurf Hawai'i]                                                  |
| ED        | Executive Director                                                                                    |
| FG        | Focus Group                                                                                           |
| FM        | Family Member(s)                                                                                      |
| HASC      | Hawai'i Adaptive Surfing Competition [hosted by AccesSurf]                                            |
| I         | Interviewee                                                                                           |
| ICF       | International Classification of Functioning                                                           |
| NCD       | Non-communicable diseases                                                                             |
| OT        | Occupational Therapist                                                                                |
| p.        | Page                                                                                                  |
| P         | Participant(s)                                                                                        |
| PAD       | Physical Activity for people with disabilities                                                        |
| PTSD      | Post-traumatic stress disorder                                                                        |
| PSAT      | Program Sustainability Assessment Tool                                                                |
| SCI       | Spinal cord injury                                                                                    |
| V         | Volunteer(s)                                                                                          |

## CHAPTER 1: Introduction

### Literature Review

Worldwide about 15% of the population has some sort of health condition causing disability (1). The proportion is even greater in the United States (US), where more than 61 million adults – or 1 in every 4 – experienced disability in 2017 (2). In 2017, 20.2% of people lived with disabilities in Hawai'i (2).

Disability has a wide range of definitions, and different programs and policies use different criteria for measuring disability, resulting in discrepancies in percentages across sources (9, 10). For the purpose of nondiscrimination laws, an individual with a disability is *'someone who: 1) has a physical or mental impairment that substantially limits one or more major life activities; 2) has a record of such an impairment; or 3) is regarded as having such an impairment (Section 503)'* (9,11). The International Classification for Functioning, Disability and Health (ICF) defines disability as an *'umbrella term for impairments, activity limitations, and participant restrictions (p.2)'* (12,13). Some sources use the following six categories--mobility, cognition, independent living, hearing, vision and self-care--to determine whether someone has a disability (2). This definition aligns with that of the World Health Organization (WHO) and its 191 Members States. Thus, disability is neither solely a biological nor social phenomenon. Rather, it signifies the interaction among individuals, their health conditions, and contextual (environmental and personal) factors (13).

In this dissertation, the disability definition follows the concept of the ICF, in which impairment is understood as *'problems in body function (the physiological, including psychological functions) and structure such as significant deviation or loss (p.5)'* (14). Examples of health conditions causing physical/mobility impairment are back or spine problems/injuries, limb or extremity stiffness/amputation, and stroke. Physical/motor impairments are sometimes referred to as physical disability. Stroke, however, can also cause other impairments that might be referred to as cognitive disabilities. Van Ploeg and colleagues adapted the ICF model for people with disabilities by adding a behavioral component (including attitude, social influence and self-efficacy), resulting in the Physical Activity for people with Disabilities (PAD) model (15).

### **The Importance of Physical Activity, Especially for People with Disabilities**

Physical activity is essential to the maintenance and improvement of physical and mental health and well-being, and is defined as: *'a bodily movement produced by skeletal muscles that requires energy expenditure'* – including activities undertaken while working, playing, carrying out household chores, travelling, and engaging in recreational pursuits (16).

The 2020 evidence-based physical activity recommendations from the WHO differentiated recommendations for sub-groups. However, for adults with and without disabilities (18-64, and 65 years and older), a minimum of 150 to 300 minutes of moderate-intensity physical activity or a minimum of 75 to 150 vigorous-intensity physical activity is recommended. Higher levels of physical activity lower the risk of all-cause mortality. Physical activity also has an inverse relationship with hypertension, type-2 diabetes, colon and breast cancer, adiposity, and symptoms of depression and anxiety. Physical activity also improves mental health, cognition, sleep, and quality of life (17).

People living with disabilities are more likely to report physical inactivity than people without disabilities (3,4). For example, among a sample of people with spinal cord injury (SCI) in a Canadian province, only 12% met the SCI-specific physical activity guidelines, and 44% reported zero physical activity (18). Physical inactivity among people with SCI contributes to their higher prevalence of chronic conditions compared to people without disabilities (2). Secondary conditions common in people with SCI are pulmonary and cardiovascular conditions (both linked to physical activity), as well as spasticity (experienced by 78% of individuals with SCI), and pain and depressive disorders (19–23). Respiratory conditions, especially infections such as pneumonia, are the leading cause of death among people with SCI (24). Unfortunately, people with disabilities have three times greater risk of developing non-communicable diseases (NCDs) than people without disabilities, yet physical activity options for people with disabilities are extremely limited (2).

### **Aquatic Physical Activity for People with Disabilities**

Rimmer and colleagues performed a literature review in 2010, looking at exercise interventions for people with disabilities, including people with impairments from stroke, multiple sclerosis, Down's syndrome, traumatic brain injury, spinal cord injury, cerebral palsy, polio, muscular dystrophy, and Parkinson's disease (25). The authors concluded that the available literature on exercise and disability is general in scope and has limited generalizability to any explicit disability group. They recommend creating evidence using stronger research designs and better measurements of key health outcomes (25). Out of the included 80 articles, most focused on land-based activities, and only eight featured aquatic exercise.

Four other reviews on exercise for people with SCI, published between 2007 and 2011, found a variety of benefits, including improvements in cardiorespiratory, cardiovascular, cardiac, metabolic, bone, biomechanical, strength, quality of life, mechanical efficiency, physical and respiratory function, endurance and wheelchair handling. However, none of the 85 studies of

three reviews and only one of the 69 studies in Hick's review, examined water-based physical activity in people with SCI (26–29).

Aquatic exercise for people with disabilities has been demonstrated as beneficial, particularly those whose movement limitations hinder land-based physical activity, such as children and adolescents with cerebral palsy (30). A review of six articles (2005 to 2010) found significant improvements in muscle strength, energy expenditure, gross motor function, and mobility performance in home and community aquatic exercise programs for people with disabilities (30). In 2017, Li and colleagues published a systematic review of articles reporting on aquatic physical activity interventions for people with SCI. Eight articles met inclusion criteria (out of 276 identified). Four studies measured physical function and four measured aerobic fitness, and generally studies found significant improvements (31).

I also conducted a systematic review of benefits of aquatic physical activity options for people with SCI to inform the development of this dissertation proposal, searching PubMed, PsycINFO, and Web of Science (32) (Appendix I). Unlike the review by Li and colleagues, all study designs were included. Articles were categorized into the six levels of evidence as suggested by the SCI-Research-Evidence-Team. The quality of all articles was assessed by 10 items from the Downs and Black scale. Of 527 articles identified, 16 articles representing 14 different studies, met the inclusion criteria. The studies examined a wide range of aquatic interventions, including aquatic immersion, hydrotherapy, walking on an underwater treadmill, swimming, scuba-diving, and kayaking. Twelve of the 14 studies reported on pool-based physical activity. One intervention was tested by a randomized controlled trial, four by quasi-experimental design, and three by single-group pre-post design. Two case reports and five cross-sectional studies also were included. Most commonly measured were pulmonary function (seven studies), cardiovascular function (five), spasticity (four), and gait function (three). All studies showed improvement in their measures, regardless of the study type. This review concluded that, although much of the research testing aquatic physical activity interventions has been weakly designed, aquatic physical activity appears to improve pulmonary and cardiovascular function, spasticity, and gait function in people with SCI. It also concluded that future studies should evaluate the effects of aquatic physical activity on psychosocial as well as physical outcomes and examine the effects of aquatic physical activity in natural settings, such as rivers, lakes, and oceans.

There is also limited research on aquatic exercise for people with cognitive and emotional/ mental difficulties. In 2016, Herold and colleagues performed a scoping review on post-traumatic stress disorder (PTSD), sensory integration, and aquatic therapy, including 18

articles. While it was found that aquatic therapy can be beneficial for adults and children with orthopedic, cognitive, emotional, and chronic illness, none of the articles addressed the impact of aquatic therapy on people with PTSD (33). However, land-based exercise in the population with PTSD has shown improved symptoms, such as depression, sleep disruption, and suicide attempts (34).

In 2019, a scoping review analyzed the findings of 40 articles on physical activity and social functioning in young people with autism spectrum syndrome (ASD), arguing that offering such programs may affect each outcome. The authors found that social functioning appears to influence physical activity (to a lesser extent) and physical activity influences social function (to a greater extent) (35). Aquatic exercise and skill teaching are especially important among people with ASD, as accidental drowning is the main reason for deaths in children with ASD under 14. However, there are no reviews on the benefits of aquatic exercise, such as swimming, surfing etc., for people with ASD. There is some limited research examining swimming programs for children with ASD. For example, an article published in 2019, evaluating a swim program for children with ASD and their families, claimed to be the first to investigate this type of program for this population. The authors found that children perceived swimming as a meaningful family activity, and that one-on-one instruction for children with ASD and their families can develop their skills for safe swimming (36).

### **Isolation and People with Disabilities**

In addition to having lower levels of physical activity, people with disabilities are also more likely to experience social isolation and loneliness, in part because of exclusion, but also because a common means of coping with a disability is to try to hide it. Loneliness can have negative consequences on a variety of health outcomes in people with and without disabilities, including decreased immunity and increased risk for dementia, cardiovascular disease (6), and premature death (7). A study with people with visible disabilities suggests that lower levels of physical independence and social skills and higher levels of social anxiety are associated with loneliness. Hence, these factors need to be considered when designing programs for people with disabilities (5).

Loneliness is also directly linked to lower physical activity (8). Inaccessible environments can lead to feeling left out, isolated, or even shunned. They also take away the opportunity to be physically active, which is discriminatory against people with disabilities. Isolation is not only experienced by the person with the impairment, but also by the families caring for a loved one with special needs (37). This takes a toll on individual and caregiver health, and further

increases the risk of isolation and inactivity. On the community level, this also results in preventable social and economic disparities and higher health care costs and burden.

### **Adaptive Surfing**

Adaptive Surfing, as the name suggests, is surfing adapted to people with physical impairments through adapted equipment. A broad review of literature between 1975 and 2021 found four journal articles on adaptive surfing, one on surf medicine, and one special issue on surf therapy (38–43).

Adaptive surfing activities fall under a larger umbrella of community-based rehabilitation, as it addresses physical activity and inclusion in people with disabilities. Community-based rehabilitation programs are known to support primary prevention of NCDs for people with and without disabilities. They also support tertiary prevention among people with disabilities by preventing further negative health consequences and activity limitations, and by promoting independence, participation, and inclusion (44). Evaluating community-based rehabilitation works best when evaluated and contextualized by the local community – *‘the evaluative process needs to be conducted in close collaboration with the local community, including people with disabilities, and to be followed by sharing the findings and taking actions’* (45). This finding supports the community based participatory research (CBPR) approach and principles that guided a previous pilot evaluation and this dissertation (46,47) with the community partner AccesSurf Hawai‘i.

### **Community Partner: AccesSurf Hawai‘i**

#### **An Organization Providing Aquatic Physical Activity for People with Disabilities**

AccesSurf Hawai‘i, an established 501(c)3 non-profit organization since 2006, was the community partner for this dissertation. The organization is based on O‘ahu, where all programs take place. The mission of AccesSurf is to *build an inclusive community that empowers people with disabilities through accessible beach and water programs* (48). AccesSurf helps people with disabilities participate in aquatic-based, namely ocean and outdoor pool-based, physical activity by modifying surfing and other equipment and/or the way a person surfs or canoes to accommodate their skills/needs. To fulfill their mission, AccesSurf has established several programs: Day-at-the-Beach (DATB), Wounded Warrior DATB, Swim, Surf and Canoe Clinics, Outreach, Surf Team, and (Volunteer) Trainings, all of which are free-of-charge and run by certified volunteers.

## **AccesSurf Activities Pre COVID-19**

Day-at-the-Beach (DATB) is AccesSurf's main out of eight programs. It has grown from about eight participants a month in 2006, to about 140 participants a month just prior to the COVID-19 pandemic (February 2020). Out of the 1,281 participants in 2018, 1,128 disclosed their health condition upon intake: 20% were people with SCI; 20% were people with autism; 7% were people with cerebral palsy, 7% had PTSD, 7% with amputation; 6% with stroke, 6% with traumatic brain injury, and 5% with vision or hearing impairment. Fewer participants had Spina Bifida, Multiple Sclerosis, Muscular Dystrophy, Erb's Palsy, Epilepsy, cancer, or some other condition. About 31% of participants were children and adolescents, 63% were adults, and 6% were seniors.

DATB is a monthly program, run on the first Saturday of each month at White Plains Beach Park on O'ahu, Hawai'i. DATB is mainly volunteer-based. AccesSurf rents a storage unit and owns two trucks with which the equipment, such as tents, an accessible mat, tables, surfboards, floating devices, rash guards and water-shoes, are taken to the site prior to the event. The set-up includes erecting tents for check-in, gear, and participants. In between the tents, a portable accessible mat is rolled out. This mat covers the beach from the grass/ground area to almost the ocean, where a water chair is located. Before each event, there is a volunteer training session for new and returning volunteers, run by key leaders within four sections: *surf*, *swim*, *water-safety*, and *transfer*. Each key leader highlights the most important information, such as water signs, safety rules, and procedures.

Participants can sign up for one or, if capacity allows, multiple timeslots for surfing and/or swimming. Within surfing and swimming there are different levels of performing the activity. Volunteers can help participants with floating, swimming, tandem surfing (the surf instructor takes the participants out on the same board), independent-assist (the participant is assisted by a surf instructor), and independent supervised (the participant is monitored for safety) surfing. Each event starts at 9 am with a welcome circle and ends at 1 pm. AccesSurf provides lunch for everyone – typically about 250 people per event. At the end of the DATB, volunteers dismantle the equipment and clean and pack the gear.

As of January 2021, AccesSurf's staff included a full-time Executive Director (ED), a half-time Program/Social Media Coordinator, a half-time Operations Assistant, a Training Director (part-time), and a Program Evaluation/Grant Writer (part-time). AccesSurf has a volunteer Board of Directors (16 Members) and a volunteer Leadership Committee (12 Members). The larger volunteer community ranges from 400-900 individuals, of which about 80 are regular volunteers. Volunteers contribute more than 16,000 volunteer hours a year, with a

rising trend (49). Aside from these metrics, AccesSurf's program has only been evaluated through a pilot study (50), explained in chapter 2 in this dissertation.

### **Community Need and Program Sustainability in Changing Conditions: The COVID-19 Pandemic**

The first case of COVID-19 in Hawai'i was confirmed by Governor David Ige on March 6, 2020 (51), and the WHO Director-General Tedros Adhanom Ghebreyesus declared the global COVID-19 outbreak a pandemic on March 11, 2020 (52,53). Since then, the world has undergone a great effort of social distancing, both recommended and enforced. AccesSurf's participants, people with disabilities and those with underlying health conditions, are predominately at higher risk to have worse outcomes if they were to be infected by COVID-19 (54). Thus, AccesSurf decided to suspend traditional in-person group programs, and first informed the AccesSurf community about this on March 13, 2020 through their email newsletter.

The negative impacts of COVID-19, not only those associated with being infected, but those resulting from the measures taken to help lower the infection rate, have increased societal risk for traumatic stress (55), isolation, and mass trauma (56). Isolation, loneliness, and low levels of physical activity, already leading issues among people with disabilities (57), are now compounded, making this population even more vulnerable to depression, lower quality of life, substance abuse, lower life expectancy and suicide (56). Negative effects, such as isolation and trauma, are not only experienced by the person with the impairment, but also by the families caring for a loved one with special needs (37). COVID-19 has disrupted family routines, which is linked to increased aggression and anxiety among people with disabilities (58) and increased burden for families.

Adaptability and sustainability are essential for programs like AccesSurf (59–62). Ongoing needs assessment is an important element of evaluation. Assessing changing needs for services with changing conditions, in this case the COVID-19 pandemic, helps with adaptability. Sustainability is defined as the small set of organizational and contextual factors that build the capacity for maintaining a public health program and the ability to maintain programming and its benefits over time (61). It can be measured using tools such as the Program Sustainability Assessment Tool (PSAT) (63–65). However, to the author's knowledge, AccesSurf has not conducted a needs assessment, sustainability assessment, or formal evaluation of services.

## Purpose

The purpose of this dissertation was to evaluate the AccesSurf program through an assessment of participant benefits, changing needs due to COVID-19, and sustainability. This dissertation reports methods and findings from three studies. Study 1 assessed participant benefits through a secondary analysis of participant surveys (n=442) and a skill tool questionnaire (n=8). Study 2 utilized a mixed-method approach to assess changing needs during COVID-19 (n=149). Study 3 used the PSAT to survey (n=15) and conduct in-depth interviews with (n=5) AccesSurf leadership on sustainability.

## Conceptual Frameworks

Two frameworks guide this research: The Centers for Disease Control and Prevention (CDC) Framework for Evaluation in Public Health (CDC-FPEPH) and the nine principles of community-based participatory research (CBPR).

### CDC Framework of Evaluation

The CDC-FPEPH is a comprehensive guide to planning, implementing, and utilizing evaluation (66). This proposal follows the outlined six steps of the CDC-FPEPH: 1) *engage stakeholder*, 2) *describe the program*, 3) *focus the evaluation design*, 4) *gather credible evidence*, 5) *justify conclusions*, and 6) *use and share lessons learned* (to assure the quality of the evaluation). The circular process (Figure 1.1) represents the reoccurrence of different steps at different times (66,67).

I have volunteered or worked with AccesSurf for ten years, and together we have completed steps 1 (*engage stakeholder*) and 2 (*describe the program*). This dissertation proposal presents our team's work on Step 3 (*focus the evaluation design*) and our design for Step 4 (*gather credible evidence*). Once data gathering was complete, we worked together on Step 5 (*justify conclusions*) and Step 6 (*use and share lessons learned*).



Figure 1.1: The Centers for Disease Control and Prevention’s Framework for Program Evaluation in Public Health (CDC-FPEPH) (66)

### Logic Model

The logic model is a common tool used by evaluators and encouraged by the CDC-FPEPH. It outlines program inputs, activities, outputs, outcomes, and assumptions. This evaluation looked at program impact on AccesSurf participants, family members, volunteers, and leadership. For AccesSurf, inputs include the staff and volunteers, program events, equipment, training programs, safety protocol, and so on. Outputs include the numbers of events, participants, and volunteers engaged in AccesSurf, as well as the reactions (e.g., satisfaction and suggestions for program improvement) of participants, volunteers, and board members. Outcomes include anticipated proximal outcomes (e.g., knowledge acquisition of participants and volunteers) and distal outcomes (e.g., improvements in skills and confidence) expected to occur as a result of program activities. Another outcome is evidence of expanded resources for people with disabilities, such as program sustainability, growth, and replication. This dissertation’s three studies target different outputs and outcomes for participants, volunteers, and board members.

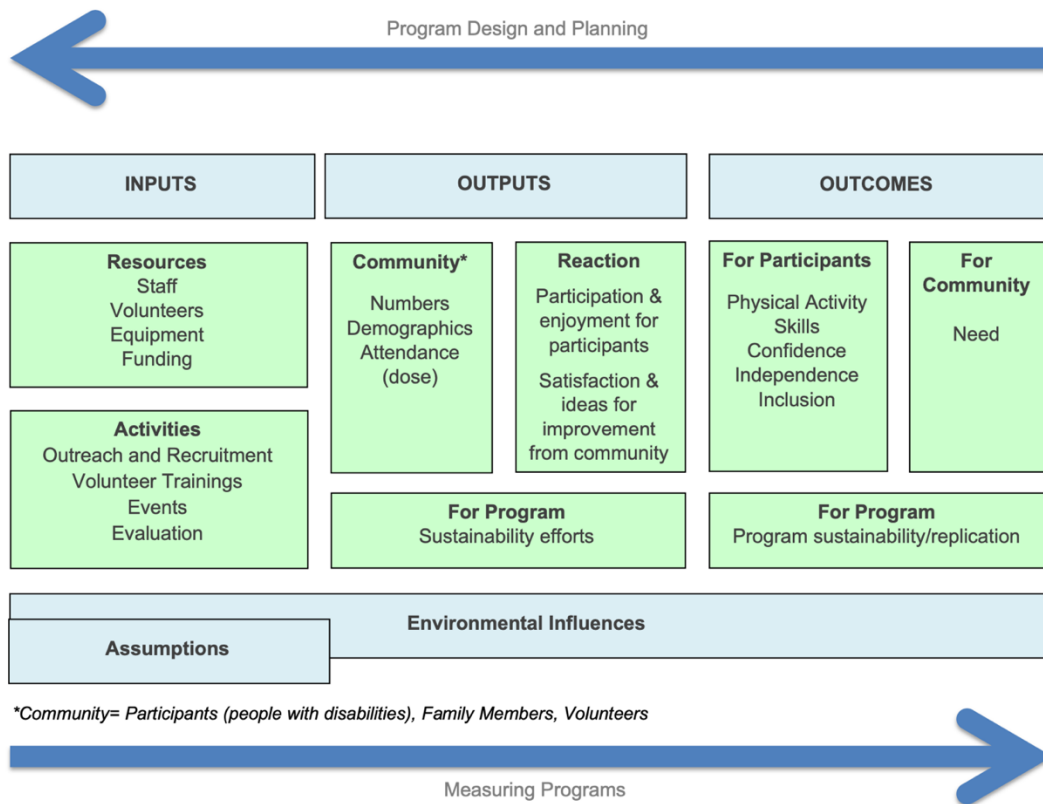


Figure 1.2: Logic Model for Program Development and Evaluation Adjusted to AccesSurf (68)

### Participatory Research

Community-based participatory research (CBPR) is defined as research that equitably involves researchers and community in all aspects of research (46). Approaches to conventional research and CBPR differ. While conventional research often is based on priorities identified through epidemiological data, CBPR aims to prioritize research based on the need defined by the community, as well as epidemiological data. CBPR helps ensure that research methods are acceptable and responsive to community needs and strengths. It also helps assure that the research is ethical and meaningful to the community (47). This approach is used worldwide and is recognized in the scientific milieu. There are many successful examples of CBPR in Hawai'i that have been conducted through community-academic partnerships, for example the Wai'anae Cancer Research project (69), and Improving Native Hawaiian Health through Community-Based Participatory Research (70). There are nine principles of CBPR (47):

- 1) Recognize community as a unit of identity.
- 2) Build on strengths and resources within community.
- 3) Facilitate collaborative, equitable partnership in all research phases, and involve empowering and power-sharing processes that attend to social inequities.
- 4) Promote co-learning and capacity building.

- 5) Integrate and achieve balance between research and action for mutual benefit of all partners.
- 6) Emphasize public health problems of local relevance, and also ecological perspectives that recognize/attend to the multiple determinants of health and disease.
- 7) Develop systems and resources through a cyclical/iterative process.
- 8) Disseminate findings/knowledge gained with all partners, and involve all partners in dissemination process.
- 9) Require long-term processes and commitment to sustainability.

CBPR aligns well with disability rights principles, such as full inclusion and creating opportunity. Reports of CBPR with people with disabilities are limited, although the field is growing (71–74). A literature review from 2014, titled *‘Nothing about us without us,’* included 21 studies using a variety of participatory approaches, including participatory action research, CBPR, emancipatory research, inclusive research, and participatory research (71). When universities used PAR, project beneficiaries become more independent and some of them started their own organizations (75). While AccesSurf already applies CBPR principles without referring to the theory, the evaluation design for this dissertation explicitly applied the CBPR approach. This was possible because of my long association with AccesSurf and ability to build on their existing CBPR cultural.

### **Investigator Fit and Positionality**

I started as an active volunteer in 2010 at AccesSurf’s main program, DATB. Since then, I have been volunteering at DATB whenever I could. My engagements and other public health experiences led to my role as the first AccesSurf intern. Between 2014 and 2016, I completed several internships with AccesSurf and steadily took on more roles. Due to my educational and professional background, I took on the tasks of grant writing and program evaluation on a volunteer basis and became a contractor in 2016. Since 2015, I have written 12 successful grant applications for AccesSurf, totaling \$552,500.

During one of my internships, I conducted a focus group, previously referred to as a pilot study. I presented the results at the Hawai’i Public Health Conference in 2016, and they were published in the Hawai’i Journal of Medicine and Public Health in 2018 (14). I also visited AccesSurf Okinawa in 2015, an organization that has asked to replicate the concept of AccesSurf Hawai’i. I have continued to support AccesSurf Hawai’i while in the PhD program at the University of Hawai’i at Mānoa. For example, I completed a community mapping of the AccesSurf community in my Cultural Competency class in fall 2016, interviewing volunteers and

asking about their perspective on the program. Also, AccessSurf was the focus of my fieldwork for a CBPR course in spring 2017. Hence, this dissertation is dedicated to AccessSurf and its community.

I was well-prepared to undertake this research because of my educational background, my involvement with people with disabilities for more than 17 years, and my involvement with AccessSurf Hawai'i (the community partner for this dissertation) for more ten years. A summary of my role in the AccessSurf community is that I am an insider (emic perspective) in terms of being a part of the AccessSurf volunteer community, a daughter of a father with disabilities from an injury on his spinal cord, and a mom of a child who is medically fragile. However, I am an outsider (etic perspective) in terms of being able-bodied (42).

## **CHAPTER 2:**

### **Benefits of Aquatic Physical Activity and Participation in AccesSurf Programs for People with Disabilities**

#### **Abstract**

Access to physical and social activities have been shown to exert significant benefits in people living with disabilities. While many studies have demonstrated benefits of land-based physical activity, there is less research on the benefits conferred by participation in aquatic activities. In study 1, I explored the benefits of aquatic physical activity and participation in AccesSurf programs for people with disabilities. I performed a secondary analysis of data from a self-reported participant post-event survey (the “Fun Wall”) (n=442) in which participants reported skill acquisition and increases in physical activity levels, socialization, and confidence. Data frequencies and percentages were calculated. I also analyzed data from a Skills Tool completed by an Occupational Therapist (OT) that rated improvement in participants’ skills over time (n=8). The Skills Tool was designed by AccesSurf, and this study is the first to test it. Improvement over time in OT-assessed skill items was tested using the Wilcoxon Signed Rank test and of three suggested scales using a paired t-test. Cronbach’s alpha was run for the suggested scales. Fun Wall data indicate that AccesSurf provides a fun experience and that participants feel they are gaining adaptive surfing skills and confidence. AccesSurf events not only allowed them to meet new people, but also offered opportunities to network with AccesSurf friends outside of AccesSurf events. These kinds of connections are critical to reducing feelings of inclusion and increasing sense of belonging to a community and society more generally. The Skills Tool identified statistically significant improvement in participants’ comfort, independence in surfing, and community integration. Taken together, findings indicate that AccesSurf increased participants’ aquatic physical skills, community integration, and confidence. The findings also suggest that the Skills Tool has promise of providing a more objective measure of participant improvement than participant-reported data.

#### **Introduction**

##### **Literature Review**

Approximately 15% of the global population lives with some type of disability (1). The proportion is even greater in the United States, where more than 61 million adults – or 1 in every 4 – experienced disability in 2016 (2,76). Hawai’i’s rate of disability is 20,2% (2). Different definitions and survey questions can result in discrepancies in percentages (10). People with

disabilities often face barriers to participation in physical activity due to their primary disability diagnosis, and the resulting sedentary lifestyle can precipitate a number of secondary diseases (3). Additionally, social isolation and loneliness driven by peer exclusion and social withdrawal can compound negative health outcomes associated with disability, including dementia, cardiovascular disease (6), decreased immunity, and a greater risk for premature death (7). Studies have established an association between loneliness and lower levels of physical independence and social skills and higher levels of social anxiety (5). Loneliness has also been directly linked to lower physical activity (8). Moreover, isolation is not only experienced by the person with the impairment, but also by the families and caregivers of individuals with special needs (37). Thus, beyond the obvious discrimination inherent to inaccessible environments from a community perspective, this creates preventable social and economic disparities and higher health care costs and financial burden.

Work exploring the impact of exercise interventions in people with disabilities has been reported and systemically reviewed. Reviews by Rimmer (25), Devillard (26), Kloosterman (27), and Sheel (28) identified health benefits associated with physical activity in people with disabilities, however, very few of the studies included in these reviews examined aquatic physical activity (26–29). Other work has confirmed that physical activity is positively associated with health-related quality of life and decreased anxiety in the general adult population (77), and reduced depressive symptoms in people with neurological impairments (78). In 2017, Li and colleagues published a systematic literature review of aquatic physical activity interventions for people with spinal cord injury. Eight articles met inclusion criteria. Two studies included swimming, two included aquatic exercise, and one an underwater treadmill. Four studies measured physical function, and four measured aerobic fitness. Generally the interventions were found to result in significant improvements; however, study validity was limited because half of the interventions were not tested against a control group, and there was a lack of blinding of participants and measurement takers (31).

In my own review of aquatic physical activity interventions for people with disabilities, and unlike the review by Li and colleagues (31), I included all study designs and found 16 articles describing 14 interventions. My literature review (Appendix I) concluded that aquatic physical activity improves mobility (spasticity, strength, balance, and gait), body composition, activity of daily living, and mental health (32). Although depressive disorders have been shown to contribute to reduced life expectancy in persons with spinal cord injury (22), only one study measured mental health as a primary outcome, another included psychological well-being as a secondary outcome. The recommendations based on my review were that future studies should

evaluate effects of aquatic physical activity on both physical and psychological outcomes, as well as examine the effects of aquatic physical activity in natural settings, such as rivers, lakes, and oceans.

None of the reviews, including the one I performed in 2016, found articles on adaptive surfing. *Adaptive Surfing*, as the name suggests, uses adaptive equipment and techniques to make surfing accessible for people with disabilities. After a broad database search in January 2021, four journal articles on adaptive surfing, one on surf medicine, and one special issue on surf therapy were found in the literature. In 1975, Bond reported on the design, construction, and testing of a piece of adaptive surfing equipment used by a variety of individuals with upper extremity impairment. The effectiveness of the equipment was evaluated from a functional perspective in a swimming pool and the ocean and was found to be effective for people with upper extremity impairment (79). The other two articles were pilot studies (39,80). One study found adaptive surfing increased physical activity in children (80). The other considered adaptive surfing as a tool to increase inclusion and disability awareness in Portugal (39). A 2018 case study demonstrated how adaptive surfing can be a powerful tool in promoting physical health and psychological well-being along with social integration and inclusion of people with disabilities (41). Surf Medicine: Surfing as a Means of Therapy for Combat-Related Polytrauma, another case study, suggests that surf therapy may be of particular benefit for individuals who have plateaued with their traditional care (42). A special issue on adaptive surfing was published by the International Surf Therapy Organization (ISTO) in 2020 (43). Articles in this special issue found benefits of adaptive surfing for children with developmental disabilities, a variety of youth groups (such as at-risk, underprivileged, and with autism), people with post-traumatic stress disorder (PTSD), young adult cancer survivors, and adults in recovery from addiction.

Adaptive surfing activities fall under a larger umbrella of community-based rehabilitation. These programs are known to support primary prevention of non-communicable diseases (NCDs) for people with and without disabilities. They also support tertiary prevention among people with disabilities by preventing further negative health consequences and activity limitations, and by promoting independence, participation, and inclusion (44). In search of indicators for evaluating community-based rehabilitation, six domains, which should be maximized for people with disabilities have been identified: (1) functional independence; (2) education; (3) economic independence; (4) participation in family and community life; (5) leadership roles for people with disabilities; and (6) participation in and ownership of the self-help group programs (81). These indicators work best when evaluated and contextualized by

the local community, as summarized by Grandisson et al who concluded in their 2014 study that *‘the evaluative process needs to be conducted in close collaboration with the local community, including people with disabilities, and to be followed by sharing the findings and taking actions’* (45). This finding supports the community based participatory research (CBPR) approach and principles that guided this dissertation study (46,47).

### **Community Partner**

My community partner was AccesSurf Hawai‘i (AccesSurf), an established 501(c)3 non-profit organization since 2006, based on the island of O‘ahu, Hawai‘i. The mission of AccesSurf is to *build an inclusive community that empowers people with disabilities through accessible beach and water programs* (48). AccesSurf helps people with disabilities participate in ocean-based physical activity by modifying surfing and other equipment and/or the way a person surfs or canoes to accommodate their skills and needs. To fulfill their mission, AccesSurf has established several programs: Day-at-the-Beach (DATB), Wounded Warrior DATB, Swim, Surf and Canoe Clinics, Outreach, a Surf Team, and (Volunteer) Trainings all of which are free-of-charge and run by trained volunteers. With the support of the community program AccesSurf Hawai‘i, we can extend existing research on adaptive swimming, surfing and canoeing for people with disabilities.

As a volunteer with AccesSurf, I conducted a focus group in 2015 to explore the perspectives of AccesSurf participants relating to the program, participant outcomes, and suggestions for AccesSurf (50). The focus group included three women and three men living with neurological health conditions causing physical impairments, ages 30 to 64 years, who had been participating at AccesSurf for 12 months to 10 years. The analysis followed a deductive-inductive approach, using pre-determined categories, but not limiting the coding nor the analysis to those categories. Participants’ discussion identified findings in three areas. First, they talked about physical and psychological improvements they noticed in themselves. Second, they talked about the success of AccesSurf in expanding options, being inclusive and safe, and reducing stigma. Third, were suggestions for improving the program, such as finding permanent space and expanding promotion. Altogether, the focus group results helped inform the development of two AccesSurf tools to capture the benefits of AccesSurf participants and their participation, namely the Fun Wall and the Skills Tool. The Fun Wall has been in place for several years, and the Skill Tool was developed over last few years and piloted in 2020. The Skills Tool is used by an OT affiliated with AccesSurf, and a representative of the participant

group, as an adaptive athlete herself, to assess and document baseline and follow-up levels of skills related to adapted ocean sports.

## **Purpose of Study**

The purpose of this study was to address a gap in research evaluating the physical and psychological outcomes of adaptive beach and ocean programs. The aim was to identify the benefits of aquatic physical activity and participation in AccesSurf programs for people with disabilities as reported by participants (on the Fun Wall) and as observed by the OT (through the Skills Tool).

## **Method**

### **Study Design**

The study included secondary analysis of AccesSurf's archived Fun Wall data and an analysis of data collected via a Skills Tool.

The Fun Wall data were collected from new and returning people with disabilities participating in monthly Day-at-the-Beach (DATB) events between 2017 and 2020 (pre-COVID-19). The Skills Tool was administered by an OT for participants at the AccessBuddy events in 2020. In terms of the Centers for Disease Control and Prevention's Framework for Program Evaluation in Public Health (CEC-FPEPH), this study collected data from AccesSurf's participants (step 1), gathered credible evidence on the programs (step 4), justified the conclusion (5), and used and shared lessons learned about the benefits of the programs (step 6) (66). This study was approved by the institutional review board (IRB) at the University of Hawai'i at Mānoa.

### **Sample**

About 60 people with disabilities attend each monthly DATB event, at which they are assisted to swim, surf, and/or canoe. New participants must complete a registration form, and new and returning participants check in at the beginning of the event. After their water experience at the event, all participants are asked to complete the Fun Wall. This was initially a big banner with six questions and response options that participants were asked to select using sticky dots. To improve accessibility, in 2019 volunteers began collecting responses on paper, approaching participants individually. Data from both approaches were transferred into Excel for analysis. Since 2017, about 500 participants have provided survey responses. Survey responses are anonymously solicited from both new and returning participants. Because returning long-term participants may have provided answers multiple times, the results present

frequency responses. To test the new Skills Tool, the OT identified eight individuals with whom she had worked with between September to December 2020 and had worked with repeatedly over time prior, recalling their skill levels upon joining AccesSurf and their skill levels upon last working with them in 2020.

## Measures

**Participants' Fun Wall measures.** The Fun Wall consists of six questions that solicit participant feedback on their experience related to fun, physical activity, skills, confidence, and inclusion (Table 2.1). The first four questions are for all participants, and the last two questions are only for returning participants. These questions were developed based on focus group findings from 2015 (50), which identified the domains of fun, physical activity, skills, confidence, and inclusion as benefits of AccesSurf.

The first question asks about the participant's experience at the day's event, with four response options: boring, ok, fun, or lots of fun. The second question, related to inclusion, asks if the participant talked to someone new, with response options of yes or no. The third question, related to physical activity skills, asks how confident the participant is entering the water, with response options of not very, a little bit, comfortable, or very comfortable. The fourth question, related physical activity skills, inclusion, and empowerment, asks if participant learned something new, with response options yes (followed by an open space to note what they learned) or no. The fifth question, related to physical activity and independence, asks returning participants if they did any physical activity outside of AccesSurf since the last event they attended, with response options of yes (and if yes, which) or no. And finally, the sixth question relates to inclusion/social well-being, asks returning participants if they saw anyone they met through AccesSurf since the last AccesSurf event (excluding AccesSurf events) they attended, with the response options yes or no (Table 2.1) (Appendix II).

Table 2.1: Fun-Wall Questions

| Questions                                                                                                                           | Response options                                      |
|-------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------|
| 1. How was today's experience?                                                                                                      | Boring, OK, Fun, Lots of fun                          |
| 2. Did you talk or meet someone new?                                                                                                | Yes, No                                               |
| 3. How confident are you entering the water?                                                                                        | Not Very, A little bit, Comfortable, Very Comfortable |
| 4. Did you learn something new?                                                                                                     | Yes (What?), No                                       |
| 5. Did you do any physical activity, such as surfing or swimming since the last AccesSurf event (you went to) outside of AccesSurf? | Yes, No                                               |
| 6. Did you meet someone who you met at AccesSurf outside of AccesSurf since the last event you attended?                            | Yes, No                                               |

**Skills Tool.** To complement the self-assessment, in 2019 AccesSurf began to design a measure of skill acquisition. This tool was developed by Ann Yoshida, OT, PhD and Paralympian, and myself. Both of us have worked with AccesSurf for more than a decade. The design was based on performance measures for the classification system that AccesSurf helped to develop with the International Surfing Association (ISA). This dissertation study provided an opportunity to test the tool, which was completed by the OT who had worked with participants more than once; the tool is meant to track improvement over time. The tool includes 29 items grouped into nine domains: Name/ Date; Access/Condition; Surfing type/ Assistance; Transfer; Comfort; Independence; Intensity/ Endurance; Community integration; and Other changes/ comments (Table 2.2). The full tool can be accessed here: (<https://www.accessurf.org/observation-questionnaire-surfing>) (Appendix III).

Table 2.2: Survey Domains and Examples of Adaptive Surfing

| Domain                        | Items in domain (#) | Items in this domain                                                                                                                                                         | Answer options/ scales                                                                                                                                                                |
|-------------------------------|---------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1) Name/ Date                 | 3 (1-3)             | 1. Participant Name, 2. Date of Most Recent Activity, 3. How long with AccesSurf?                                                                                            | Open-answer fields                                                                                                                                                                    |
| 2) Access/ Condition          | 2 (4-5)             | 4. Water access, 5. Environmental conditions                                                                                                                                 | Beginner, 2 Intermediate, 3 Advanced                                                                                                                                                  |
| 3) Surfing Type/ Assistance   | 2 (6-7)             | 6. Surfing style<br>7. Need of assistance in the water                                                                                                                       | Prone, Sitting, Kneeling, Standing, Other<br>Independent, Assisted, Dependent                                                                                                         |
| 4) Transfer                   | 1 (8)               | 8. How does the participant access the water?                                                                                                                                | Carried by others, Beach Wheel-Chair, Crawling, Walking assisted, Walking unassisted, Other                                                                                           |
| 5) Comfort                    | 4 (9-12)            | How comfortable is the participant: 9. ... talking to other people? 10. ... entering the water? 11. ... in the water (on the surfboard)? 12. ... when falling off the board? | 1 Very uncomfortable, 2 uncomfortable, 3 neutral, 4 comfortable, 5 very comfortable                                                                                                   |
| 6) Independence               | 9 (13-21)           | Surf preparation & set up: How (in)dependently can participant set up their equipment? Surf/ water skill level: How (in)dependently can they paddle out/catch a wave)?       | 1 Totally dependent, 2 Maximum assist, 3 Minimum assist, 4 Verbal assist, 5 Self direct, 6 Totally independent                                                                        |
| 7) Intensity level/ Endurance | 2 (22-23)           | 22. Intensity<br>23. Endurance                                                                                                                                               | 1 Low, 2 Medium, 3 High<br>< 20 min., 20 min., 40 min., 1 hour, 1.5 hours, 2 hours, > than 2 hours, Other                                                                             |
| 8) Community integration      | 4 (24-27)           | The participant ...: 24. Initiates greetings, 25. Developed support system, 26. Has ability to access new locations.<br>27. Has Outside (non-AccesSurf) participation        | 1 Always disagree, 2 Sometimes disagree, 3 Neutral, 4 Sometimes agree 5 Always agree<br><br>None, 1x a month (or only at Day-at-the-Beach events), 2x a month, 1x a week, > 1x a week |
| 9) Other changes/ comments    | 2 (28-29)           | Specific changes or improvements observed by the volunteer; Comments                                                                                                         | Open-answer fields                                                                                                                                                                    |

Domain 1: The first three items collect participant characteristics including name, date of activity, and how long they have been with AccesSurf, with open-ended answer options (Table 2.2).

Domain 2: The next set of two items asks about water access and environmental condition with response options: beginner, intermediate, and advanced.

Domain 3: The next set of two items ask about surfing type and assistance needed. Item 6 has the response options: surf prone, sitting, kneeling, standing or other. Item 7 has the response option independent, assisted, dependent.

Domain 4: The next item (item 8) asks about transfer with the response options: 1) walking unassisted, 2) walking assisted, 3) crawling, 4) beach wheel-chair, 5) carried (fireman's, princess, backpack, etc.);

Domain 5: The four items in this domain ask about comfort of the participant: 1) to talk to people (item 9: post-testing this was re-grouped into Domain 8), 2) to enter the water (item 10), 3) in the water (on the surfboard) (item 11), and 4) when falling off the board (item 12). Response options are: 1) very uncomfortable, 2) uncomfortable, 3) neutral, 4) comfortable, 5) very comfortable. The Cronbach's alpha estimate for the three last of the four items relating to comfort around the water activity was .82; thus, we summed responses for these items into a "Comfort Score" (Table 2.2).

Domain 6: The nine items in this domain solicit judgments on independence within surf preparation, set up, paddling out, and surfing, ranging from 1=dependent to 6=independent. The Cronbach's alpha estimate for the nine items was .87; thus, we summed responses for these items into a "Independence Score".

Domain 7: The two items ask about intensity and endurance. The intensity of the surfing (item 22) can be rated low, medium, or high. Endurance (item 23) relates to time the participant can spend in the water, with 7 response options: less than 20 minutes, 20 minutes, 40 minutes, 1 hour, 1.5 hours, 2 hours, more than 2 hours.

Domain 8: The first three items in this domain ask whether the participant initiates greetings (item 24), has developed a support system (item 25), and has the ability to access new locations (item 26), with responses ranging from 1=always disagree to 5= always agree. The fourth item (item 27) asks if the participant has any outside (non-AccesSurf event) participation, with response options: none, 1x month (or only at Day-at-the-Beach events), 2x a month, 1x a week, and >1x a week. The Cronbach's alpha estimate for a total of five items (the four items from domain eight plus item 9 from domain five) was .74; thus, we summed responses for these items into a "Community Integration Score".

Domain 9: The last questions solicit open-ended answers to the questions of other changes observed and comments (items 28 and 29).

## **Procedures**

**Fun Wall.** Since 2017, about 500 participants provided answers to Fun Wall questions after their participation at DATB. All Fun Wall responses are anonymous. Prior to analysis, data from different events were combined in Excel.

**Skills Tool.** The OT completed the Skills Tool, recalling the skill levels at baseline (when the participant first started with AccesSurf) and their skill levels upon last working with them in 2020. The results were managed in Excel. The participants were de-identified, e.g., I coded Participant 1 as P1. The code book was kept separately on a password-protected computer. Once cleaned, the data were transferred to SPSS for analysis.

## **Data Analysis**

For the Fun Wall, frequencies and population percentages were calculated in Excel. For the Skills Tool completed by the OT, data were analyzed using SPSS. The levels of improvement (difference between pre- and post-AccesSurf) were counted for each item. Cronbach's alpha was calculated for domains with three or more items, namely the Comfort Score, Dependency Score and Community Integration Score, to estimate internal consistency. Because we are still testing this tool, findings from all items are reported for each of the eight participants. I used the Wilcoxon Signed Rank test to test for significance of change between baseline and follow-up for each item and three suggested Scales. This test was used because it is appropriate for repeated measures for the same subjects under two different conditions, when a large variance in baseline scores is expected, and when follow-up scores are very much dependent on baseline scores. Also, this test can be used with ordinal data (82).

## **Results**

### **Fun Wall**

Between 2017 and 2020, the Fun Wall was completed at 29 DATB events (Table 2.3). The total responses per question varied between 442 (Question 2) to 557 (Question 3). Most participants either had fun or lots of fun at the AccesSurf event (97.6%) and met someone new (97.5%). Most participants were either comfortable or very comfortable in the water (89.9%). Three-quarters of participants learned something new at an event (75.4%). Among returning participants, about two-thirds participated in physical activity (64.4%) and spent time with an AccesSurf friend (67.9%) between AccesSurf events.

Table 2.3: Fun Wall Results

| Question                                                                                                      | Total answers | Percent |
|---------------------------------------------------------------------------------------------------------------|---------------|---------|
| How was your experience? (n=540)                                                                              |               |         |
| Boring                                                                                                        | 2             | 0.37    |
| Ok                                                                                                            | 11            | 2.04    |
| Fun                                                                                                           | 83            | 15.37   |
| Lots of fun                                                                                                   | 444           | 82.22   |
| Did you talk or meet someone new? (n=442)                                                                     |               |         |
| Yes                                                                                                           | 431           | 97.51   |
| No                                                                                                            | 11            | 2.49    |
| How confident are you to enter the water? (n=557)                                                             |               |         |
| Not Very                                                                                                      | 11            | 1.97    |
| A little bit                                                                                                  | 45            | 8.08    |
| Comfortable                                                                                                   | 119           | 21.36   |
| Very comfortable                                                                                              | 382           | 68.58   |
| Did you learn something new? (n=492)                                                                          |               |         |
| Yes                                                                                                           | 371           | 75.41   |
| No                                                                                                            | 121           | 24.59   |
| Have you surfed or swam since the last Day-at-the-Beach? (n=527)                                              |               |         |
| Yes                                                                                                           | 346           | 65.65   |
| No                                                                                                            | 181           | 34.35   |
| Did you meet someone who you met at AccesSurf outside of AccesSurf since the last event you attended? (n=536) |               |         |
| Yes                                                                                                           | 364           | 67.91   |
| No                                                                                                            | 172           | 32.09   |

These are examples of what participants stated they learned:

Water- related:

- That the life jacket keeps my head up
- Saltwater taste better here than in the XXX
- Hard to roll over
- New surfing phrases, "white water" etc.
- To get in the water without chair
- Water safety
- To hold my head up in the water
- I can float/swim without a life vest

Surf-related:

- Learned about how waves change
- Paddle on surfboard (first time doing so)
- 1st time surfing lots of fun
- Learned how to surf first time
- How to position myself correctly and paddle
- How to catch waves
- How to manage wave

- I learned how to stand up!!
- How to surf and not be afraid of the water. I was terrified to be in the water by myself before today.
- I learned how to pump to connect to inside
- Trusting in my foot placement when surfing
- Doing poses

#### Social-aspect:

- Found I am pictured w/ XX in the surfer magazine
- Met four new people; it is fun to learn from people with disability
- Another person born on XXs birthday
- I made lots of new friends
- About video games from a new friend

Participants reported acquiring a range of benefits like newly learned information or skills. The skills they learned during the water activity were usually more tangible in nature, such as learning how to stand up on a board, for which learning several smaller skills is required. Some comments were of the social nature, speaking to making new friends.

### Skills Tool

Between September and December 2020, the Skills Tool was completed by the OT for one female and seven male participants, all of which she worked with during the timeframe. Data are shown in Table 2.4. The eight participants had been surfing with AccesSurf between one and five years.

In terms of surfing (item 6), three showed improvement. Seven of the eight participants started with prone surfing, and one started with kneeling surfing. At follow-up, five of the participants are still prone surfing; however, two are now seated while surfing. The one who started with kneeling surfing had progressed to standing while surfing. Hence, three showed advancement in their surf style.

For item 7, five showed improvement. Upon baseline, four participants were dependent on the instructor in the water, two were assisted by the instructor, and two were independent. At follow-up, one of the four who was dependent are now only assisted in the water; the other three who were dependent and the one who was assisted are now independent.

For item 8, seven of eight showed improvement. Specifically, at baseline, seven participants were totally dependent on AccesSurf to get in the water, facilitated either by a beach wheelchair or fireman's carry, while one was walking to the water with assistance. At follow-up, four of the seven who were dependent could access the water independently by crawling on the beach, and the person who walked with assistance could walk independently to the water.

For item 9, all eight showed improvement. At baseline, six participants were either not very or not comfortable talking to other people. At follow-up, four of the eight participants were either comfortable or very comfortable in talking to people. At least seven of eight participants also showed improvements between baseline and follow up on the other three comfort items, i.e., comfort entering the water, in the water, and when falling off the board.

For items 13-21, all eight participants showed improvements between baseline and follow up on eight of the nine items measuring independence, including setting up, getting to the water, paddling out, selecting a wave, catching a wave, riding a wave, recovering, managing in the water, and directing need and wants. One did not show improvement in managing off-board/in the water situations.

Seven out of eight participants increased the level of intensity of the surf session (item 22), and all eight improved their endurance in terms of the length of time spent surfing (item 23).

Participants also showed improvements between baseline and follow up for three items under community integration: 1) demonstrating improvement in initiating greetings (item 24), 2) developing a support system (item 25), and 3) accessing new locations (item 26). Finally, item 27 suggests that six were participating in more water activities upon follow up. At baseline, five participants had no community participation, and two participants had no participation outside of AccesSurf events. At follow-up, only one participant remained in the same category, while the seven others increased their outside activities, with two now participating at minimum once a month, three participate in activities twice a month, two participate in activities once a week (Table 2.4).

Cronbach's Alpha was above 0.7 for all three scales--Comfort, Independence and Community Integration--suggesting that scales (rather than individual items) could be used in the future to measure improvement in larger samples of participants for whom the Skills Tool is completed. In that case, scale means could be compared at baseline and follow-up using the paired T-test. However, due to the same sample in this piloting of the tool, a Wilcoxon signed rank test was done on the magnitude of change in the three suggested scales, and all test results suggested that participants made significant improvement between baseline and follow-up (Table 2.4).

Table 2.4: Level of Improvement by Item and Three Scales: Comparing Pre- and Post-Via Wilcoxon Signed Rank Test

| Years with AccesSurf                                   |                           | Participant Number                                                            |          |          |          |          |        |          |          | p-value |
|--------------------------------------------------------|---------------------------|-------------------------------------------------------------------------------|----------|----------|----------|----------|--------|----------|----------|---------|
|                                                        |                           | 1<br>1-2                                                                      | 2<br>1-2 | 3<br>2-3 | 4<br>1-2 | 5<br>1-2 | 6<br>5 | 7<br>< 1 | 8<br>< 1 |         |
| Item #                                                 | Max levels of improvement | Number of levels of improvement between pre- and post-AccesSurf participation |          |          |          |          |        |          |          |         |
| 6 Surfing style                                        | 4                         | 0                                                                             | 0        | 0        | 1        | 1        | 0      | 0        | 1        | .15     |
| 7 Assistance in water                                  | 3                         | 2                                                                             | 2        | 1        | 0        | 2        | 1      | 0        | 0        | .05*    |
| 8 Access water                                         | 4                         | 1                                                                             | 1        | 0        | 1        | 1        | 2      | 0        | 1        | .03*    |
| COMFORT (3 items) Cronbach's Alpha 0.82                |                           |                                                                               |          |          |          |          |        |          |          |         |
| 10 Entering the water                                  | 5                         | 3                                                                             | 3        | 3        | 3        | 3        | 0      | 4        | 3        | .01*    |
| 11 In the water (on surfboard)                         | 5                         | 3                                                                             | 3        | 3        | 3        | 3        | 1      | 3        | 1        | .01*    |
| 12 When falling of the board                           | 5                         | 4                                                                             | 4        | 2        | 3        | 2        | 0      | 3        | 2        | .02*    |
| Comfort Score Total                                    |                           | 10                                                                            | 10       | 8        | 9        | 8        | 1      | 10       | 6        | .01*    |
| INDEPENDENCE (9 items) Cronbach's Alpha 0.87           |                           |                                                                               |          |          |          |          |        |          |          |         |
| 13 Set up / Prepare                                    | 6                         | 1                                                                             | 1        | 3        | 1        | 3        | 2      | 3        | 3        | .01*    |
| 14 Path to enter the water                             | 6                         | 5                                                                             | 5        | 2        | 3        | 5        | 4      | 3        | 4        | .01*    |
| 15 Paddle out to surf                                  | 6                         | 5                                                                             | 5        | 3        | 3        | 3        | 4      | 5        | 4        | .01*    |
| 16 Select surfable waves                               | 6                         | 2                                                                             | 2        | 2        | 2        | 5        | 4      | 3        | 2        | .01*    |
| 17 Catch waves                                         | 6                         | 5                                                                             | 5        | 3        | 2        | 5        | 1      | 4        | 5        | .01*    |
| 18 Ride waves                                          | 6                         | 5                                                                             | 5        | 2        | 2        | 3        | 4      | 5        | 3        | .01*    |
| 19 Recover after wiping out                            | 6                         | 3                                                                             | 3        | 1        | 3        | 2        | 4      | 5        | 4        | .01*    |
| 20 Mange under water situation                         | 6                         | 5                                                                             | 5        | 2        | 2        | 3        | 0      | 5        | 4        | .02*    |
| 21 Directs needs and wants                             | 6                         | 2                                                                             | 4        | 4        | 2        | 4        | 5      | 3        | 3        | .01*    |
| Independence Score Total                               |                           | 33                                                                            | 35       | 22       | 20       | 33       | 28     | 36       | 34       | .01*    |
| 22 Intensity                                           | 3                         | 1                                                                             | 2        | 2        | 1        | 0        | 2      | 1        | 1        | .02*    |
| 23 Endurance                                           | 7                         | 1                                                                             | 1        | 2        | 5        | 2        | 2      | 2        | 2        | .01*    |
| COMMUNITY INTERGRATION (5 items) Cronbach's Alpha 0.71 |                           |                                                                               |          |          |          |          |        |          |          |         |
| 9 Talking to other people                              | 5                         | 3                                                                             | 3        | 2        | 3        | 3        | 2      | 1        | 3        | .01*    |
| 24 Initiates greetings                                 | 5                         | 3                                                                             | 3        | 1        | 3        | 4        | 2      | 4        | 2        | .01*    |
| 25 Developed support system                            | 5                         | 2                                                                             | 2        | 2        | 3        | 3        | 3      | 3        | 2        | .01*    |
| 26 Ability to access new location                      | 5                         | 3                                                                             | 3        | 1        | 3        | 4        | 0      | 3        | 5        | .02*    |
| 27 Outside activity                                    | 5                         | 3                                                                             | 3        | 1        | 2        | 2        | 1      | 0        | 1        | .02*    |
| Community Integration Score Total                      |                           | 14                                                                            | 14       | 8        | 14       | 17       | 7      | 12       | 13       | .01*    |

\* p&lt;0.05 = significant

## Discussion

AccesSurf participation at Day-at-the-Beach, an adaptive aquatic program, and its adaptive surf program appears to confer increased community integration, as well as levels of aquatic physical activity skill and confidence for participants.

The Fun Wall results show that AccesSurf provides a fun experience. Participants meet new people and build a network of AccesSurf friends with whom they can socialize beyond AccesSurf events (contributing to feelings of integration). Most participants reported that they learned new skills while participating at AccesSurf and gained confidence with ocean-based activity, especially entering the water. Despite the fact that the Day-at-the-Beach program has a lot of beginners, and beginners usually are out of their comfort zone not realizing that they are learning and improving their skills, three-quarters of participants stated that they are learning something new. Almost two-thirds of participants reported that they have surfed or swam since the last event. AccesSurf has previously found out that many of their participants have no community engagement or physical activity prior to participation at AccesSurf, so these improvements are notable.

Some participants may come to AccesSurf following a recommendation from existing participants. For these individuals, the event may strengthen friendships and bolster the feelings of community integration. We show here that AccesSurf also creates opportunities for forming new friendships that endure beyond the program. Indeed, we found that 431 people reported new interactions, and these interactions led to 364 independent interactions with AccesSurf peers outside of the program.

Interestingly, the self-reported new learnings ranged from small incremental steps to larger leaps and covered a spectrum of social and physical benefits. While anecdotal, this serves as a reminder of the potentially wide-ranging impact of facilitating access to physical and social settings for people with disabilities.

The Skills Tool appears to be a useful complement to participant self-assessment, providing an objective clinical assessment of improvement. In this study, the outcomes indicate improvement in assistance requirements, water access, intensity, endurance, comfort, independence, and community integration.

While individuals' surfing style increased in difficulty across the evaluation period of the Skills Tool, the change was not statistically significant. This was expected. Being able to change surfing style (e.g., from prone to sitting) is hard to achieve depending on one's level of function. Indeed, one could argue that different surfing styles represent entirely different sports, and that

remaining within the same surf style might simply indicate that the surfer was placed in the correct 'sport' at baseline. For these reasons a participant might never change surf styles. As such, this survey question might serve to determine whether all surf styles were used at events but may be removed from analysis of change over time.

Similar to the surf style, the increments of the 'access to the water' scale are large and may not provide meaningful insight into the beneficial outcomes of an event. The one exception is when a participant reaches 'crawling' to the water as a form of transport, which speaks to their confidence level and skill level. As found in the focus group discussion (50), acquisition of this skill level was associated with participant's decreased feelings of shame and discomfort around the visibility of their disability. Their willingness to 'crawl' to the water, which is a form of independence, may also be a measure of increased confidence.

Item 9 can be used to crosscheck the answers from items 24 to 26, as comfort in talking to new people goes along with community integration. In this sample, this is the case. Hence, item 9 was later combined with the community integration items.

Overall, one can see that participants improved across all domains. Their comfort in the water increased, as did their fitness level (intensity and endurance). They still have room for improvement in their surfing skills.

For the scales, comfort (3 items), independence (9 items), and community integration (5 items), all three scales show fairly high Cronbach's alpha, however, a larger dataset and a factor analysis would be ideal to improve the scales. Also, the portion of the Skills Tool on community integration could be extended by adding items such as on non-verbal communication and communication cue questions to help build connections. Another level of this Skills Tool could include factoring in environmental aspects (size of wave, conditions etc.) and/or fitness level (intensity and endurance) to get a more accurate picture of the level at which the participant is surfing.

Findings from both the Fun Wall and the Skills Tool align with, and extend the results of, focus groups conducted by AccesSurf in 2015 (50). Together, they show that a community accessible surf program can not only provide valuable physical activity to people with disabilities, but also can improve their skills, lower dependency, and increase social integration, which can reduce loneliness (5).

## **Strengths and Limitations**

**Fun Wall.** To our knowledge, this is the first tool of its kind to measure outcomes of an adaptive aquatic sports community-based program. However, the data have multiple flaws.

Because it is collected anonymously, the Fun Wall data are not linked to gender, age, and disability status. However, it was decided to collect data anonymously to decrease the potential of social desirability bias (83). Since all participants were invited to participate in the Fun Wall at each event, new and returning participants provided data. Thus, counts likely included responses from the same person at multiple time points, and one cannot compare the answers to see if there is a change over time. Each question has a different number of responses, meaning that not all individuals answered all the questions when completing the questionnaire. There was no obvious pattern to the omissions that might explain why certain questions received fewer responses, however, it would be helpful to know why someone skips a question. Finally, the confidence question in the Fun Wall may not have much value, as one cannot claim that any confidence is linked to the program participation. The AccesSurf team needs to decide if they want to remove it from the Fun Wall or revise it.

**Skill Tool.** This is the first tool of its kind to measure improvements in adults with disabilities stemming from a community adaptive surfing program. The Skills Tool was designed and administered by an OT who has been with AccesSurf since its founding year, 2006, and she worked with a national group to develop a scoring system for adaptive surfing, on which this tool is based. Another strength of the tool is that it includes variables related to inclusion and integration. These items are not usually measured, although they have been suggested and shown to be important benefits of community adaptive rehabilitation programs (81), and surf programs for people with disabilities (39,50).

A limitation to the testing of the Skills Tool was the small sample (only eight observations). However, small samples are not uncommon in disability research and in surfing research. For example, in ten studies assessing the aerobic/oxidant uptake (VO<sub>2</sub> peak) in able male surfers, samples ranged from five to 12 participants (84). Another limitation is that the Skills Tool has not been validated. Future research is needed with larger samples to accomplish this. Moreover, due to COVID-19, the OT was constrained to complete baseline assessments by recalling baseline skill levels, which is inherently subject to the subjective nature of memory. Also, different amounts of time elapsed between the OT's baseline and follow-up assessments for individual participants. For example, a participant who had been with AccesSurf only one year would likely have less opportunity to improve than a participant who had been with AccesSurf more than two years. In future studies, baseline data should, and will, be collected when participants join AccesSurf and subsequently at a pre-determined follow-up time. There are also no data on other activities that participants may have initiated or been engaged in during this time period. Given the noted increased feelings of integration, it is entirely possible

that participants were more comfortable to actively seek additional opportunities to engage physically and socially outside of AccesSurf, which may have been responsible for some of the gains identified in this data.

Based on Cronbach's alpha scores of 0.70 or higher, I created three scales. However, in discussing findings with the OT, suggestions were made to "move" items from one domain to another. In the future, and with a larger sample, a factor analysis should be conducted to better determine best-fitting domains and items.

## **Implications**

The findings lead to implications for programming and research. For programming, AccesSurf should continue performing evaluations and using a mix of tools to evaluate the program from the perspective of participants and from a more clinical perspective. This will help AccesSurf to improve the program for participants, as well as document physical improvements and increase in inclusion and independence. This information will not only be helpful for AccesSurf to work with other adaptive programs across the country and the world, but also to obtain funding for the program (possibly not only from grants, but eventually from insurance).

While adjustments have been made to the Fun Wall, this research suggests other ways it can be refined. More research is also needed for the Skills Toll, such as testing it on a larger sample. The tool should be used prospectively, and the follow-up time period should be standardized. Further analysis of the structure of the domains should be pursued. For example, factor analysis may suggest that some items could be regrouped or even eliminated in the measurement of participants' comfort, independence, and community integration. The tool also could be tested on the adaptive surf team and adapted for use with other sports, like adaptive paddling or canoeing.

## **Conclusion**

The results presented here are the first of their kind for people with disabilities participating in a community aquatic and surf program. The Fun Wall results show that AccesSurf provides an enjoyable experience. Participants not only meet new people, but also build a network of AccesSurf friends with whom they can get together when there is no AccesSurf events. Participants demonstrated increased feelings of integration, as well as improved levels of aquatic physical activity skill and confidence. The ratings by the OT showed statistically significant improvement of participants in comfort, independence, intensity, and community integration. Taken together, findings indicate that AccesSurf increased participants' aquatic physical skills, community integration, and confidence. While this study has limitations, it

is a first analysis of a mix of self-reported participant data and observations by an OT for people with disabilities and an evaluation of their AccesSurf experience.

## **CHAPTER 3: Community Needs Assessment**

### **Abstract**

The unprecedented situation of the COVID-19 pandemic and the measures implemented on national, state and local level to minimize spread have changed living conditions around the world. Little is known about the current needs of communities affected by those changes. Study 2 involved a mixed-method approach to identify the programming needs of the AccesSurf community during the COVID-19 pandemic. In Part I, an open-ended questionnaire aimed to broadly define community needs (Part I) (n=89). Responses were analyzed and grouped into emerging themes using an inductive approach to design a closed-ended questionnaire (Part II) (n=149) with help from the AccesSurf community. For the Part II analysis, frequencies were calculated, and chi-square tests were used to analyze differences across sub-groups (participants, family members, and volunteers). There was high program awareness and satisfaction of pre-COVID in-person programs among the AccesSurf community across all programs, including the newly added virtual programs. There was a significant difference between community sub-groups in terms of feeling the effects of COVID-19, with participants and family members feeling more isolated and less able to access the ocean than volunteers. The results provide insight into current community needs, including smaller in-person sessions, virtual programming, and combinations of these approaches. The findings from the question about COVID-19's impact on socialization align with the current literature, suggesting that social isolation has increased due to COVID-19 restrictions, especially for people with disabilities and their family members.

### **Introduction**

The COVID-19 pandemic has increased isolation and decreased community integration, especially for people with disabilities (85,86). Prior to the pandemic, isolation was already a concern for people with disabilities (57), and restrictions imposed by the pandemic have further compounded the issue and made this population even more prone to depression, lower quality of life, lower life expectancy, and suicide (56). The seismic shift in circumstances driven by the COVID-19 pandemic and its unprecedented nature triggered an assessment of community needs for AccesSurf Hawai'i. AccesSurf is a non-profit organization whose mission is to build an inclusive community that empowers people with disabilities through accessible beach and water programs. AccesSurf has previously relied upon both on-going and ad hoc informal in-person assessments of community needs. In the face of the COVID-19 pandemic and its restrictions on social gatherings, AccesSurf Hawai'i conducted its first formal needs assessment in summer

2020. The goal for this mixed-method needs assessment was to inform adaptations of AccesSurf programs during COVID-19 based on the current community need. This called for creative ways to reach the community while keeping everyone safe. During this time, larger in-person sessions were suspended and were later re-imagined as a one-on-one or small group (maximum of five people) sessions.

### **Needs Assessment(s)**

Needs assessments have a long history, are defined in various terms, and employ a wide range of models, tools, and techniques to assess the needs of a target population. The theory and practice of needs assessment are closely aligned to planning and evaluation (87). As such, assessing the need of the community is an important part of evaluation and is included in step 2 of The Centers for Disease Control and Prevention's Framework for Program Evaluation in Public Health (CDC-FPEPH) (66,67,88). Typically, a needs assessment evaluates a population's (unmet) needs (89,90) for services, and then evaluates the gap between what currently is available and what should be available (87). Needs assessments can also seek information on client satisfaction with services and ways to improve them, the impact of a changing community context, and the impact of old/new services on key evaluation outcomes, like program awareness, program access, program communication strategies, and inclusion. While the driving force for needs assessments in many organizations and programs may be funder requirements, accreditation requirements, and/or state and national guidelines, such as those issued by the Department of Health and Human Services (91) or the CDC (92), needs assessments can play an important role in driving programming at all organizations (93), especially as internal and external conditions change.

Evaluating program awareness, access, and satisfaction is tied to community-based participatory research (CBPR) Principle 3, to facilitate collaborative, equitable partnership in all research phases (47), but especially during evaluation (CDC-FPEPH) (66). To judge program satisfaction, program awareness and access is necessary. Inaccessible environments and programs may lead participants to feel isolated and/or rejected (94). Satisfaction is a commonly used metric, as it represents a three-way exchange between participants, volunteers, and the organization (93,95). Asking about satisfaction also provides data for direct and continuous program and training improvement (96). Satisfaction is commonly evaluated only at the post-test, with questions addressing how much participants liked the program, preferably with 5 answer categories (e.g., very satisfied to not at all satisfied) along with open-ended prompts to solicit ideas for improvement (97). Moreover, the Rehabilitation Services Administration and the

Rehabilitation Act of 1973 mandates that program evaluation for state agencies include consumer satisfaction (98).

### **Impact of COVID-19 on AccesSurf Programming**

The first case of COVID-19 in Hawai'i was confirmed by Governor David Ige on March 6, 2020 (51), and the WHO Director-General Tedros Adhanom Ghebreyesus declared the global COVID-19 outbreak a pandemic on March 11, 2020 (52,53). Since then, the world has implemented strategies of social distancing, both recommended and enforced. Furthermore, AccesSurf's participants, which include people with disabilities and those with underlying health conditions, are at higher risk of more severe outcomes if infected by SARS-CoV-2 (54). Thus, AccesSurf, the community partner for this dissertation, made the responsible decision to halt traditional in-person group programs for the safety of its community. AccesSurf first informed its community about this on March 13, 2020 through their e-mail newsletter.

The negative impacts of COVID-19, not only those associated with being infected, but also those associated with restrictions imposed to help lower the infection rate, are affecting all levels of society. Social distancing and quarantine are leading to increased isolation causing traumatic stress (55) and COVID-19 related mass trauma (56). PTSD, historically associated with trauma such as war, sexual assault, child abuse and accidents, has now been extended to include traumatic experiences linked to COVID-19 (56), including trauma of separation and loneliness. While there is a research gap in terms of exact numbers of individuals affected by PTSD, it is known that those with underlying mental health conditions and disabilities are more likely to develop PTSD. Untreated mental health issues decrease physical health, and increase the risk of substance abuse, self-harm, and suicide.

Loneliness is directly linked to lower physical activity (8) and a raft of negative consequences on a variety of health outcomes including decreased immunity, dementia, cardiovascular disease (6), and a greater risk of premature death (7). Critically, isolation and loneliness, already leading issues among people with disabilities (57), are now compounded by pandemic measures, making this population even more vulnerable to depression, lower quality of life, lower life expectancy and suicide (56). A study of people with visible disabilities suggests that lower levels of physical independence and social skills and higher levels of social anxiety are associated with loneliness. Hence, these factors need to be considered when designing programs for social integration (5) and also for substitute virtual programming.

Negative effects, such as, isolation and trauma, are not only experienced by the person with the impairment, but also by the families caring for a loved one with special needs (37).

Disruption of daily life caused by pandemic measures can include disruption of services and hence disruption of essential routines within families with a member with disabilities. Interruption of these routines is linked to increased aggression and anxiety among people with disabilities (58), increasing the burden on families and caregivers and ultimately risking a further isolation and inactivity. At the community level, this also results in preventable social and economic disparities and higher health care costs and burden.

### **Transition of AccesSurf's Programs in the Face of the COVID-19 Pandemic**

The mission of AccesSurf is to build an inclusive community that empowers people with disabilities through free, accessible beach and water programs and social connections. Programs are available to any person of any age, gender, ethnic, social, or financial background with a physical, mental, or cognitive disability. Over the past 14 years, pre-COVID-19 pandemic, AccesSurf has grown from providing a single community-based aquatic program in 2006, to providing eight in 2020. The organization has held over 160 Day-at-the-Beach (DATB) events, 75 Wounded Warrior DATB events, and 35 sports clinics, all of which empower participants to improve their water skills, ability, and independence. To help provide programs to more than 8,000 people with disabilities, AccesSurf has recruited and trained more than 12,000 volunteers through about 80 volunteer trainings annually. Training is designed for volunteers to increase awareness and confidence to serve people with disabilities; Advanced Volunteer Training offers in-depth knowledge to lead volunteers and include keynote speakers, and simulation trainings. AccesSurf also formalized an adaptive surfing sports team and sponsors adaptive surfing competitions. Pre-COVID-19 pandemic, all programs offered a variety of accessible beach and aquatic adaptive activities (swim, surf, paddle) and were held monthly. Programs and trainings were established in different years and are of different sizes (Table 3.1):

Table 3.1: AccesSurf Pre-COVID-19 (In-Person) Programs

|   | Program                 | Details                                                                                                                                                              |
|---|-------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1 | Day-at-the-Beach (DATB) | Since 2006, monthly, average of 66 people with disabilities and 100 volunteers/event                                                                                 |
| 2 | Wounded Warrior DATB    | Since 2010, monthly, average 30 people with disabilities with 50 volunteers                                                                                          |
| 3 | Sports clinic: swim     | Since 2015, quarterly, 8 to 15 people with disabilities                                                                                                              |
| 4 | Sports clinic: surf     | Since 2006, quarterly, 8 to 15 people with disabilities                                                                                                              |
| 5 | Sport clinic: paddle    | Since 2019, quarterly, 8 to 15 people with disabilities                                                                                                              |
| 6 | Team                    | Since 2005, 26 surfers with disabilities                                                                                                                             |
| 7 | Competition             | Since 2008, AccesSurf has hosted an annual surf competition, but also sends teams to participate in a variety of competitions; partners with competitions            |
| 8 | Trainings               | Since 2006, on-going, New Volunteer Orientation, Advanced Training, Ambassador Training, Profile Training, Observation Training, Lifeguard and Water safety training |

During the COVID-19 pandemic in 2020, AccesSurf was able to quickly adapt their programs in response to unexpected changes, serving 674 participants through Virtual Meetings, Clinics, the May Move Challenge, Exercise Programs and Specialized Trainings, and one-on-one or small-group assistant programs (Table 3.2). For example, about 6,000 viewers attended AccesSurf's Instagram Talk Story Tuesday either in real-time or by viewing a recording.

Table 3.2 COVID-19 Virtual and Modified In-Person Programs

| Amount name                                                                                                                                                      | Time                       | Length                 | Content/ Size                                                                                                                                                               |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------|------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 29 Weekly Virtual Meetings<br>3 Clinics (virtual)                                                                                                                | Since<br>April 22,<br>2020 | 60 min. per<br>meeting | Virtual gathering to connect, average of 3-9 people/session for a total of 209 participants                                                                                 |
| 1 May Move Challenge (virtual)<br>2 Exercise Programs (virtual)                                                                                                  | May 1-<br>31, 2020         | 30 to 60<br>min.       | Adaptive community activities for 58 participants                                                                                                                           |
| 12 Talk Story Tuesdays<br>(virtual)                                                                                                                              | Since<br>June 9,<br>2020   | 30-60 min.             | Talk story sessions with AccesSurf's Executive Director or other community representatives as the lead on topics important to our community: average of 500 viewers/session |
| 69 One-on-one or small-group<br>assistant programs:<br>11 practices (in-person), 4 clinics<br>(in-person) and 1 in-person<br>picture for online surf competition | Since<br>July 22,<br>2020  | 1 to 4<br>hours        | Assisted for access: for a total of 405 O'ahu participants                                                                                                                  |
| 10 Specialized Training<br>(virtual)                                                                                                                             | Since<br>August<br>2020    | 1-2 hours<br>trainings | On a variety of topics and skills for 31 volunteers, but especially to support the one-on-one programming. *                                                                |

*\*Traditionally, AccesSurf had volunteer responsibilities and skill requirements split across several volunteers, but since the group sizes need to be limited, each volunteer needs to acquire more skills.*

The transition to virtual and small in-person programs started in April 2020 and has been ongoing. The aim of this study was to identify the programming needs of the AccesSurf community during the pandemic and to assess the impact of the COVID-19 pandemic on the perception of isolation.

## Methods

### Study Design

This study addressed four steps of the CDC-FPEPH framework. It involved data collection from a variety of AccesSurf community members referred to as stakeholders (step 1 and 4) to describe current program needs (step 2) and share lessons learned and inform next steps (step 6) (66). There are several approaches to designing a needs assessment (89,90,99–102). Here, a mixed-method approach was used to collect both qualitative and quantitative data (99,103). Mixed-methods research integrates qualitative and quantitative methods of data

collection, such as either merging, connecting, or embedding data, to draw on the strengths of each (104). In this needs assessment, we started with a qualitative study (Part I) to inform the development of a closed-ended questionnaire, which was then administered to participants, family members, and volunteers with AccesSurf (Part II) (104). Due to COVID-19, both the qualitative and quantitative data were collected through web-based platforms.

## Methods for Part I

### Measures

The first data collection instrument was developed and piloted in collaboration with the AccesSurf community, including staff, volunteers, participants and family members. The readability of each question was screened using Readability Formulas (105). All questions were rated at grade five level. The final qualitative online questionnaire collected stakeholder information and data through six open-ended questions shown in Table 3.3. Stakeholder demographic information was collected to describe the respondents in terms of age group, sex, and type of stakeholder to discover whose voices were represented by the data. The six open-ended questions asked about program experience and improvement (#1, #2), inclusion and communication (#3, #4), and COVID-19 concerns and suggestions (#5, #6). The Part I questionnaire was piloted by four stakeholders: one employee, one volunteer, and two participants. It took 3 to 7 minutes for each of these four individuals to complete the survey.

Table 3.3: Needs Assessment Questions (Part I)

|                                                                                                                                                                                                                                                                                             |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <i>Stakeholder information</i>                                                                                                                                                                                                                                                              |
| A) Age group: Children/ Adolescents, Adults, Seniors<br>B) Sex: Female, Male, Other<br>C) Type of stakeholder: Participant, Family member/ Caregiver, Volunteer, Leadership Volunteer, Board of Directors, Staff and other (with the option to tick all that apply), gender and age group], |
| <i>1. How can we make the AccesSurf experience better for you overall?</i>                                                                                                                                                                                                                  |
| <i>2. What would you like to see with regards to our programs and events? Changes or things we can add to our programs and events?</i>                                                                                                                                                      |
| <i>3. How can we help you to feel more included?</i>                                                                                                                                                                                                                                        |
| <i>4. How do you feel about our communications regarding AccesSurf programs, activities, and opportunities? What is the best way to connect with you?</i>                                                                                                                                   |
| <i>5. What are your COVID-19 related concerns coming back to an AccesSurf event?</i>                                                                                                                                                                                                        |
| <i>6. What are your suggestions on how we can deliver a safer experience at our programs due to COVID-19?</i>                                                                                                                                                                               |

## Data Collection

The invitation to complete the questionnaire was initially sent on June 9, 2020, and data collection closed on June 25, 2020. The invitation and link were sent out via the monthly e-mail newsletter to about 3,000 addresses and by social media invitation (one post via Facebook). Invited were any community members who wanted to speak to the questions, predominately participants, participants' family members and caregivers, volunteers (including Leadership Committee and Board of Directors members), and staff.

Staff were also able to complete the questionnaire for other AccesSurf community members, such as participants that could not do it themselves. The responses were transferred to Excel. The analysis was done in several steps: 1) the closed-ended demographic data were tallied; 2) the open-ended responses were coded via an inductive approach (106); and 3) emerging themes were examined to provide information about the community needs and to guide the development of the Part II quantitative questionnaire.

There were 91 responses to the qualitative questionnaire. Two responses were excluded, as one respondent did not answer the open-ended questions, and one was a duplicate response, leaving 89 responses for analysis.

## How Part I Finding Were Used to Inform the Part II Questionnaire

Of the 89 included responders, 52% were female, 45% male, and 2% identified as other. Most participants (74%) were adults aged between 20 and 64, 22% were seniors aged 65 and over, and 4% were children and adolescents, aged up to 19 years. The responses comprised participants, participants' family members and caregivers, volunteers, Leadership Committee and Board of Directors members, and staff. (Table 3.4).

Table 3.4: Part I Survey Participants' Demographics

| Respondents (n=90) |                                         | N (%)     |
|--------------------|-----------------------------------------|-----------|
| Sex                | Male                                    | 40 (45)   |
|                    | Female                                  | 46 (52)   |
|                    | Other                                   | 2 (2)     |
|                    | Total                                   | 88 (100)  |
| Age groups         | Children & adolescents (up to 19 years) | 4 (4)     |
|                    | Adults (20-65 years)                    | 65 (74)   |
|                    | Seniors (65+ years)                     | 19 (22)   |
|                    | Total                                   | 88 (100)  |
| Stakeholder groups | Participants                            | 32 (30)   |
|                    | Volunteers                              | 52 (49)   |
|                    | Family members                          | 20 (19)   |
|                    | Staff                                   | 2 (2)     |
|                    | Total (could tick multiple options)     | 106 (100) |

In Part I, stakeholders were allowed to tick several options, and 18 identified with more than one stakeholder group. This was adjusted for Part II, with stakeholders asked to select only one option to represent their primary role with AccesSurf, either as a participant, a family member/caregiver, or volunteer.

Several themes emerged from the Part I survey. These included program awareness and satisfaction (148 comments), programming during COVID-19 (131 comments), suggestions for program improvements (54 comments), communication satisfaction (44 comments), communication preferences (78 comments), and inclusion (72 comments).

More than half (61%: 90 out of 148) the comments on program satisfaction could be classified as generally positive. Many provided affirmative comments, especially regarding AccesSurf's correspondence, leadership, programming, accessibility, empowerment and experience. However, these answers only related to the pre-COVID-19 pandemic in-person programs, and no scale was used to measure the level or extent of satisfaction. In response to the pandemic, AccesSurf had started virtual programming between the first and second parts of the needs assessment, so program awareness and satisfaction with newly added programs had to be captured in Part II. This was done using a 5-item Likert scale of satisfaction.

There were 71 comments related to concerns about the spread of COVID-19, and 60 comments related to the spread of COVID-19 and programming. Of these, 41% had no concern with in-person programs despite the risk of COVID-19. While 59% saw COVID-19 as a problem, about a third of them trusted that AccesSurf would implement appropriate safety measures. However, AccesSurf needed to know which stakeholders had concerns, e.g., participants, family/caregivers, or volunteers. As 60 respondents commented on changes or additions to programming, they would like to see in relation to COVID-19, including smaller events (n=7), safety measures like masks and testing (n=7), and timeslots (n=5), it was decided that AccesSurf needed to ask everyone about these issues through closed-ended questions in Part II.

Other comments pertained to scheduling, location and frequency, content of training and virtual programs, and communication preferences. To capture those preferences across the community, closed-ended questions on these topics were included in Part II.

Communication was also mentioned in relation to inclusion, such as the use of messaging that made community members feel included to participate. Hence, in Part II seven questions on how respondents felt about different aspects of communication and whether they felt included were added, with 5-item Likert-scored response options from (1) disagree completely to (5) completely agree. Finally, individual comments made on opportunities and

feelings of isolation in Part I prompted AccesSurf to look more closely in Part II at community experience in light of no in-person programming and other restrictions caused by COVID-19.

The development of Part II was an iterative process. I presented the findings from Part I to the staff first, and these formed the basis of the initial Part II instrument design. Based on discussions and further synthesizing of the Part 1 results, I presented a summary to the Board of Directors and Leadership Committee, which led to further input for the Part II questionnaire. There were four rounds of major revisions, including feedback from community members, who received an infographic summary of the findings (Appendix IV), and piloting of the instrument by participants, family members, volunteers, and staff.

## **Methods for Part II**

### **Measures**

The second data collection instrument was developed with the AccesSurf community and piloted by ten people: three participants, two family members, two volunteers, and three staff. Additionally, the readability of each question was screened using Readability Formulas (105). All questions were rated to be at the grade five level. The final quantitative online questionnaire included 20 closed-ended items (Appendix V). This included three demographic questions and 17 items related to the themes that emerged from Part I. The first set of questions revolved around five AccesSurf programs, assessing awareness of the program, attendance, and satisfaction (on a 5-point Likert scale). The next question asked about preferences for more in-person, virtual, or hybrid programming over the subsequent six months. This was followed by questions on preferences for frequency of attendance (daily, weekly, monthly) and questions to ascertain more detail on each type of programming, e.g., locations of in-person events, scheduling and length of events, size of events, and content of events. For the virtual programming, questions were asked about preferences for passive vs. active sessions, platform, length, and content. Three questions evaluated communications: 1) how you would like to hear about events? 2) are you satisfied with the amount of communication? and 3) what are your preferences for new partnerships, e.g., with schools, hospitals, media, other? Seven sub-questions addressed satisfaction with communication and inclusion approaches at AccesSurf, rated on a 5-point Likert scale. Two questions asked about preferences for expanded networks and participation opportunities, as well as feeling connected and included in the community or through AccesSurf. Finally, two open-ended questions solicited general feedback. Respondents were eligible to enter a drawing to win a prize; one prize was available for each batch of 50 respondents.

## **Data Collection**

The email list from Part I was cleaned, expanded, and moved to a different platform for Part II. The invitation and link for Part II were sent to an average of 4,731 of the same email addresses in a newsletter, with reminders in seven additional newsletters. This mailing list is comprehensive and includes legislators, funders, board members, and staff, former participants and volunteers who have relocated away from O'ahu; it also, but not exclusively includes the target audience of the Part II survey, current participants (estimated at 170), their active family members (estimated at 50) and regular volunteers (estimated at 80). An average of 1,154 people opened the email, and between one and 102 people per newsletter clicked on the survey link, for a total of 288 people. The most clicks were seen when the invitation was mentioned as the first item in the newsletter. The invitation was also included in four Instagram posts, which resulted in seven clicks to the link. Every 50<sup>th</sup> data collection entry was selected to get an AccesSurf "swag bag" with selected AccesSurf items. The first winner agreed to have his photo taken for future advertisement of the study, and this was included in one of the email newsletters. The questionnaire was open for completion from 9/25/2020 to 10/26/2020. Staff were also able to complete the questionnaire on behalf of participants unable to do it themselves.

## **Analysis**

Data were input and cleaned in Excel. The analysis was done in SPSS. For the five questions related to program satisfaction and the seven questions related to feelings around inclusive communication and the effect of COVID-19, the ratings on the 5-item Likert scale were skewed to the positive end of the scale. Thus, responses to these 12 items were dichotomized as into 1=satisfied (with ratings of 4 or 5) and 0=unsatisfied (all other ratings). Pearson's Chi-square (two-tailed) was used to identify any statistically significant differences between groups (e.g., participants versus volunteers).

## **Results**

### **Response Rate and Demographics**

There were 153 responses to Part II and of these, four were removed: two that had no answers and two that were duplicates, leaving 149 for analysis. The 149 represents only 3% of the 4,731 email addresses to which newsletters include the survey link were sent. However, as noted above, the mailing list is comprehensive and includes legislators, funders, board members, and staff, former participants and volunteers who have relocated away from O'ahu.

We propose that the responses came from among the currently active members, which includes about 170 participants, 50 family members, and 80 volunteers, or about 300 people, suggesting a response rate closer to 50%. Also, the email management service noted that only 1,154 recipients of the email opened it, and only 287 clicked on the survey link. Of the 287 who clicked the link, 149 responded to Part II. If we assume that only current members clicked on the survey link, this suggests a response rate of 52%.

Among respondents, 50 (34%) were participants, 66 (44%) were volunteers, and 33 (22%) were family members or caregivers of participants. Most (83%) respondents were adults, 11% were seniors, and 5% were children or adolescents (Table 3.5). The sex distributions varied across subgroups (not shown in table): 64% of participants were male, while only 45% of volunteers and 12% of family members were male.

Table 3.5: Demographics Needs Assessment Part II

| Responders (n=149) |                                   | N (%)     |
|--------------------|-----------------------------------|-----------|
| Sex                | Male                              | 66 (44)   |
|                    | Female                            | 83 (56)   |
|                    | Other                             |           |
|                    | Total                             | 149 (100) |
| Age groups         | Children & Adolescents (up to 19) | 7 (5)     |
|                    | Adults (20-65)                    | 124 (83)  |
|                    | Seniors (65+)                     | 17 (11)   |
|                    | Total                             | 148 (100) |
| Stakeholder groups | Participants                      | 50 (34)   |
|                    | Volunteers                        | 66 (44)   |
|                    | Family Members                    | 33 (22)   |
|                    | Total                             | 149 (100) |

### Program Awareness and Satisfaction with the AccesSurf Experience

Of the 149 respondents, 140 (94%) knew about AccesSurf's pre-COVID-19 in-person programming. Among the virtual programs, 124 (84%) knew about the online Adaptive Surf Competition, 114 (76%) knew about the May Move Challenge, 95 (64%) knew about the Talk Story Program, and 100 (68%) knew about the Weekly Virtual Meetings. Across the subgroups, family members were least aware of all four virtual programming options. Even though a respondent may have been aware of the program, he/she may not have attended. Among those that attended each event, the percentage of satisfied or very satisfied is shown by subgroup in Table 3.6. Generally, satisfaction with events was high, with 75-100% of attendees rating their satisfaction level as satisfied or very satisfied.

3.6: Program Awareness, Attendance, and Satisfaction:  
Total (T); Participants (P), Family Members (FM), Volunteers (V)

| Program                         | Group   | n (%) Knew,<br>among those who<br>answered | n (%) Attended<br>among those who<br>knew | n (%) (Very) Satisfied,<br>among those who<br>attended |
|---------------------------------|---------|--------------------------------------------|-------------------------------------------|--------------------------------------------------------|
| In-person program               | T (149) | 140 (94)                                   | 129 (92)                                  | 125 (97)                                               |
|                                 | P (50)  | 45 (90)                                    | 39 (87)                                   | 37 (95)                                                |
|                                 | FM (33) | 30 (91)                                    | 27 (90)                                   | 26 (96)                                                |
|                                 | V (63)  | 65 (98)                                    | 63 (97)                                   | 62 (98)                                                |
| Online Adaptive Surf<br>Contest | T (148) | 124 (84)                                   | 49 (40)                                   | 41 (96)                                                |
|                                 | P (50)  | 40 (80)                                    | 18 (45)                                   | 15 (94)                                                |
|                                 | FM (33) | 23 (70)                                    | 8 (35)                                    | 7 (88)                                                 |
|                                 | V (65)  | 61 (94)                                    | 23 (38)                                   | 23 (100)                                               |
| May Move Challenge              | T (149) | 114 (76)                                   | 42 (37)                                   | 37 (88)                                                |
|                                 | P (50)  | 39 (78)                                    | 16 (41)                                   | 11 (81)                                                |
|                                 | FM (33) | 24 (73)                                    | 4 (16)                                    | 3 (75)                                                 |
|                                 | V (66)  | 51 (77)                                    | 22 (43)                                   | 21 (96)                                                |
| Talk Story                      | T (148) | 95 (64)                                    | 33 (35)                                   | 28 (85)                                                |
|                                 | P (50)  | 28 (56)                                    | 12 (43)                                   | 10 (83)                                                |
|                                 | FM (33) | 17 (51)                                    | 3 (18)                                    | 3 (100)                                                |
|                                 | V (65)  | 50 (77)                                    | 18 (36)                                   | 15 (83)                                                |
| Weekly Virtual<br>Meetings      | T (149) | 100 (68)                                   | 26 (26)                                   | 24 (92)                                                |
|                                 | P (50)  | 33 (66)                                    | 14 (42)                                   | 14 (100)                                               |
|                                 | FM (33) | 20 (61)                                    | 0 (-)                                     | 0 (-)                                                  |
|                                 | V (65)  | 47 (73)                                    | 12 (26)                                   | 10 (83)                                                |

### Type and Frequency of Programs

**Type.** Respondents could choose the type of program they wanted AccesSurf to offer over the coming six months. Most (71%) voted for a combination of virtual and in-person programs. However, about a quarter only wanted in-person programs, despite the pandemic. A small minority (three community members) wanted virtual programs only (Table 3.7).

**Frequency.** Most respondents preferred monthly programming (53%), followed by weekly (19%) or multiple times per week (8%). Participants preferred weekly (36%) and monthly (32%) events (Table 3.7).

Table 3.7: Preferred Program Type and Frequency

|                                                             | Total (%) | Participant (%) | Family Member (%) | Volunteer (%) |
|-------------------------------------------------------------|-----------|-----------------|-------------------|---------------|
| <i>Program Type (1 option was allowed)</i>                  |           |                 |                   |               |
|                                                             | (n=149)   | (n=50)          | (n=33)            | (n=66)        |
| In-Person Programs Only                                     | 37 (27)   | 14 (29)         | 12 (40)           | 11 (18)       |
| Virtual Programs Only                                       | 3 (2)     | 1 (2)           | 0 (-)             | 2 (3)         |
| Both                                                        | 99 (71)   | 34 (69)         | 18 (60)           | 47 (78)       |
| <i>Preferred frequency of events (1 option was allowed)</i> |           |                 |                   |               |
|                                                             | (n=130)   | (n=44)          | (n=27)            | (n=60)        |
| Annually                                                    | 3 (2)     | 0 (-)           | 2 (7)             | 1 (2)         |
| Monthly                                                     | 69 (53)   | 14 (32)         | 12 (44)           | 43 (72)       |
| Every Other week                                            | 19 (15)   | 4 (9)           | 8 (30)            | 7 (12)        |
| Weekly                                                      | 25 (19)   | 16 (36)         | 1 (4)             | 8 (13)        |
| Multiple times per week                                     | 11 (8)    | 6 (14)          | 4 (15)            | 1 (2)         |
| Daily                                                       | 4 (3)     | 4 (9)           | 0 (-)             | 0 (-)         |

### In-person Programs

**Program type.** On the question of in-group versus individual programs, of 142 respondents who had a preference, 22% chose groups and 11% chose individual programs only. The majority (67% across all groups) voted for both. Similar distributions were seen for participants, family, and volunteers (Table 3.8).

**Scheduling.** Overall, among those who had a preference regarding weekday versus weekend events, 62% preferred weekend only, 29% weekend and weekdays, and 9% weekdays only. This pattern was similar for volunteers; however, participants voted more evenly between the choice of weekend only or both (weekend and weekdays), whereas no family members chose weekdays only, and their strongest preference was for weekend only (77%). Of those who voted on combining weekdays versus weekend with morning or afternoon, most wanted programs to be held on weekend mornings (35%), followed by weekend afternoons (28%). Among the sub-groups, volunteers preferred morning to afternoon, as did participants; however, caregivers preferred weekend afternoons (42%).

**Length.** Half (50%) chose events longer than two hours, followed by 44% who chose two hours. The least popular option was one hour for in-person programs. This pattern was similar across all sub-groups.

**Location.** Most people preferred to have an event hosted on the South shore (33%), followed by the West side (27%), North side (21%) and East side (19%). The location priorities were the same across all sub-groups.

**Type.** Most people preferred AccesSurf events for leisure (56%), followed by clinics (37%), or both (9%). This pattern was the same across the volunteer and family member

groups, but a higher proportion of participants were interested in clinics (47%) than the other groups.

Table 3.8: Preferred Program Size, Scheduling, Length, Location, Type

|                                                                          | Total (T) (%) | Participant (P) (%) | Family Member (FM) (%) | Volunteer (V) (%) |
|--------------------------------------------------------------------------|---------------|---------------------|------------------------|-------------------|
| <i>Preference in program type (1 option allowed)</i>                     |               |                     |                        |                   |
|                                                                          | (n=142)       | (n=49)              | (n=31)                 | (n=62)            |
| Groups only                                                              | 31 (22)       | 6 (12)              | 6 (19)                 | 19 (31)           |
| Individual only                                                          | 16 (11)       | 6 (12)              | 5 (16)                 | 5 (8)             |
| Both                                                                     | 95 (67)       | 37 (76)             | 20 (65)                | 38 (61)           |
| <i>Preferred scheduling: Weekdays versus weekend (1 option allowed)</i>  |               |                     |                        |                   |
|                                                                          | (n=134)       | (n=46)              | (n=30)                 | (n=58)            |
| Weekdays only                                                            | 12 (9)        | 6 (13)              | 0 (-)                  | 6 (10)            |
| Weekend only                                                             | 83 (62)       | 20 (43)             | 23 (77)                | 40 (69)           |
| Both                                                                     | 39 (29)       | 20 (43)             | 7 (23)                 | 12 (21)           |
| <i>Preferred scheduling: Am versus Pm (1 option allowed)</i>             |               |                     |                        |                   |
|                                                                          | (n=96)        | (n=40)              | (n=20)                 | (n=36)            |
| AM only                                                                  | 43 (45)       | 17 (43)             | 4 (20)                 | 22 (61)           |
| PM only                                                                  | 20 (21)       | 5 (13)              | 8 (40)                 | 7 (19)            |
| Both                                                                     | 33 (34)       | 18 (45)             | 8 (40)                 | 7 (19)            |
| <i>Preferred scheduling: Combinations of days/ time (all that apply)</i> |               |                     |                        |                   |
|                                                                          | (n=178)       | (n=89)              | (n=38)                 | (n=51)            |
| Weekdays AM                                                              | 36 (20)       | 21 (24)             | 4 (11)                 | 11 (22)           |
| Weekdays PM                                                              | 31 (17)       | 19 (21)             | 7 (18)                 | 5 (10)            |
| Weekend AM                                                               | 62 (35)       | 27 (30)             | 11 (29)                | 24 (47)           |
| Weekend PM                                                               | 49 (28)       | 22 (25)             | 16 (42)                | 11 (22)           |
| <i>Preferred Length (1 option allowed)</i>                               |               |                     |                        |                   |
|                                                                          | (n=141)       | (n=49)              | (n=30)                 | (n=62)            |
| 1 hour                                                                   | 9 (6)         | 4 (8)               | 2 (7)                  | 3 (5)             |
| 2 hours                                                                  | 62 (44)       | 21 (43)             | 11 (37)                | 30 (48)           |
| > 2 hours                                                                | 70 (50)       | 24 (49)             | 17 (57)                | 29 (47)           |
| <i>Preferred Location (all that apply)</i>                               |               |                     |                        |                   |
|                                                                          | (n=308)       | (n=106)             | (n=68)                 | (n=134)           |
| South                                                                    | 101 (33)      | 36 (34)             | 19 (28)                | 46 (34)           |
| West                                                                     | 82 (27)       | 28 (26)             | 19 (28)                | 35 (26)           |
| North                                                                    | 65 (21)       | 25 (24)             | 16 (24)                | 24 (18)           |
| East                                                                     | 60 (19)       | 17 (16)             | 14 (21)                | 29 (22)           |
| <i>Preference in Type (1 option allowed)</i>                             |               |                     |                        |                   |
|                                                                          | (n=137)       | (n=49)              | (n=29)                 | (n=59)            |
| Leisure only                                                             | 77 (56)       | 22 (45)             | 18 (62)                | 37 (63)           |
| Clinics only                                                             | 51 (37)       | 24 (47)             | 8 (28)                 | 20 (34)           |
| Both                                                                     | 9 (7)         | 4 (8)               | 3 (10)                 | 2 (3)             |

## Virtual Programs

**Type and length.** Across the AccesSurf community, most (77%) people preferred interactive virtual programming, and 23% preferred passive virtual programming. This distribution was similar across sub-groups. The preferred length was one hour (55%), followed by 30 minutes (36%). However, there was a difference in length preference between groups. Among participants, 64% wanted 1-hour virtual programs, while only 19% wanted 30-minute programs. Also, 10% of participants wanted virtual programs over 2 hours, compared with no family members and only 2% of the volunteers.

**Platform.** The most popular tool for online programming was Zoom (56%), followed by Facebook (50%), YouTube (38%), Instagram (34%), Webinar (21%) and Twitter (3%). This was similar among participants and family members. However, after Zoom, volunteers preferred Instagram (41%) to Facebook (35%) or YouTube (32%).

**Content.** Most people wanted adventures with AccesSurf (60%), followed by learning new things (56%), educational training (50%), exercise/workout (49%), ocean safety (45%), interviews/ talk story (37%), social calls (32%) and advanced volunteer training (31%). These patterns are similar across all groups, with two exceptions: participants (44%) and family members (47%) want more social calls than volunteers (17%), and 50% of volunteers would like Advanced Volunteer Training.

Table 3.9: Preferred Type, Length, Platform, Content

|                                                   | Total (%) | Participant (%) | Family Member (%) | Volunteer (%) |
|---------------------------------------------------|-----------|-----------------|-------------------|---------------|
| Preferred type ( <i>1 option allowed</i> )        | (n=126)   | (n=44)          | (n=27)            | (n=55)        |
| Interactive (able to ask questions in real time)  | 97        | 33 (75)         | 20 (74)           | 44 (80)       |
| Passive (previously recorded video)               | 29        | 11 (25)         | 7 (26)            | 11 (20)       |
| Preferred length ( <i>1 option allowed</i> )      | (n=121)   | (n=42)          | (n=27)            | (n=52)        |
| 30 minutes                                        | 44 (36)   | 8 (19)          | 12 (44)           | 24 (46)       |
| 1 hour                                            | 67 (55)   | 27 (64)         | 14 (52)           | 26 (50)       |
| 2 hours                                           | 5 (4)     | 3 (7)           | 1 (4)             | 1 (2)         |
| More than 2 hours                                 | 5 (4)     | 4 (10)          | 0 (-)             | 1 (2)         |
| Preferred platform ( <i>1 vote per platform</i> ) | (n=149)   | (n=50)          | (n=30)            | (n=66)        |
| Zoom                                              | 84 (56)   | 30 (60)         | 19 (63)           | 35 (53)       |
| FaceBook                                          | 66 (44)   | 25 (50)         | 18 (60)           | 23 (35)       |
| YouTube                                           | 57 (38)   | 24 (48)         | 10 (33)           | 21 (32)       |
| Instagram                                         | 51 (34)   | 14 (28)         | 10 (33)           | 27 (41)       |
| Webinar                                           | 31 (21)   | 14 (28)         | 7 (23)            | 10 (15)       |
| Twitter                                           | 5 (3)     | 3 (6)           | 1 (3)             | 1 (2)         |
| Preferred content ( <i>1 vote per option</i> )    | (n=149)   | (n=50)          | (n=30)            | (n=66)        |
| Adventures with the AccesSurf Community           | 80 (54)   | 30 (60)         | 12 (40)           | 29 (44)       |
| Educational/Training                              | 74 (50)   | 25 (50)         | 17 (57)           | 32 (48)       |
| Learning new things with the AccesSurf Community  | 74 (50)   | 28 (56)         | 18 (60)           | 28 (42)       |
| Exercise/Workout                                  | 73 (49)   | 30 (60)         | 16 (53)           | 27 (41)       |
| Ocean Safety                                      | 67 (45)   | 23 (46)         | 13 (43)           | 31 (47)       |
| Interviews/Talk Story Tuesdays                    | 56 (38)   | 19 (38)         | 17 (57)           | 21 (32)       |
| Social Calls                                      | 47 (32)   | 22 (44)         | 14 (47)           | 11 (17)       |
| Advanced Volunteer Training                       | 46 (31)   | 7 (14)          | 6 (20)            | 33 (50)       |

## Communication

**Communication and satisfaction.** E-mail was the first choice (83%), followed by Social Media (42%), and then Website (26%) (Table 3.5). Most people (91%) thought that AccesSurf's external communication is just right, only 8% thought there was too little, and one volunteer thought there was too much (Table 3.10).

**Outreach recommendation.** Most people (71%) thought that AccesSurf should foster more outreach with other non-profits, schools (69%), hospitals (56%) and media (40%). These patterns were similar across all sub-groups, with one exception, the volunteers' first choice was schools (74%).

Table 3.10: Preferred Communication Method, Satisfaction with Amount of Communication, and Outreach Suggestions

|                                                       | Total (%) | Participant (%) | Family Member (%) | Volunteer (%) |
|-------------------------------------------------------|-----------|-----------------|-------------------|---------------|
| <i>Preferred communication tool (1 vote per tool)</i> |           |                 |                   |               |
|                                                       | (n=146)   | (n=50)          | (n=30)            | (n=66)        |
| Emails                                                | 123 (83)  | 39 (78)         | 29 (88)           | 55 (83)       |
| Social Media                                          | 62 (42)   | 18 (36)         | 18 (55)           | 26 (39)       |
| AccesSurf Website                                     | 38 (26)   | 11 (22)         | 10 (30)           | 17 (26)       |
| Phone (text/call)                                     | 33 (22)   | 19 (38)         | 6 (18)            | 8 (12)        |
| In Person                                             | 15 (10)   | 10 (20)         | 1 (3)             | 4 (6)         |
| Media/Tv/ Newspaper                                   | 14 (9)    | 5 (10)          | 2 (6)             | 7 (11)        |
| Letter in the Mail                                    | 10 (7)    | 6 (12)          | 3 (9)             | 1 (2)         |
| <i>Amount satisfaction (1 option was allowed)</i>     |           |                 |                   |               |
|                                                       | (n=126)   | (n=44)          | (n=27)            | (n=55)        |
| Just right                                            | 115 (91)  | 39 (89)         | 23 (85)           | 53 (96)       |
| Too little                                            | 10 (8)    | 5 (11)          | 4 (15)            | 1 (2)         |
| Too much                                              | 1 (1)     | 0 (-)           | 0 (-)             | 1 (2)         |
| <i>Outreach recommendation (1 vote per option)</i>    |           |                 |                   |               |
|                                                       | (n=146)   | (n=50)          | (n=30)            | (n=66)        |
| NPO                                                   | 90 (71)   | 35 (70)         | 16 (53)           | 39 (59)       |
| School                                                | 87 (69)   | 23 (46)         | 15 (50)           | 49 (74)       |
| Hospitals                                             | 70 (56)   | 25 (50)         | 7 (23)            | 38 (58)       |
| Media                                                 | 50 (40)   | 21 (42)         | 9 (30)            | 20 (30)       |

### Inclusion: Communication

Six questions were asked about AccesSurf's communication in relation to inclusion, with a seventh on the COVID-19 pandemic and its effects on feelings. The answer options were "1" (totally disagree) to "5" (totally agree) and "don't know", with the numbers and percentages for the two highest ratings (4 and 5) combined and presented for the overall group and sub-groups in Table 3.11.

Generally, agreement with the statements was high, with 86-98% of attendees either agreeing or totally agreeing with the six items. Results suggest that AccesSurf creates positive images around people with disabilities in the media, uses appropriate language, is accessible for people with disabilities, encourages people to participate, and provides enough information about AccesSurf events. Overall, family members gave the lowest rating in all items, such as whether they thought there is enough information on AccesSurf events and activities available to them (question 6), except for question 2, where family members have the highest percentage in agreement with the statement of feeling included in the AccesSurf community because of communication.

There is a significant variation among the sub-groups when considering responses on the perceived feeling on information about AccesSurf events (question 6) and the effect of the

COVID-19 pandemic (question 7). Specifically, 82% of participants and 75% of family members felt there is enough information compared to 95% of the volunteers feeling that way; 80% of participants and 93% of family members reported that COVID-19 has made them feel more isolated and unable to access ocean activities, compared to only 45% of volunteers (Table 3.11).

Table 3.11: Feelings Around Inclusion by Groups: Those who Agreed and Totally Agreed out of All Who Expressed a View: Total (T), Participant (P), Family Member (FM) and Volunteers (V)

| Groups                                                                                                      | T<br>(n=149)<br>N (%) | P<br>(n=50)<br>N (%) | FM<br>(n=33)<br>N (%) | V<br>(n=66)<br>N (%) | Chi-Square<br>Sign. |
|-------------------------------------------------------------------------------------------------------------|-----------------------|----------------------|-----------------------|----------------------|---------------------|
| I feel:                                                                                                     |                       |                      |                       |                      |                     |
| (1) that AccesSurf's media communications encourage me to participate in water activities.                  | 109 (85)              | 41 (87)              | 21 (81)               | 47 (84)              | .76                 |
| (2) included in AccesSurf's community because of its communication.                                         | 120 (87)              | 42 (84)              | 25 (89)               | 53(88)               | .73                 |
| (3) that AccesSurf creates positive representation of people with disabilities in the local news and media. | 132 (98)              | 49 (98)              | 24 (96)               | 59 (98)              | .79                 |
| (4) that AccesSurf's language is appropriate.                                                               | 135 (98)              | 48 (98)              | 24 (92)               | 63 (100)             | .26                 |
| (5) that AccesSurf's communication is easily accessible for people with disabilities.                       | 109 (92)              | 44 (92)              | 21 (88)               | 44 (94)              | .68                 |
| (6) that there is enough information about AccesSurf events and activities available to me.                 | 121 (86)              | 41 (82)              | 21 (75)               | 59 (95)              | .04*                |
| (7) that COVID-19 and its effects have made me feel more isolated and unable to access ocean activities.    | 93 (68)               | 40 (80)              | 28 (93)               | 25 (45)              | .00**               |

\*  $p < 0.05$  statistically significant; \*\*  $p < 0.001$  statistically highly significant

### Inclusion Community

This question with three answer options (Table 3.12) explored the desire to expand one's networks. Overall, 68 (50%) of 136 community members who answered the question said they would like to increase their network of friends and have more opportunities to participate in ocean activities. However, looking at the groups separately, 66% of participants and 60% of family members wanted to increase their networks, compared with only 20% of volunteers. On opportunities to participate in ocean activities, 94 (69%) of 136 respondents wanted more opportunities. Only 42 (31%) responders said they had a sufficient network of friends and enough opportunities to get into the ocean. Of these, the majority, 37 (88%) were volunteers, five (12%) were participants, and no family members felt that way (Table 3.12). Responses to the last question showed a significant difference at  $< .0001$  level between groups via the Chi-Square test, with volunteers having networks, and participants and family members wanting more networks and opportunities than volunteers (answer option a and c).

Table 3.12: Perception of Need for an Increased Network and/or Opportunities  
(1 choice allowed)

| Question: Which of the following option applies to you?<br>Answer Option:                                               | All: Total<br>(n=136)<br>(%) | Participants<br>(n=50) (%) | Family<br>Members<br>(n=29) (%) | Volunteers<br>(n=57) (%) | Chi-Square<br>Sign. |
|-------------------------------------------------------------------------------------------------------------------------|------------------------------|----------------------------|---------------------------------|--------------------------|---------------------|
| a) I have a network of friends and have plenty of opportunity to participate in ocean activities.                       | 42 (31)                      | 5 (10)                     | 0 (-)                           | 37 (65)                  | .00**               |
| b) I have a network of friends and would like more opportunity to participate in ocean activities.                      | 26 (19)                      | 12 (24)                    | 9 (31)                          | 5 (9)                    | .02*                |
| c) I would like to increase my network of friends and would like more opportunities to participate in ocean activities. | 68 (50)                      | 33 (66)                    | 20 (69)                         | 15 (26)                  | .00**               |

\*  $p < 0.05$  statistically significant; \*\*  $p < 0.001$  statistically highly significant

Table 3.13 shows the answers to questions on perception of inclusion and isolation; survey participants were asked to select all that apply (selecting an answer options means yes, not selecting it no). These showed significant differences by type of respondent. For example, volunteers were most likely to feel connected and included in the community of their preferred water sport (70%, vs. 34% of participants and 12% of family members) and least likely to want more opportunities to socialize with other AccesSurf people (5%, compared to 34% and 42% of family members). Percentages did not differ across groups on feeling included in the AccesSurf community (item 3) and feeling included in the community in which they live (item 4).

Table 3.13: Perception of Inclusion and Isolation

|                                                                                                               | All: Total<br>(n=143)<br>(%) | Participants<br>(n=50) (%) | Family<br>Members<br>(n=33) (%) | Volunteers<br>(n=60) (%) | Chi-Square<br>Sign. |
|---------------------------------------------------------------------------------------------------------------|------------------------------|----------------------------|---------------------------------|--------------------------|---------------------|
| 1) I feel connected and included in the community of my preferred water sport (surf, swim, paddle community). | 63 (44)                      | 17 (34)                    | 4 (12)                          | 42 (70)                  | .00**               |
| 2) I feel I am able to access water activities through AccesSurf.                                             | 47 (33)                      | 21 (42)                    | 13 (39)                         | 13 (22)                  | .02*                |
| 3) I feel included in the AccesSurf community.                                                                | 63 (33)                      | 22 (44)                    | 10 (30)                         | 31 (52)                  | .30                 |
| 4) I feel included in the community that I live in.                                                           | 49 (34)                      | 18 (36)                    | 7 (21)                          | 24 (40)                  | .29                 |
| 5) I feel isolated and would appreciate more opportunities to socialize with other AccesSurf people.          | 34 (24)                      | 17 (34)                    | 14 (42)                         | 3 (5)                    | .00**               |
| 6) I need help to get out and socialize.                                                                      | 19 (13)                      | 11 (22)                    | 8 (24)                          | 0 (-)                    | .00**               |

\*  $p < 0.05$  statistically significant; \*\*  $p < 0.001$  statistically highly significant

## **Discussion**

### **Summary of Findings Compared to the Literature**

This study yielded valuable data on program awareness, attendance, satisfaction, and the variety of needs of the AccesSurf population and its sub-groups. Assessing satisfaction is the gold standard for program evaluation and improvement of programs for people with disabilities (11). In this needs assessment, respondents' perceptions of the programming (both in-person and virtual) were favorable. This aligns with literature which has shown that satisfaction is higher for any consumer-directed personal assistance for people with disabilities compared to non-consumer-directed programs (107). Moreover, satisfaction has been shown to be impacted by interpersonal bonds (98); AccesSurf has always focused on interpersonal relationships, which might be reflected in the high satisfaction-scores.

The results also show significant difference in how the COVID-19 restrictions have affected the different sub-groups engaged in AccesSurf, including participants, family members, and volunteers. All populations were affected by COVID-19 and its restrictions; however, our findings suggest that those with disabilities and their family members are disproportionately affected in terms of isolation and loneliness (108). Although this was the case before the COVID-19 pandemic (57), the extent of the issue within the AccesSurf community during the pandemic can now be confirmed through this needs assessment. Because feelings of isolation and loneliness can negatively affect health, this finding suggests that AccesSurf's participants and family members may be at increased risk for health issues due to COVID-19 restrictions. Thus, AccesSurf's community is in need of AccesSurf services now more than ever.

Findings also show that most participants and family members would like to increase their networks and have more opportunities to access ocean activities. Although the focus of AccesSurf has been on people with disabilities, these findings reveal that family members want to be included and need the opportunities to engage in AccesSurf activities as much as the participant. Participants and family members also differed from volunteers on feeling excluded, wanting more opportunities through AccesSurf, and wanting more help in general to socialize. This is in line with other findings throughout the data collection instrument, again, revealing that participants and family members are in need of AccesSurf programs. We need to pay attention to the disproportional impact and need upon these groups, addressing those through services such as AccesSurf can provide. Hence supporting programs like AccesSurf, through provision of resources and funds is essential, because in the long run it costs a society so much more if we do not follow the basics outlined here.

We also recorded different programming needs across groups. For example, family members wanted more individual in-person programs for people with disabilities, while volunteers wanted more group programs. One could speculate that family members who report higher feelings of isolation have a greater desire for in-person opportunities. These respondents may also have been impacted by cancellation of other programs (108) in the community. Also, not all people with disabilities are able to participate in online programming. Conversely, volunteers, who might have decreased risk of symptomatic and/or severe COVID-19 are more comfortable with larger group programs than the other two sub-groups, who preferred small group or one-on-one settings. This aligns with the literature (54,55). Limitations alone that cause disability may not be related to higher risk or getting severely ill from COVID-19, but many people with disabilities have other underlying health conditions that may increase their risk of severe disease (54). Thus, engaging in large-group activities during COVID-19 could cause additional anxiety among people with disabilities and their family members (55).

Across all groups, there was a preference for events to be held weekend mornings for two or more hours on the South or West Shore, focusing on leisure events. This aligns with AccesSurf's pre-COVID-19 pandemic programming. As in-person gathering numbers now have to be restricted, AccesSurf might have more flexibility; small groups of participants are more likely to be able to find mutually agreeable, appropriate, and accessible locations and times that extend beyond the traditional offerings. Others may have found the large social gatherings overwhelming and intimidating to such an extent that they may have opted out of participation, or will opt out in future based on new norms initiated by the pandemic. In this way, the pandemic may provide an opportunity to cater to individuals who may previously have found large AccesSurf activities to be challenging. Many of the programming preferences are in line with anecdotal knowledge of the AccesSurf community's routines. Some families have reported to AccesSurf that a 9am start means a 3am wake up to do all their morning duties prior to participating (109).

A different preference was shown for virtual programs, with a clear preference across all groups for interactive virtual programming of about an hour. The preferred platform is Zoom across all groups. There was high interest in a range of new content, including education/ training, learning new things with the AccesSurf community, exercise/ workout and ocean safety. This can help AccesSurf design a variety of online programs that will benefit community members not only during the pandemic, but also after, as new norms around community gatherings may remain in place for some time (110,111).

## **Addressing the Identified Need: Implications for AccesSurf Programs**

The findings suggest a number of recommendations for AccesSurf as the organization moves forward to meet the needs of participants, family members, and volunteers. These are listed here and will be shared with AccesSurf stakeholders:

- Across all activities, keep family members in mind when designing new programs, as they have specific preferences for type and timing of activity, as well as needs for socialization.
- Offer a mix of small in-person programs and virtual programs. Re-introduce large in-person events when safe to do so.
- For in-person:
  - Increase the number of small and safe in-person programs (land and water based), keeping in-person program to a maximum of five people (or as state regulations allow)
  - Schedule program dates based on preferences, namely for participants (weekdays and weekends), family members (weekend) and volunteers (weekend).
  - Accommodate family members of persons with severe disability by offering more afternoon programs.
  - Offer in person activities at a variety of locations.
- For virtual programs:
  - Identify scheduling preferences specifically to virtual programs
  - Increase promotion of new online programs especially through email, and for family members to address low awareness
  - Make any virtual program available on zoom
  - Design a variety of events with different topics of interest for the community, such as education/ training, learning new things with the AccesSurf community, exercise/ workout and ocean safety
  - Consider designing special programs for family members.

## **Needs Assessment and its Mixed-Method Approach**

AccesSurf found this process of a formalized needs assessment very helpful. Findings mostly confirmed anecdotal conversations with community members, but also complemented them with numbers, adding depth. There is little literature on use of mixed-methods approaches (using open-ended questions to develop a closed-ended item survey) to need assessments to understand how programs should pivot during COVID-19. However, two recent studies on the impact of COVID-19 used a mixed-method approach (112,113). One study researched the impact of COVID-19 on Latinx sexual minority men and transgender women and reported increased conflicts, alcohol consumption and job loss, next to less medical attention and disruption of medication (112). The second one developed a pandemic tailored framework for

physicians, based on solicited answers from a qualitative and quantitative online data tool, similar to this study, with the recommendations to increase collaboration, to advocate for patients and providers, and to offer avenues for social connection and wellness (113).

### **Study Strengths and Limitations**

This is the first formal needs assessment for AccesSurf, thus providing a model and standard. Part II was informed by Part I and allowed for analysis by sub-groups. The mixed-methods approach is a strength of the study. Moreover, due to COVID-19, both parts were conducted via online data collection instruments, which minimizes the influence of social desirability bias (83).

While the change of the email platform between Part I and Part II was unexpected, the questionnaires were largely sent to the same email addresses. The new platform accumulated response rate data. Response rates were relatively low compared to the number of people on the mailing list (3%), however, we could not determine how many of the email addresses of the mailing list are actually part of the three groups (volunteers, participants, and family members) asked to participate. A truer response rate may be closer to 50%, as suggested by the percentage of respondents from among those who clicked the survey link (52%) or the number of active participants, family members and volunteers (50%). A low response rate has been a growing issue with online surveying (114); and no research has examined realistic response rates during a pandemic. The attempts of using incentives and reminders to increase the response rate, are unfortunately known to not always work (115). Nevertheless, this might have introduced selection bias, with only the very satisfied or the very unsatisfied responding. As noted in other studies during COVID-19, there might be many reasons why people do not respond to online surveys. For example, responses may be difficult for people who have lost their routines or feel too low to answer emails and surveys, or for people too busy adjusting to the changes that they do not have the time to respond (112,113). Also, anonymous studies can have lower response rates. Also, some people may have had difficulty accessing data collection instruments due to no internet or inability to complete online surveys. AccesSurf attempted to address this by verbally “interviewing” participants with staff members entering the data for them. While this was discussed and was supported, there is no record of how many questionnaires were completed that way.

## **Conclusion**

This study used an online survey with open-ended items to develop items and response options for a closed-ended survey to assess the community needs and preferences for programming during the COVID-19 pandemic. This is the first formal needs assessment for AccesSurf Hawai'i. AccesSurf community members showed high satisfaction with AccesSurf programming and external communications. Program preferences and ratings are aligned across the two forms of data collection. The findings of this needs assessment align with the literature regarding isolation and the disproportionate effects of COVID-19 restrictions on people with disabilities and their family members. AccesSurf can use these findings to improve activities and services to better address the needs of its community, especially family members.

## **CHAPTER 4: AccesSurf's Sustainability Assessment**

### **Abstract**

Sustainability of public health programs is a significant issue. Programs require funding for staff, space, and supplies in order to provide their services. Sustainability also has become of increased interest to funders, who hope for long-lasting, positive effects from their investment. Sustainability is of particular importance to programs for which there is no reimbursement from federal or private health insurance, despite the measurable improvement in health outcomes of participants as a result of their programs (116). This study explored the factors contributing towards AccesSurf's success and sustainability through a mixed-method approach utilizing the Program Sustainability Assessment Tool (PSAT) to conduct cross-sectional surveys (n=15), followed by in-depth interviews (n=5) of organizational stakeholders. Overall, this study discerned three areas of strength, including: 1) AccesSurf's ability to adapt their programs to changing conditions, 2) high level of support from internal and external champions, and 3) AccesSurf's effective communication and program promotions strategies. The study also identified three areas for improvement: 1) strategic planning for future resource needs and programs, 2) funding stability, such as a variety of funding streams and mixture of stable and flexible funding, and 3) partnerships with other community organizations and leaders. Findings can inform similar organizations that are providing innovative, recreational Physical Activity options for people with disabilities.

### **Introduction**

Sustainability of public health programs is a significant issue, as they require funding for staff, space, and supplies in order to provide their services. Sustainability has also become a significant issue for funders, who want to see long-lasting, positive effects from their investment. Sustainability is of particular importance to programs for which there is no reimbursement from federal or private health insurance (116). For these reasons, evaluations of sustainability should be considered as an additional stage within program implementation (117). In fact, one of the critiques of dissemination and implementation science is that it fails to include aspects of what happens to programs after their implementation (118). Post-implementation outcome evaluations are often limited to the continued existence of the program over a short timeframe. However, programs with long-term sustainability have a better chance of improving participants and community outcomes than short-lived programs (118). Often programs end once the funding is over, unless they can find other funding streams.

## **Sustainability definition**

There are a variety of meanings and types of sustainability, as well as different opinions on how to measure sustainability and what its influencing factors are (60–62,117,118). Scheirer (2005) explained that sustainability is not limited to a dichotomy between whether a program is ongoing or not (59) and outlined three definitions of sustainability and five factors that influence program sustainability. Sustainability can be measured as: 1) whether all or part of the program activities were continued, 2) whether the benefits or outcomes for new clients were continued; and/or 3) whether community capacity was maintained. The five sustainability factors taken from 17 studies were 1) ability to be modified over time, 2) champions, 3) program fits into organization's mission, 4) benefits to staff and/or clientele, and 5) support through stakeholders (59).

In a systematic literature review published in 2010, Hutchison found 33 tools measuring some aspect of sustainability, and concluded that there were diverse definitions of sustainability and lack of rigorous measurement of these constructs (60). Hutchison explained that the diversity of definitions may reflect the fact that sustainability should be viewed as different points on a continuum, ranging from the simple continuation of a pilot project to the long-term maintenance of benefits that it brings to a community. The four definitions most used in literature identified through Hutchinson are: 1) the continuation of successful pilot programs after major or seed funding is terminated; 2) the capacity to continue to deliver a program through a network of agencies, in addition to or instead of, the agency which initiated the program ('spinning off'); 3) the extent to which pilot programs or new practices become 'taken up' and embedded as core programs or practices within an institution or host agency ('institutionalization'); and 4) the maintenance of program benefits in a community over the long-term through the development of increased community capacity.

In 2011, Scheirer and Dearing designed a Sustainability Framework. The framework is outcome-based and focuses on whether the program can sustain anticipated results. It is organized around several key research components: dependent variables ('outcomes'); independent variables ('inputs,' 'factors,' and 'financial resources'); data-collection methods; and overall research designs. The authors disclosed that the Framework represents a variety of, but not all, influencing factors. They hypothesized that financial resources are important factors that influence sustainability and lasting outcomes; however, they are not to be mistaken for sustainability by itself (117). These sustainability outcomes by Scheirer and Dearing mirror the various ways in which a program can continue to have the intended effects. Sustainability outcomes are the variety of elements that a program can sustain, such as its activities,

community-level partnerships, organizational practices, benefits to its clients, and the prominence of the program's core focus.

In 2013, Schell, Luke and colleagues defined sustainability as the small set of organizational and contextual factors that build the capacity for maintaining a public health program, its activities, and its benefits over time (61). Based on their research, they defined sustainability capacity formally '*as the existence of structures and processes that allow a program to leverage resources to effectively implement and maintain evidence-based policies and activities (p.2).*' The authors' intent of this rather broad definition is that it includes, in addition to program characteristics, organizational and systems characteristics that might positively influence sustainability. The authors' literature review, input from an expert panel, and concept mapping were used to identify the core domains of a conceptual framework for public health program capacity for sustainability. The mapping identified **nine domains** of capacity for sustainability: 1) Political Support, 2) Funding Stability, 3) Partnerships, 4) Organizational Capacity, 5) Program Evaluation, 6) Program Adaptation, 7) Communications, 8) Health Impacts, and 9) Strategic Planning (Figure 4.1) (61).

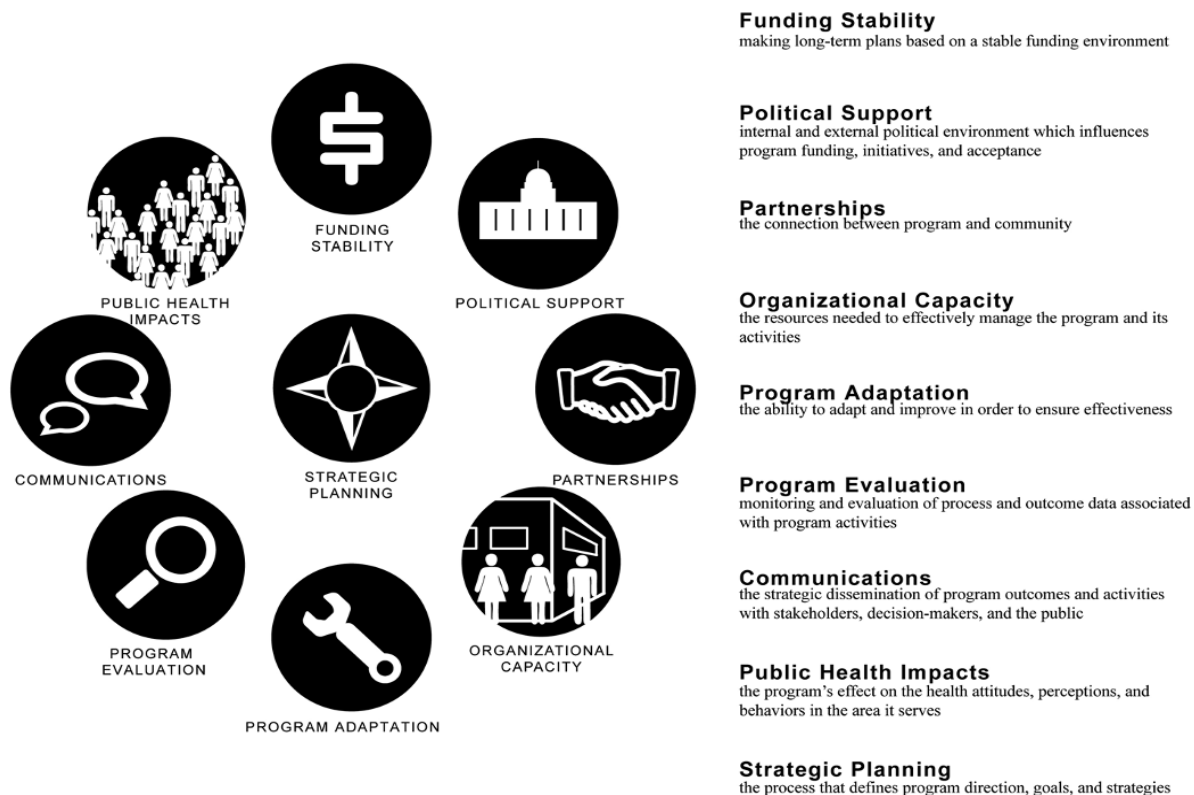


Figure 4.1: Definitions of Identified Domains for Sustainability (61)

Luke and colleagues used these nine domains to develop the Program Sustainability Tool (PSAT) to rate the sustainability capacity of a program to support futuristic planning (62). In 2014, the PSAT was tested for reliability with a new working group. Program managers and staff (n=592) from 252 community- and state-level health programs analyzed their programs' sustainability based on the PSAT. The average PSAT program score was 4.8 out of 7, on a scale from 1=low to 7=high. Through a psychometric process that tested the pilot model, one domain/subscale (Public Health Impact) and 23 items were eliminated. Public Health Impact was eliminated because it appeared to measure sustainability outcomes rather than a program's capacity for sustainability and had high subscale inter-correlations with other domains. Compatibility of the data within the remaining eight domains was confirmed by confirmatory factor analysis. The subscales had high internal consistency (average Cronbach's  $\alpha$  was 0.88, ranging from 0.79 to 0.92) (62). Additional programs have used it on national and international levels (64). It can be used also for social services, and educational programs next to public health programs (64). The final version of the PSAT V2 (version 2) contains 40 items, with five items for each of the remaining eight domains, using the label Environmental Support instead of Political Support domain (64,119).

Additionally, a series of open-ended questions was developed for each domain (65). These can be used in interviews with stakeholders to solicit in-depth qualitative data. Quantitative scores and results from the open-ended questions can provide valuable information on program and organizational characteristics (62) and factors that can promote long-term program sustainability (118). It is also important to demonstrate a program's sustainability before replicating a program elsewhere (117).

The goal of this study was to assess AccesSurf's sustainability through the perspectives of their Board members and Executive Director by using the PSAT tool. AccesSurf Hawai'i, an established 501(c)3 non-profit organization since 2006 on O'ahu, for more detail see Chapter 1. The results can be extrapolated to assist similar organizations, by discerning areas of strength and opportunity for organizations providing innovative, recreational (aquatic) Physical Activity (PA) options for people with disabilities.

## **Methods**

In line with previous PSAT evaluations, this study used the sustainability definition by Schell, Luke and colleagues (61,62) and the PSAT for AccesSurf's sustainability evaluation.

## Study Design

This mixed-methods study was completed using the closed-ended questionnaire and open-ended interview questions of the PSAT. This study addressed three steps of the CDC Framework for Evaluation in Public Health (CDC-FPEPH) (66). Data were collected from AccesSurf's stakeholders, namely the Executive Director and the Board of Directors, to gather credible evidence on program sustainability (step 4), to justify the conclusion (step 5), and to develop and share lessons learned about program sustainability (step 6) (66).

## Sample

**Survey Sample.** The AccesSurf Executive Director (ED) and all 16 members of the Board of Directors (BOD) were asked to participate in the PSAT survey. Of these 17 stakeholders, 15 completed the questionnaire (88% return rate). Because PSAT is an anonymous survey, demographic information for the participants is not available. But in general, at the time of the study, half of the BOD was female and half male (with the ED: 9 female and 8 male). Eight members were in the age range of 30 to 50 years, and nine members were between 51 and 70 years. Their involvement ranged from under one year (two recently added BOD members) to over 13 years, with the three members having been involved between 1 up to 3 years, three members between 3 to 5 years, five members between 5 to 7 years, and three members over 8 years. Seven members are also involved as program volunteers at events on a regular basis. Two members are also participants and one is a participant parent.

**Interview Sample.** Among those who completed the PSAT, purposive sampling was used to identify interviewees. Because I (the grant writer) had occasionally attended BOD meetings since 2015, I was familiar with the length and intensity of most BOD members' involvement (especially related to the PSAT domains). Based on their length and intensity of commitment, perceived willingness to help, and their area of expertise within AccesSurf that aligns with one or several PSAT domains, I invited five survey participants to complete an interview. I also consulted the ED about her perception of involvement and expertise on PSAT domains on BOD members; however, I made the final decision and did not disclose who was interviewed. After three interviews there were repetitive comments, and saturation was reached after five interviews. All five invited interviewees (3 female, 2 male) participated in the interview (100%).

## Measures

**Survey Tool.** The 40-item PSAT questionnaire was developed by Stoll at Washington University in St. Louis (63). The eight factors of the PSAT are: Environmental Support, Funding Stability, Partnerships, Organizational Capacity, Program Evaluation, Program Adaptation,

Communication and Strategic Planning (62). For example, an item in the Environmental Support domain is, *'The program has strong advocacy support'*, and an item in the Partnership domain is, *'Community members are passionately committed to the program.'* Response choices are on a Likert scale, ranging from 1 (little or no extent) to 7 (a very great extent). The average time to answer the 40 closed-ended items the survey (see Appendix VI) is 15 minutes.

**Interview Schedule.** The published open-ended questions developed by Stoll, which specifically complements the PSAT tool, were used for interviews (65) (Appendix VI). An example of a question in the Political Domain is: *'Who are your champions or advocates? In what ways do they advocate for the program (or have they advocated, or you hope they will advocate)? Can you provide an example?'* A sample question in the partnership's domain is: *'How do you see partner organizations or community members contributing to the sustainability of your efforts to improve care coordination?'*

For this study, a question was added at the end of the interview asking: *'Do you think your answers would have been different if we weren't currently facing the COVID-19 pandemic?'* This was to determine the impact (if any) of COVID-19 on participants' responses.

## **Procedures**

The BOD president and two other BOD members were asked for approval of the PSAT study prior to my proposal defense. The rest of the BOD was introduced to the study at the BOD meeting following my proposal defense and over email by the ED. After applying for institutional review board (IRB) approval, the University of Hawai'i IRB determined this study to fall under 'quality improvement,' so a consent form was not required or used.

**Survey Procedures.** The questionnaires and reminder notifications were sent via the PSAT website to the ED and BOD (n=17). The survey was open from June 14<sup>th</sup> to July 7<sup>th</sup>, 2020. Follow up emails were sent to those who had not completed the survey at three time points. Survey participants received a copy of their own results.

**Interview Procedures.** Upon agreement to participate in an interview, I emailed participants the questions in advance so they could prepare (1-2 days prior to interview). Interviewees were also invited to bring their personal ratings to the PSAT questionnaire. The five interviews were held between August 6<sup>th</sup> and August 18<sup>th</sup>, 2020 and lasted between 1 and 2 hours each. Interviews were conducted over Zoom or GoToMeeting (120,121). Green's interview guidelines were followed (122) on interviewing skills, such as neutral behavior and objective language to not influence the responses. Interviews were audio and video recorded, with permission requested at the beginning of the interview. The qualitative interviews complemented the quantitative PSAT survey findings, allowing interviewees to discuss each

domain and its definition, and to explain and even change their scores based on increased understanding and changes that happened between the survey and interview. I started the interviews by sharing a summary of the group results, followed by an explorative comparison of the overall survey ratings and the individual interviewee score made for the organization. Afterwards, each domain was discussed.

## **Data Analysis**

**Survey.** All survey data were compiled and shared via the PSAT website administration. The means and range for each of the 40 items, as well as an average for each of the domains were calculated and are presented in the findings.

**Interviews.** Audio recordings were transcribed using either the closed captions software included in Zoom or an external transcribing company (TEMI) plus re-listening and correcting the draft of transcription (123). I coded the finalized transcriptions using MAX QDA Pro 20 software following a deductive-inductive approach (5). Deductive categories were established based on the eight domains used in the PSAT questionnaire, while allowing inductive free coding (126) across domains and under each domain. This combination of approaches allowed the analysis to be more explorative and open-ended, compared to a purely deductive approach (125).

Interview findings are presented under the category/domain they are related to. Some sections of the interview transcript had multiple codes since they fell under several categories. Multiple-coded sections of text are either presented under one category or split/linked between different categories. Salanda suggests including interrelations between categories/themes (126).

**Rigor.** To increase the rigor of this qualitative study I addressed credibility, transferability, dependability and confirmability in multiple ways (127). For example, I had prolonged engagement with the community partner for this study, AccesSurf Hawai'i (credibility). In terms of transferability, I described site, setting, population, and methods, so findings might be transferable to other disability groups. Dependability was ensured by discussing this research with colleagues and by journaling the process. I also described methods and kept transcripts and coding (and audit trails) to ensure conformability. I maintained a reflective journal during the process of coding. The journal was held within the coding software as suggested by Vicary and colleagues (credibility and confirmability) (128).

## Results

This section starts by presenting the overarching survey results and observations from the mixed-method process. The remaining results are presented by domain, from highest to lowest ranking, providing domain scores and illustrative stories and quotes from the individuals interviewed. When a quote is included, it is attributed to one of the five interviewees, i.e., I-1, I-2, I-3., I-4, or I-5.

### Overarching Survey Results and Observations

Out of 17 invited BOD members and the Executive Director, 15 completed the survey (88.2%). The overall sustainability score was 5.2 out of 7. Breaking down the findings into individual domains, the highest score (5.8), given for Environmental Support domain, and the lowest score (4.7), given for Strategic Planning, were relatively close to each other. The domains are ranked in order of their average scores from highest to lowest in Table 4.1.

Table 4.1: PSAT Domains Scores

| Domain                  | Average score* | Range   |
|-------------------------|----------------|---------|
| Environmental support   | 5.8            | 4.4-7.0 |
| Program adaptation      | 5.6            | 4.2-7.0 |
| Communication           | 5.6            | 3.6-7.0 |
| Organizational capacity | 5.4            | 4.0-7.0 |
| Program evaluation      | 5.0            | 3.2-6.7 |
| Partnerships            | 4.8            | 3.8-7.0 |
| Funding stability       | 4.8            | 3.4-6.7 |
| Strategic planning      | 4.7            | 3.0-6.6 |

*\* Response choices for ratings was from 1 (lowest rating) to 7 (highest rating); domains are listed by scores from highest to lowest*

There were two overarching observations from the interviews: 1) alignment of survey and interview scores; and 2) need for definitions due to confusion and conflation of definitions and domains.

**Rating-interview alignment.** Interviewees were asked to compare their personal results with overall results from the 15 survey participants. The scores of the five interviewees were very similar and mostly in the same order as the full sample, suggesting that the five interviewees were representative of the 15 survey participants. One notable exception was that three interviewees stated that the domain Program Adaptation now appeared to them as the strongest domain, instead of the second strongest domain, as they had previously rated it. This was possibly due to the elapsed time between the survey and interviews, and the AccesSurf activities during that time.

**Confusing and conflation of domains.** The predominant discussion during all five interviews was defining program sustainability and the domains. For example, in talking about

program sustainability, interviewees named different elements to sustain the program, such as *‘having the right people in the right places [...] and a sound plan of strategic action [I-2]’*; *‘making AccesSurf a household name [I-3]’*, *‘Program Adaptation [I-4]’*, and *‘developing the BOD [I-5].’* One interviewee asked whether program sustainability meant only looking at the financial side of the organization or at everything. Three interviewees expressed confusion about the word ‘stakeholders.’

## PSAT domains

### Environmental Support

PSAT items in the Environmental Support domain focused on internal and external supporters such as champions, leadership, public support, and political supporters, which influences program funding, initiates and acceptance. Overall, the domain scored well, 5.8 out of 7. The five survey items in this domain, along with their mean scores, are shown in Table 4.2. Within the domain, the highest scoring item was in the area of leadership within the organization (6.2), and the lowest were around public support (5.4). Some interviewees linked these questions exclusively back to the financial domain, such as donors and sponsors, and the lack of Environmental Support within fundraising.

Table 4.2: Environmental Support

| Environmental Support                                                  | Score average* |
|------------------------------------------------------------------------|----------------|
| The program has leadership support within the larger organization.     | 6.2            |
| Champions advocate for the program.                                    | 6.1            |
| The program has strong champions with the ability to garner resources. | 5.7            |
| The program has leadership support from outside of the organization.   | 5.6            |
| The program has strong public support.                                 | 5.4            |

\* Response choices for ratings was from 1 (lowest rating) to 7 (highest rating); questions are listed by scores from highest to lowest

All five interviewees noted that the AccesSurf mission is appealing to a wide range of people. This is an example from one interviewee.

- *‘I can’t tell you how many, like it’s constant influx of stories of all of the people. I just mentioned. Volunteers, participants, staff, sponsors that love, love, love talking about what we do and their experience [I-5].’*

However, three interviewees added the importance of identifying areas in which more support and champions are needed, and integrating and educating community connections especially newly elected officials and healthcare communities. One interviewee lamented the difficulty and limitations of fundraising during COVID-19 and not being able take people to the

beach. Any virtual programming is to him/her 'invisible programming' [I-3]. Even though internal support was ranked high, two interviewees mentioned that the BOD could be more supportive of the ED.

### Program Adaptation

Program Adaptation refers to the ability of the organization to adapt to ensure its ongoing effectiveness. The domain scored well, 5.6 out of 7 (Table 4.3). Within the domain, the highest scoring items were that the program adapts its strategies as needed (5.8) and adapts to changes in the environment (5.8). The lowest scoring item was that the program periodically reviews the evidence base (5.1).

Table 4.3: Program Adaptation

| Program Adaptation                                                                          | Score average* |
|---------------------------------------------------------------------------------------------|----------------|
| The program adapts strategies as needed.                                                    | 5.8            |
| The program proactively adapts to changes in the environment.                               | 5.8            |
| The program adapts to new science.                                                          | 5.6            |
| The program makes decisions about which components are ineffective and should not continue. | 5.5            |
| The program periodically reviews the evidence base.                                         | 5.1            |

\* Response choices for ratings was from 1 (lowest rating) to 7 (highest rating); questions are listed by scores from highest to lowest

Although this domain did not rank the highest in the questionnaire, three interviewees indicated that they would now list program adaptation as the strongest domain overall. All five interviewees gave examples of AccesSurf adapting, modifying equipment and activities based on participants' and volunteers' needs, and modifying programs before and during the COVID-19 pandemic. None of the interviewees stated any major concerns in terms of program adaptation. One interviewee equated AccesSurf's strength of adaptation to the program's sustainability, especially if virtual programs are made 508 compliant, meaning it includes accessibility standards for information and communication technology covered by Section 508 of the Rehabilitation Act (129) (e.g., making it accessible for someone who is hearing impaired/deaf through captioning).

- *'So, I think it positively impacts the sustainability of the program, as long as sustainable products or services result from the adaptation. [...] you know we're creating all of this online content. And as long as, right, we ensure that that content can be used into the future by recording it, by making sure it's 508 compliant, by making sure that we have, that we're providing the material or the online material in a way that's accessible to our community members who are disabled. I think it plays a big role in sustainability [I-1].'*

### Communications

The PSAT Communication domain refers mainly to strategic dissemination of program outcomes and activities with stakeholders, decision-makers, and the public. The

Communications domain scored well: 5.6 out of 7 (Table 4.4). All domain items scored closely between 5.5 to 5.7. (Table 4.4).

Table 4.4: Communications

| Communications                                                                  | Score average* |
|---------------------------------------------------------------------------------|----------------|
| Program staff communicate the need for the program to the public.               | 5.7            |
| The program is marketed in a way that generates interest.                       | 5.6            |
| The program demonstrates its value to the public.                               | 5.6            |
| The program increases community awareness of the issue.                         | 5.5            |
| The program has communication strategies to secure and maintain public support. | 5.5            |

\* Response choices for ratings was from 1 (lowest rating) to 7 (highest rating); questions are listed by scores from highest to lowest

Interviewees' understanding of this domain were mostly aligned with the PSAT items focusing on external communication. All five interviewees agreed that communication was important:

- *'Very important because the more people know about us and the great work that we're doing the more that we become a trusted charity that they will, if they have the money would be willing to support [1-2].'*

Overall, external communication was categorized as strong, as AccesSurf has BOD and staff members who are excellent with external communication, getting the AccesSurf brand name in the marketplace, and brand trust established [1-4]. The BOD president's personal partnership with a media company has been very productive for external communication. However, AccesSurf still has room for improvement by refining the mission, including the educational component (e.g. need and impact of program in community), outreach and sharing publicly content such as evaluation results (formal and informal) or organizational (funding) needs. Two interviewees recommended greater transparency between the BOD and ED, and stronger policies around which information and dissemination tasks can be given to the BOD or the administrative assistant, especially due to AccesSurf has growth. Two interviewees connected establishing guidelines and a communication committee to strengthening this domain but also sustainability in case there is a change in BOD or staff:

- *'[...] the more clear we are on things, the easier it is for somebody to step into AccesSurf, that's never seen it before, doesn't know [the ED] or you or anyone else involved in the organization...having that stuff clearly outlined is extremely important [1-3].'*

### Organizational Capacity

The PSAT Organizational Capacity domain refers mainly to having the internal support and resources needed to effectively manage your program and its activities. The Organizational Capacity domain scored well, 5.4 out of 7 (Table 4.5). Within the domain, the highest scoring item was that leadership effectively articulates the vision of the program to external partners

(5.8) and the lowest was about leadership efficiently managing staff and other resources (5.2) (Table 4.5).

Table 4.5: Organizational Capacity

| Organizational Capacity                                                            | Score average* |
|------------------------------------------------------------------------------------|----------------|
| Leadership effectively articulates the vision of the program to external partners. | 5.8            |
| The program has adequate staff to complete the program's goals.                    | 5.4            |
| The program is well integrated into the operations of the organization.            | 5.4            |
| Organizational systems are in place to support the various program needs.          | 5.2            |
| Leadership efficiently manages staff and other resources.                          | 5.2            |

\* Response choices for ratings was from 1 (lowest rating) to 7 (highest rating); questions are listed by scores from highest to lowest

However, interviewees defined capacity differently. One interviewee referred to staff capacity solely as skills, whereas another interviewee included 'time' in the definition of staff capacity, and a third one said it applied to the having the right person with the right skills in place to make a task successful. A fourth interviewee also referred to capacity as resources such as funding and equipment. Two interviewees identified the '*dedicated, passionate staff and volunteers [I-1]*' and '*the growth of the ED [I-2]*' as strong organizational capacities. Additionally, all interviewees referred to the leadership as currently being in transition due the recent BOD training and changes in BOD.

Four interviewees identified transparency (linked to Communication) and staff development (from choice of staff to position definitions, and to trainings) as areas with room for improvement. The concerns were '*whether the right program staff are in place [I-1]*' and their efficiency. For adequate position descriptions and filling of such, the organization needs to identify the required staff time (e.g., full time vs. part time) based on the organizational need '*and the person that fills that position should have the expertise and the time commitment that is needed to fill that position [I-1]*'; also stating that this has not always been done in the past. Interviewees pointed out avenues and benefits of delegating more duties to staff, which would free up ED time to oversee operations and focus on fundraising. All interviewees suggested that additional leadership training for the ED might be beneficial given the rapid growth of the organization. Additional training for the ED could also help with transparency and re-directing weaknesses in staff.

### Program Evaluation

The Program Evaluation domain refers to assessing one's program to inform planning and to document results. The Program Evaluation domain scored 5.0 out of 7 (Table 4.6). Within this domain, the highest scoring item was in the area of having strong evidence about the

impact for the public (5.4) and the lowest was using program evaluation results to report back to funders and other key stakeholders (4.7) (Table 4.6).

**Table 4.6: Program Evaluation**

| Program Evaluation                                                                                  | Score average* |
|-----------------------------------------------------------------------------------------------------|----------------|
| The program provides strong evidence to the public that the program works.                          | 5.4            |
| The program reports short term and intermediate outcomes.                                           | 5.3            |
| Evaluation results inform program planning and implementation.                                      | 4.9            |
| The program has the capacity for quality program evaluation.                                        | 4.9            |
| Program evaluation results are used to demonstrate successes to funders and other key stakeholders. | 4.7            |

*\* Response choices for ratings was from 1 (lowest rating) to 7 (highest rating); questions are listed by scores from highest to lowest*

This domain shows both conflation and confusion in that it overlaps with the Program Capacity and Funding Stability domains. Since the survey questions ask whether there is enough capacity to do program evaluation, some interviewees thought that the evaluation should also include the staff evaluation (resource, time usage, and task efficiency). Four interviewees referred to Program Evaluation mostly as informal evaluation, such as feedback and reputation, rather than a formal evaluation processes that monitors satisfaction with events and beneficial outcomes experienced by participants.

Three interviewees thought that the formal program evaluation has improved due to the two staff members with skill sets that support the evaluation efforts. While they could not speak to whether enough capacity for program evaluation is given, they verbalized the need to further support monitoring and evaluation efforts by automating participant registration and recommended increased transparency of evaluation activities and findings within all levels of the organization. They also recommended developing standards related to evaluation, for example, considering type and timing of evaluation activities and reports for different events, different stakeholders, and to the BOD and staff.

Three interviewees referred to financial evaluation, monitoring the allocation of funding to different line items, a proximity donor analysis, and that the staff efficiency evaluation could support the concern raised under capacity whether the right program staff is in place.

## **Partnerships**

The PSAT Partnership domain refers to cultivating connections between a program and its stakeholders. The Partnership domain scored 4.8 out of 7 (Table 4.7). Within this domain, the highest scoring item was in the area of community leaders being involved with the program (5.3) and the lowest was community engagement in developing program goals (4.5) (Table 4.7).

Table 4.7: Partnership

| Partnerships                                                                | Score average* |
|-----------------------------------------------------------------------------|----------------|
| Community leaders are involved with the program.                            | 5.3            |
| Community members are passionately committed to the program.                | 4.9            |
| The program communicates with community leaders.                            | 4.7            |
| Diverse community organizations are invested in the success of the program. | 4.7            |
| The community is engaged in the development of program goals.               | 4.5            |

\* Response choices for ratings was from 1 (lowest rating) to 7 (highest rating); questions are listed by scores from highest to lowest

Interviewees included community members, participants, volunteers, and donors in their definition of Partners. All five interviewees talked very highly of the program, its visibility and what the organization has to offer to their partners, and all level of society. Interviewees referred to AccesSurf's programs as '*life-changing*', the '*magic that happens*', its variety of activities and inclusivity on many levels. Two interviewees referred to the BOD president's partnership with a media company, which has helped AccesSurf not only with external communication (stated above), but also with what AccesSurf can offer to partners, such as public service announcements, ultimately increasing AccesSurf's visibility and fundraising.

Three interviewees mentioned that the ED's strong suit is turning provided opportunities into donor partnerships. Also, the ED was able to keep the recent sponsors to their commitment despite the virtualization or cancellation of many of the AccesSurf activities due to COVID-19. There are plans to train BOD members in fund raising and using their connections to '*open doors [I-2].*'

The interviewees identified multiple areas of room for improvement for partnerships, especially those that could lead to financial support. As such, interviewees would like to strengthen relationships with donors, young leaders, and leaders in politics and healthcare. While AccesSurf has some long-term supporters, it experiences high turn-over in donors. Two interviewees recognized that strengthening those relationships could turn short-term donors into long-time supporters instead. Young leaders could help groom future BOD and strengthen partnerships in the community.

One interviewee predicted that partnerships were going to be weakened by two factors: a) the virtual instead of in-person programs ('*I think in person attendance totally changes the way their brain works and their pocket for that matter, too [I-3].*') and b) the resignation of the BOD president ('*I think that we're going to have a big gap in our organization when s/he leaves [I-3].*'

## Funding Stability

The PSAT Funding Stability domain refers to establishing a consistent financial base for the program. The Funding Stability domain scored 4.8 out of 7 (Table 4.8). Within this domain, the highest scoring item was funding variety and the lowest was sustained funding (Table 4.8).

Table 4.8: Funding Stability

| Funding Stability                                                 | Score average* |
|-------------------------------------------------------------------|----------------|
| The program is funded through a variety of sources.               | 5.4            |
| The program has a combination of stable and flexible funding.     | 4.9            |
| The program exists in a supportive state economic climate.        | 4.7            |
| The program implements policies to help ensure sustained funding. | 4.6            |
| The program has sustained funding.                                | 4.3            |

\* Response choices for ratings was from 1 (lowest rating) to 7 (highest rating); questions are listed by scores from highest to lowest

Interviewees' understanding of this domain mostly aligned with the PSAT items. Three interviewees mentioned that the funding structure in 2020 shifted from the past years: funding from grants increased, while donations decreased. Due to COVID-19, typical fundraising events had to be canceled, and a new online strategy had to be engaged.

Two interviewees mentioned that, while they wished for improved funding stability in the future, they were aware that *'AccesSurf always seems to find funding because, I think, because of what we do have lots of lots of sources willing to support us [I-1]'*, and that *'considering we are in COVID-19, I'm ecstatic about it [the current funding situation] [I-2].'*

Four interviewees commented that they would like for AccesSurf to be able to stop *'chasing after the money [I-1].'* Three interviewees identified the issue that while AccesSurf has a variety of funding sources, most of it is short term and needed to ideally develop into long term stable funding. The longest active funding period at AccesSurf is a one-year Government in Aid Grant (GIA) from the City and County of Honolulu. To address the possible upcoming shortage after the GIA grant ends and to improve funding stability, three interviewees would like to improve and/or add the revenue streams, seeking grants and donations with multi-year commitments. Two interviewees mentioned that the organization, however, needs to take steps to get *'ready for them [multi-year/ bigger grants]'* [I-1]. All interviewees stated ideas about returns of possible investments. Two interviewees wanted to aim for partnering either with a *'big multimillion-dollar business(es), that need a tax relief [I-1]'* or partner with another organization and start a business for revenue.

- *'The trick is to get them to commit to your organization. Instead of, you know, a lot of them like to spread the wealth, right, or spread the charity. So, the real hook is to first identify somebody who can work for a nonprofit and number two, somebody who is really to commit to your nonprofit till, you know, till forever, until one of you stops existing [I-1].'*

Two interviewees were convinced that AccesSurf should be able to generate revenue with their surf competition (*'that event should be generating at least at least a hundred thousand dollars [1-2]'*) or through Insurance reimbursement. One interviewee was concerned about where the funding is being spent. S/he would like a more business-like analysis to see if financial resources spent on staff are being used for the right positions and identifying insufficiencies in time usage. S/he suggested that every staff member should be aware of funding needs and shortages, and possibly take certain responsibility for funding. With expansion, staff costs have increased, and s/he thought that certain costs could be cut.

All interviewees identified past and current personal contributions to AccesSurf's funding, such as financial and in-kind donations, time to help with operations, marketing, communication, fundraising, building capacity and grant writing. Three interviewees spoke about the need for and potential of the BOD to *'open up doors for [the ED]'* by connecting her with connections the BOD might have, especially those interested in AccesSurf's mission.

### Strategic Planning

The PSAT domain for Strategic Planning refers to using processes that guide a program's direction, goals, and strategies. The Strategic Planning domain scored 4.7 out of 7 (Table 4.9). Within the domain, the highest scoring item was the program's goals being understood by stakeholders (5.4) and the lowest was having a sustainability plan (4.1) (Table 4.9).

Table 4.9: Strategic Planning

| Strategic Planning                                                            | Score average* |
|-------------------------------------------------------------------------------|----------------|
| The program's goals are understood by all stakeholders.                       | 5.4            |
| The program plans for future resource needs.                                  | 5.2            |
| The program clearly outlines roles and responsibilities for all stakeholders. | 4.7            |
| The program has a long-term financial plan.                                   | 4.2            |
| The program has a sustainability plan.                                        | 4.1            |

\*1 the lowest rating to 7 the highest rating; questions are listed by scores from highest to lowest

This PSAT domain conflates with Funding Stability, so did the interviewees . There was no consensus among the interviewees on what constitutes a proper strategic plan. Three interviewees equated strategic planning exclusively to financial planning. To others, these elements did not equate to a proper strategic plan, as important elements, such as an evaluation of mission alignment, organizational policies and procedures including an action plan and its monitoring, and an annual review for consistency and accountability were missing:

- *'It's just that there were no action plans included in what was developed [...] take what we've already developed and add the action plans to that. Then we can finalize the strategic plan [1-1].'*

There was some disagreement as to the length of time that should be addressed in a strategic plan, ranging from annual, to 3 to 5 years. Two interviewees wanted to include input from staff and the leadership committee. To improve the Strategic Planning overall, one interviewee suggested to also train the ED, and another mentioned that the BOD needed to have the strategic planning skills among its members or needed to get trained themselves.

Several documents that needed to be put in place or updated were referred to by individual interviewees, including: 1) the conflict of interest and confidentiality agreement; 2) the operational manual with financial policies and procedures, and 3) a day-to-day operations manual with job descriptions and qualification requirements, and clear roles and responsibilities of staff positions and BOD members. One interviewee stated the difficulty of: *'how to task the board and [the ED] with making sure that those policies and procedures are followed, that everybody is aware of them, and that everybody knows what's inside of them [1-1].'*

## Discussion

This study found that AccesSurf's sustainability score is above average. Findings identified notable strengths such as AccesSurf's appealing mission and adaptability, visible valuable program benefits and external communication, and invested individuals and champions. But it also identified ways to improve, such as: 1) adding strategic planning for future resource needs and programs; 2) attending to funding stability; and 3) expanding partnerships with other community organizations and leaders. The mixed-methods approach provided dual insight allowing us to obtain quantifiable data as well as the more nuanced insights that can be gleaned from the qualitative approach. Consistent with similar studies (62,130), we identify similar and complementary findings using the two approaches. The following discussion will look at the scoring, ranking, and interconnectedness of the domains, and address the factors that contribute to AccesSurf's success and sustainability, opportunities for growth, and the advantages and drawbacks of the approaches used to draw these conclusions.

The higher the score in a domain, the higher the extend of the domain that supports the program. However, there is no minimum rating that guarantees the sustainability of a program. Lower ratings simply indicate which domain a program should focus on (131). AccesSurf's overall sustainability score of 5.2 is higher than the average score of 4.8 of 252 previous public health programs assessments (62). In congruence with the literature, one of the top-rated domains for AccesSurf was Program Adaptation. AccesSurf's ratings are also similar to the literature for Funding Stability, which was rated the as one of the two lowest. However, unlike

the literature, Program Evaluation was rated as the third lowest domain, whereas it was second highest in the review of 252 programs. This might be due to an increased research connection of programs that are linked to a university or a grant that requires formalized evaluation efforts via paid staff.

Several participants changed their ratings between the survey and the interview, especially for Program Adaptation. This may be attributable to several factors. First, the survey was completed in June/July 2020, while the interviews were done about two months later. During that time AccesSurf was visibly adapting its activities due to the COVID-19 pandemic. There was also a BOD training in early August. Thus, interviewees were more attuned to AccesSurf's operations and their own responsibilities as BOD members. Also, between the survey and interviews, interviewees learned that the BOD president was leaving the board, which caused concerns about partnerships, funding and sustainability. There was also confusion over the definitions of multiple domains in the PSAT tool. The predominant topic discussed during all five interviews was the domain definitions. In future studies, providing definitions prior to administering the PSAT may mitigate some of the discrepancy. Additionally, information was available to me (as AccesSurf staff), as I had done the background research in preparation of this study and the interviews. However, when conducting the interviews, the explanation of domains and AccesSurf operations were standardized as much as possible, to prevent biasing the interviews.

The three single items with the lowest average ratings were from the two domains of Funding Stability (*The program has sustained funding*, which scored 4.3) and Strategic Planning (*The program has a sustainability plan*, which scored 4.1, and *The program has a long-term financial plan*, which scored 4.2). This suggests a lack of long-term secured funding sources, as most interviewees linked a sustainability plan to financial resources. This aligns with previous findings of a review of 49 projects by Schreier and Stoll, because non-profits are often only able to access short-term funding opportunities (130,132). The qualitative findings also highlighted the interconnectedness between domains, such as the Strategic Planning and Funding Stability domains, also described by Stoll's finding in 2015 (130). Schell et al. also found that all domains were connected, and later clustered them by external domains (funding stability, environmental supports, and partnership) versus internal domains (communication, strategic planning, program adaptation, program evaluation, and organizational support), as depicted in Figure 4.2. Schell et al. found this bisectionality of domains helpful in explaining sustainability to program managers (61). Including a diagram like Figure 4.2 may reduce confusion about domains among individuals participating in a PSAT survey.

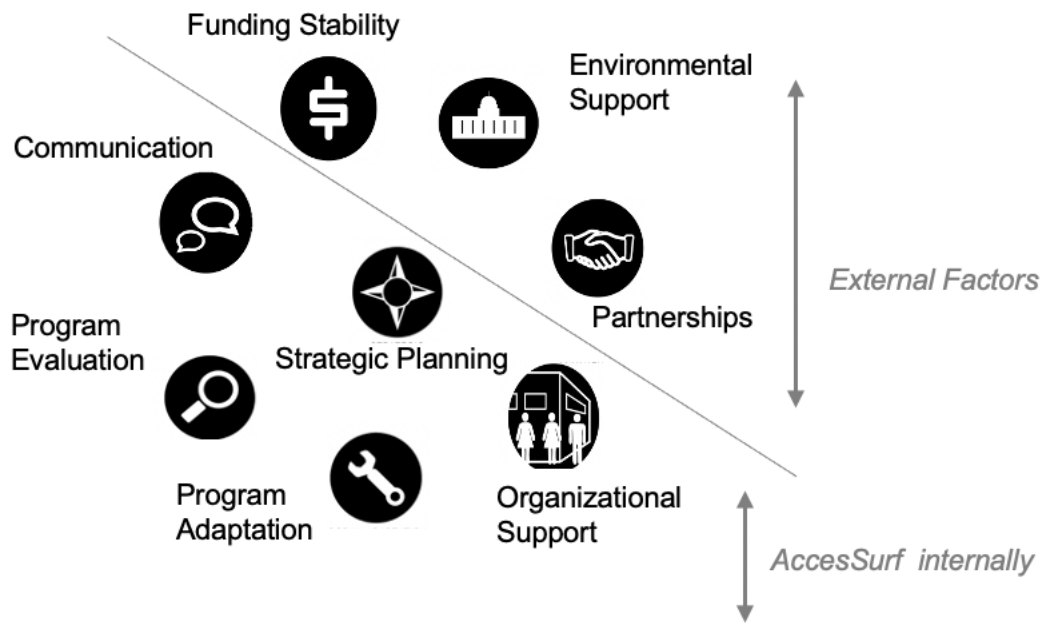


Figure 4.2: Updated and Adapted Sustainability Framework from Schell et al. (61)

Overall, the PSAT findings and interviews suggested that AccesSurf has several strengths. AccesSurf's vision, mission and activities have been identified as an organizational strength itself, as well as how the organization is perceived not only as addressing a need for people with disabilities, but also appealing for supporters (volunteers, but also supporters of a financial nature). AccesSurf's main focus on adaptive sports for their participant population seemed to have not only made them an expert in the field of adaptive aquatic sports, but also in adaptability in general, which was another major factor contributing to AccesSurf's success according to the present study. With the skills in adapting equipment, activities, and programs, it goes without saying for AccesSurf that everyone is welcomed. Hence, another AccesSurf strength is its inclusiveness. However, since programs were moved online due to the pandemic, there is now a need for 508-compliant virtual programming. Making virtual programs 508 compliant means including accessibility standards for information and communication technology (ICT) covered by Section 508 of the Rehabilitation Act (129), such as captioning all spoken materials so someone who cannot hear can read content.

All of the strengths are enhanced by visible benefits for and impact on the community, as well as AccesSurf's external communication. The more recent successes are within grant funding and training the BOD. While the interviewees might have been more critical due to their

recent training, it is a major improvement in organizational capacity and leadership, as it includes setting up processes for the organization, identifying gaps in expertise, and buy-in for additional trainings to address those gaps.

As such, when AccesSurf was smaller, the key staff, mainly the ED and a few invested individuals drove this organization forward (organizational capacity). However, with the growth of the organization and the population it is serving, shared definitions (e.g., defining capacity, staff positions and responsibilities), systems and processes across the organizational levels are needed (lessons learned within Organizational Capacity and Communication domains). Also, additional expertise is needed to sustain the organization, such as in the area of strategic planning. More specifically, the findings suggest a need for greater transparency of operational data across all levels of the organization. For example, it was clear that interviewees did not know about formal evaluation activities that AccesSurf had conducted, calling for a formal, cross-organizational evaluation plan (lesson learned within Program Evaluation). Interviewees did not understand what each staff member did and what the ED delegated to staff. Although the BOD met monthly, they did not feel that they received enough information about operations and budget and what they could do to help. The BOD did a recent training that was facilitated by a BOD member who was leaving. They identified weakness in their own role as the BOD and are addressing those, for example by building sub-committees for different areas within the organization to better support the ED, and hence improving leadership within the organization (Environmental Support). Additionally, sub-committees have the potential to not only strengthen the domain they are for, but overall communication throughout the organization.

The findings also highlight Strategic Planning, Funding Stability and Partnership, as areas with most opportunity for growth. The knowledge gap in Strategic Planning is on skills, templates, importance, and a lack of agreement on a plan's timeframe (1 year, 3 years, 5 years). AccesSurf's Funding Stability is limited to short-term stable funding. This domain can be improved by turning short-term funding into long-term funding, such as multi-year instead of annual grants, recurring instead of one-time donors, and turning selected events into annual income-generating events. Improved stakeholder management would not only improve the Partnership domain itself, but can benefit Funding Stability. Additional recommendations based on the findings can be found under recommendations (Table 4.10).

### **Study Strengths and Limitations**

The PSAT survey (88% of the invited ED/BOD members) and interviews (100% participation of invited) had high participation. The survey is closed-ended and designed to be

straight-forward. However, this limits the results to the ratings without room for explanations. This weakness was addressed by adding the interview component. Hence, a strength of this study is its mixed-method approach, where the quantitative data was used to inform the subsequent data collection, called connecting data (104). The qualitative interviews complemented the quantitative PSAT survey findings, allowing interviewees to discuss each domain and its definition, and to explain and even change their scores based on increased understanding and changes that happened between the survey and interview. This was also found by Stoll (130) and Luke (62). A strength of the interviews was that a single person (myself) who had a long history with AccesSurf conducted them, while still being far enough removed from the interviewees to minimize bias resulting from excessive familiarity. While my insight helped facilitated the discussions, I also found perspectives that differed from mine, which prompted discussion and deepened my understanding of issues related to sustainability. Although it is impossible to ignore the possibility of social desirability, to minimize it, confidentiality of responses was emphasized and leading questions were avoided (133). The current state of flux of the AccesSurf BOD may also have impacted responses, introducing concerns and variability that might not exist in periods of stability. Furthermore, while the interviews reached saturation, it does not exclude the possibility that opinions of non-interviewees were missed. The plan was to invite those to speak during the presentation of the findings, which has not happened. Lastly, the generalizability of findings might be limited to AccesSurf's usage and only partially applicable to similar other programs.

### **Recommendations for AccesSurf**

Though AccesSurf's overall sustainability mean score was 5.2, which is higher than the average score of 252 programs noted in the PSAT validity study (62), this process still identified areas for improvement. The recommendations for action items, based on the findings are shown in Table 4.10. The table shows three overall recommendations, which include: 1) establishing and clarifying definitions across and within sustainability domains and organizational documents; 2) improving transparency, internal communication and systems; and 3) training BOD and ED in strategic planning and other areas to increase their ability to assist and help sustain the organization. Table 4.10 shows specific and detailed recommendations to improve each domain. They are organized by suggested priority, from the weakest (Strategic Planning) to the strongest domains (Program Adaptability and Environmental Support). Addressing Strategic Planning first and foremost has the greatest potential to improve all other domains (see Strategic Planning's central location in Figure 4.2).

Table 4.10: Recommendations for AccesSurf Listed by Suggested Priority (from Weakest to Strongest Score Domain)

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Overall: The organizational overall goals within sustainability planning should be:

- 1) Establish and clarify definitions (including clarifying definitions across and within sustainability domains), and organizational documents (guidelines, procedures and organizational information)
- 2) Improvement of internal communication across all organizational levels and transparency/ access of information, including shared information system (independent from ED)
- 3) Training for BOD and ED (in areas with most room for improvement if expertise is missing among BOD e.g. strategic planning) also to increase BOD support for ED

Strategic Planning (primary focus as strengthening Strategic Planning will benefit all domains)

- Define content (e.g. financial, programmatic, organizational capacity planning; including Action Plan), timelines, plan, resources for Strategic Planning; include regular assessment and planning for sustainability as part of the strategic planning activities
- Identify and use of template(s) for strategic planning
- Acknowledge that expertise for strategic planning is needed within the organization: review a) is expertise available among current BOD members? If not include person with expertise or provide training for BOD and ED on strategic planning, such as through the Hawai'i Alliance of Nonprofit Organization (Hano) (134)
- Include staff and Leadership committee; possibly external partners to ensure buy-ins to program goals and direction
- Set deadlines that are known within the organization
- Increase transparency on all levels on expectations, as such prepare documents, namely 1) the conflict of interest and confidentiality agreement; 2) the operational manual with financial policies and procedures, and 3) a day-to-day operations manual with job descriptions and qualification requirements, and clear roles and responsibilities of staff positions and BOD members (link to Org. Capacity)

Funding Stability

- Focus on building long term stable funding through donors, grants and return of investment (ROI) of events and adding a business revenue
  - Donors: Identify new donors (BOD opening doors for potential donors for ED); free up EDs time to tend to donors; donor maintenance and cultivation of the relationship to turn donors into recurring donors; if possible, identification of big donors that make AccesSurf their main focus instead of splitting amount with other organizations
  - Grants: Take identified needed steps to get AccesSurf ready to apply for bigger grants; possible partner with another organization for Senior Corps grant
  - Turn events, such as Surf Contest, into ROI
  - Partner with another organization and create business for ROI
- Address the concern that during COVID-19 it is harder to convince possible donors/ partners to commit because of the lack of in person programs and what it does to people coming along – make problem known and come up with solutions: such as having testimonial videos of participants that are positively affected by COVID-19 programming

Partnerships

- Create stakeholder management plan to support ED and BOD based on a finalized overview and analyze existing partners and stakeholder: Which organizations or individuals will require a lot of time and energy to keep involved? Who has a lot of influence?
    - Acknowledge if partnership should be continued or not
    - Visualize what ED is currently doing (calls, meetings, thank you cards etc) and revise. Who can support her?, How can evaluation data be better shared for those interested?;
    - Honor donors and grantees on AccesSurf's website etc. (link to communication)
    - Identify possible threat to partnership: e.g. turnover in positions: Action plan for if people in AccesSurf or partner organizations are leaving how to stay connected with both, the organization (who is the replacement etc.) and the person (also under communication),, e.g. President and link to media company
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- Identify organizations and individuals that are not currently involved in program efforts but are impacted by the issues AccesSurf program addresses; e.g area of health care/ insurance and political partnerships. Determine how they could contribute to or benefit from your work and engage them in your program.
- Identify the goals for each partnership. What does your program need from this partner? How can this partner benefit from working with your program?
- Consider inclusion of external partner(s) in strategic planning
- Create young leader committee

#### Program Evaluation

- Improve transparency of activities and result sharing of formal evaluation across organization: e.g. performed analysis of programs by BOD for Evaluator; Evaluators activities and results (e.g. logic model, result of needs assessment etc.), e.g. make PSAT results accessible for all stakeholders
- Design timelines for recurring evaluation activities and to review data
- Define evaluation activities: Are 'proximity of donor analysis', 'efficiency in resource usage' and 'efficiency in staff' part of Accessurf's evaluation?
- Capture informal evaluation (such as feedback and reputation)

#### Organizational Capacity

- Define capacity (e.g. skill exclusively, or include time allowance per staff etc.)
- Review staff positions (based on need for organization)
- Train: Leadership Training for ED due to rapid growth of organization/ staff; make trainings and development opportunities available for essential staff members

#### Communications

- External:
  - Include testimonials and evaluation findings in external communication
  - Moving away from PR around brand trust to public health outreach
  - Address turnover in other organizations (and AccesSurf) in general but esp. during COVID-19, AccesSurf should make sure if there is a turnover, it still keeps connected with organization and person (can be put in the plan for partnerships)
  - Acknowledge support/ thank donors in personal unexpected ways start with website etc. (again procedures so that if the ED was not available staff knows how to go about it)
  - Visualize and share what ED is currently doing, revise and make procedure
- Internal: Establish shared system(s)/ platform(s) of communication and document storing, monitoring and evaluation (overall goal 1 and 2)
- Both: Internal and External: Update and communicate updated mission (update the focus to be on inclusion of people with disabilities (over the physical activity component) and community engagement) (link to Environmental Support, to keep strong, but also to extend to additional support)
- Link to partnerships: honor partnerships

#### Program Adaptation

- Improve 508 compliance
- Improve link to (formal) evaluation (in planning due to Needs Assessment)

#### Environmental Support

- Identify areas in which champions are needed
- Integrate and educate community connections included (newly) elected officials (major and city council members) and healthcare communities
- Develop an 'ask' and talking points and identify the appropriate decision-maker. Your ask is the action that you want this decision maker to take on behalf of AccesSurf (what is realistic to ask?) (135)
- Internal: Improve ED support by BOD

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\* COVID-19 is short for COVID-19 pandemic, ROI: return of investment

## **Next Steps**

I recommend four next steps. First, I presented the preliminary findings to the ED on 11/04/2020 via zoom, using power point. Second, I would like to present it to the BOD at their next meeting. I would encourage all BOD members, but especially those who were not interviewed, to add their opinions (*Do they agree or not?; Do they want to add anything major?*). However, the ED preferred to present partial results herself in meetings with subcommittees. If given the opportunity, I would also discuss the domains to assure a shared understanding, let the BOD interpret the strengths and weaknesses and come up with their own recommendations. If time is available, Table 4.10 can be shared, discussed and edited based on BOD's input. Third, I would encourage the BOD to create an action plan, turning recommendations into achievable objectives, specifying who will do the work, what does success look like, what non-financial resources are needed and where they will come, and due dates. Finally, I would recommend incorporating the PSAT evaluation as part of an annual strategic planning activity.

## **Implications for Other Organizations**

The findings also have more general implications. Central is that the PSAT pointed out the need and importance of for regular strategic planning for the sustainability of organizations. As best practices, a full strategic planning should be performed at minimum every three years, with annual updates or in case of major changes (136), and the PSAT should be done to inform it. To avoid confusion about domains, it may be helpful to include a figure like Figure 4.2 and clear definitions of the domains. In any case it is important to identify if the leadership has expertise for strategic planning, or whether it is needed.

While the mixed-method approach for the PSAT evaluation was found to be helpful to identify organizational strengths and weaknesses to support sustainability, it definitely requires buy-in and time commitment from the survey takers and interviewees. When using PSAT, it is recommended to complement the quantitative survey with answers to the qualitative questions. However, adding the interviews leads to a bigger time commitment for interviewees and the person conducting and coding the interviews. If time and resources are scarce, evaluation could be limited to the questionnaires only.

Identifying strengths, weaknesses, and growth opportunities can be done at any time of an organizational lifetime. Establishing and clarifying definitions (including across and within sustainability domains) and organizational documents (guidelines, procedures and organizational information) should be started early so that, as the organization grows, they can be updated and provide adequate support.

## **Conclusion**

This study explored the factors contributing towards AccesSurf's success and sustainability through a mixed-method approach utilizing the PSAT survey and in-depth interviews of organizational stakeholders. Overall, this study discerned three areas of strength, including 1) AccesSurf's ability to adapt their programs to changing conditions, 2) high level of support from internal and external champions, and 3) AccesSurf's effective communication and program promotions strategies. The study also identified three areas for improvement: 1) strategic planning for future resource needs and programs; 2) funding stability, such as a variety of funding streams and mixture of stable and flexible funding; and 3) partnerships with other community organizations and leaders. Findings can inform similar organizations that are providing innovative, recreational Physical Activity options for people with disabilities.

## **CHAPTER 5: Conclusion**

The analyses presented in this dissertation define key strengths, weaknesses and growth opportunities for AccesSurf and its programs from the perspective of participants, volunteers, family members, and executive board members, collected predominately during the COVID-19 pandemic. In this chapter, I summarize the findings of each study and discuss the larger implications for public health policy and practice, including directions for further research.

### **Summary of findings**

Study 1 showed that participation in aquatic physical activity (AccesSurf programs) helped people with disabilities realize improvements in aquatic physical activity skills, independence, confidence, and community integration.

Study 2 identified community needs during the COVID-19 pandemic. There was high program awareness of pre-COVID in-person programming and high satisfaction among the AccesSurf community across all programs, including the newly added virtual programs. There was a significant difference between sub-groups in terms of feeling the effects of the COVID-19 pandemic and its restrictions, with participants and family members feeling more isolated and less able to access the ocean than volunteers.

Using the Program Sustainability Assessment Tool (PSAT), followed by in-depth interviews of organizational stakeholders on sustainability, Study 3 discerned three areas of strength, including 1) AccesSurf's ability to adapt programs to changing conditions, 2) high level of support from internal and external champions, and 3) effective external communication and program promotions strategies. The study also identified three areas for improvement: 1) strategic planning for future resource needs and programs, 2) funding stability, such as securing a variety of funding streams including a mixture of stable and flexible funding, and 3) partnerships with other community organizations and leaders.

Each study employed two sub-parts, predominately mixed-method approach, which complemented and strengthened the findings within and across all three studies. Following the logic model helped identify different stakeholders and outcomes to be included. The Centers for Disease Control Framework for Evaluation in Public Health (CDC-FPEPH) framework and community-based participatory research (CBPR) principles served as a reminder to include the community in the different steps of each study. Together the findings confirmed that AccesSurf benefits participants, that participants are satisfied with services, that needs assessment can

identify community needs within a changing context, and that the program has strengths and weaknesses within the area of sustainability.

## **Implications and Recommendations**

Results from this evaluation have practical implications for AccesSurf and other similar programs more generally, as well as recommendations for future research.

### **Implications for AccesSurf**

The first recommendation is to modify and extend programs by offering a mix of in-person and virtual programs, and to include family members, especially through the COVID-19 pandemic. The second recommendation is to strengthen and share AccesSurf's program evaluation and strategic planning. To strengthen program evaluation, AccesSurf should share all activities and findings across all groups, from participants to staff and the board of directors, and expand current evaluation personnel and activities. Combined, the actions will assure that AccesSurf uses data to improve services and ultimately its sustainability, as it addresses the three growth opportunities identified. Sharing the findings will also create buy-in for future evaluations from stakeholders, such as staff and the board of directors. Concurrent expansion of evaluation resources and activities includes the creation of an evaluation team, allocating staff hours, modifying tools, and informing strategic planning.

Steps have already been taken to achieve these goals. AccesSurf was recently awarded a grant that included funds for staff evaluation hours, but additional resources are required. An AccesSurf evaluation team could and should continue to develop tools, and to collect and share data to inform programming. One example would be to further refine and prospectively use the Skills Tool on new clients and at standardized follow-up times. Because this tool rates skills against objective milestones, it provides a more objective measure of participant improvement than self-report.

Expanding evaluation activities and transparency will show synergistic effects, strengthening the program and ongoing documentation will increase funding stability and variety, strategic planning and partnerships, and ultimately AccesSurf's sustainability.

Notably, funding stability was one of the key areas for improvement within sustainability identified using the program sustainability assessment tool (PSAT). The PSAT results also highlighted the importance of regular strategic planning, driving a recommendation to gather PSAT data to inform strategic planning at minimum every three years. Another area of

improvement is partnerships, which can be strengthened by sharing evaluation framework, tools, and methods with similar organizations, and other collaborations.

### **Implications for Programs in general**

The findings also have more general implications. Central among those is the value of evaluation systems for organizations like AccesSurf that provide services to people with disabilities. The following elements are recommended: a) logic model(s) and frameworks that help guide evaluation; b) tools that help involve clientele; and c) mixed methods to complement and strengthen evaluation elements. Evaluations are essential for program survival both for defining benefits and for attracting funding. Evaluations can be time intensive and expensive, but there are ways to minimize costs or acquire grant funding to cover those expenses.

All members need to be aware of and learn how to navigate between two evaluation approaches: bottom-up (community-oriented) and top-down (external evaluator oriented). Navigation between the two was demonstrated in this dissertation. While external evaluators often set the terms of evaluation, this dissertation was guided by CBPR principles, including an internal evaluator and AccesSurf staff and participants engaged in the development of each tool. This made the evaluation process more complex, but also allowed for a learning-oriented approach, rather than a pass-fail approach. Including a bottom-up approach also reflects a democratic notion of an organization, which leverages its strengths rather than fighting its values (137). A variety of evaluation layers and subsequent timeframes should be defined. Lastly, communication paths between stakeholders and members of the evaluation team should be established. This should include how the community is informed of the findings.

### **Recommendations for Future Research**

Non-profit organizations can significantly contribute to building scientific evidence for program evaluations, tool development, and usage, especially for the population for which they are specialized. They can do so by themselves, or in collaborations with universities and other organizations.

To further study the outcomes and impacts of community-based adaptive aquatic programs, programs like AccesSurf and others should collaborate with universities to evaluate programs and to deepen their understanding of how their participant population is best served. Those collaborations should not only be CBPR-based but should include a focus on testing and modifying how to best include all layers of people in evaluating a program that is for them. For example, written assessments may be limiting for some individuals with disability, and verbal assessment may be limiting for others. This would skew the data collected by either approach.

Hence, verbal assessment was included in this dissertation, in addition to written assessment in some cases for study 2 where staff filled in some questionnaires for people who could not do so themselves. However, we may still have missed the voices who cannot do either. Originally, the family members were considered to speak for participants who cannot do either, however, in this evaluation family members spoke for themselves. All stakeholders should be represented in the evaluation. In general, the mix of program evaluations within this dissertation is a start to include access for people with different abilities in program evaluation, however, there is room for improvement.

Establishing collaborations with an academic department specializing in Special Education or Disability Studies would bring useful insight to further design and test appropriate evaluation tools. Evaluating participants' improvements via objective tools, such as heart rate monitors and metabolic equivalents (METs) studies, along with measures of self-identity, should be considered. Again, partnerships with university departments, such as the Physical Therapy Department, Kinesiology and Rehabilitation Science, and the Department of Psychology could be beneficial, extending the literature for the adaptive surf, swim and canoe community.

Additionally, AccesSurf should continue to work with national organizations, such as the international surfing association (138). Within those collaborations, AccesSurf can share the tools developed, which could be further tested in a wider community. While an Occupational Therapist completed the Skills Tool used in this study, AccesSurf would like to train volunteers to do this. In fact, AccesSurf and I have developed a volunteer training on the Skills Tool. For other interested organizations, training materials can be shared by AccesSurf, or the training can be facilitated by AccesSurf. In the eventuality that different volunteers complete the instrument, inclusion of tests of inter-rater reliability are recommended. Lastly, feedback to the PSAT group (for example on the overlap of domains found in this dissertation) can be given, or the PSAT group can be possibly joined to do research on this sustainability measure in other community settings.

## **Conclusion**

This dissertation reports on an evaluation of AccesSurf and demonstrates that community organizations like AccesSurf can significantly contribute towards quality of life for people with disabilities. Findings from this evaluation can guide improvements in AccesSurf programming and can inform the work of other organizations that provide innovative recreational physical activity options for people with disabilities. Program evaluation requires resources, but provides valuable data for program funding and sustainability, as well as internal improvement.

With these findings, AccesSurf can pass on lessons learned to smaller organizations with less experience in evaluation and can partner with universities and national organizations in refining research tools for adaptive surfing.

## References

1. WHO. World Report on Disability. Malta: World Health Organization [Internet]. 2011 [cited 2021 Feb 11]. Available from: [http://www.who.int/disabilities/world\\_report/2011/report/en/](http://www.who.int/disabilities/world_report/2011/report/en/)
2. CDC. Disability & Health U.S. State Profile Data: Hawaii | CDC [Internet]. Centers for Disease Control and Prevention. 2019 [cited 2020 Oct 27]. Available from: <https://www.cdc.gov/ncbddd/disabilityandhealth/impacts/hawaii.html>
3. CDC. Disability and Health. Increasing Physical Activity among Adults with Disabilities [Internet]. 2020 [cited 2020 Feb 16]. Available from: <http://www.cdc.gov/ncbddd/disabilityandhealth/pa.html>
4. CDC. Disability and Health Related Conditions | CDC [Internet]. Centers for Disease Control and Prevention. 2019 [cited 2021 Feb 18]. Available from: <https://www.cdc.gov/ncbddd/disabilityandhealth/relatedconditions.html>
5. Hopps SL, Pepin M, Arseneau I, Frechette M, Begin G. Disability Related Variables Associated with Loneliness Among People with Disabilities. *J Rehabil*. 2001 Sep 7;67(3):42.
6. Xia N, Li H. Loneliness, Social Isolation, and Cardiovascular Health. *Antioxid Redox Signal*. 2018 Mar 20;28(9):837–51.
7. House JS, Landis KR, Umberson D. Social relationships and health. *Science*. 1988 Jul 29;241(4865):540–5.
8. Hawkey LC, Thisted RA, Cacioppo JT. Loneliness Predicts Reduced Physical Activity: Cross-Sectional & Longitudinal Analyses. *Health Psychol Off J Div Health Psychol Am Psychol Assoc*. 2009 May;28(3):354–63.
9. U.S. Department of Labor. How does the federal government define “disability”? [Internet]. [cited 2021 Feb 18]. Available from: <https://www.dol.gov/agencies/odep/publications/faqs/general#2>
10. Erickson W, Lee C, von Schrader S. 2018 Disability Status Report - United States [Internet]. NY: Cornell University Yang-Tan Institute on Employment and Disability (YTI); 2020 [cited 2018 Mar 23]. Available from: [https://www.disabilitystatistics.org/StatusReports/2018-PDF/2018-StatusReport\\_HI.pdf](https://www.disabilitystatistics.org/StatusReports/2018-PDF/2018-StatusReport_HI.pdf)
11. Rehabilitation Services Administration. The Rehabilitation Act 1973 [Internet]. 2017 [cited 2021 Jan 29]. Available from: <https://www2.ed.gov/policy/speced/reg/narrative.html>
12. WHO. WHO - International Classification of Functioning, Disability and Health (ICF). 2021 Feb 18; Available from: <http://www.who.int/classifications/icf/en/>

13. WHO. Towards a Common Language for Functioning, Disability and Health: ICF The International Classification of Functioning, Disability and Health. 2002.
14. World Health Organization. How to use the ICF - A Practical Manual for using the International Classification of Functioning, Disability and Health (ICF). Geneva; 2013.
15. Van der Ploeg HP, Van der Beek AJ, Van der Woude LHV, Van Mechelen W. Physical Activity for People with a Disability. *Sports Med.* 2004 Aug 1;34(10):639–49.
16. WHO. Physical activity - Key Facts - What is physical activity? [Internet]. 2020 [cited 2021 Feb 18]. Available from: <http://www.who.int/mediacentre/factsheets/fs385/en/>
17. Organisation mondiale de la santé. WHO guidelines on physical activity and sedentary behaviour. Geneva: World Health Organization; 2020.
18. Rochi M, Routier F, Latimer-Cheung A, Ginis K, Noreau L, Sweet S. Are adults with spinal cord injury meeting the spinal cord injury-specific activity guidelines? A look at a sample from a Canadian province. *Spinal Cord.* 2017;55(5):454–9.
19. DeVivo MJ, Krause JS, Lammertse DP. Recent trends in mortality and causes of death among persons with spinal cord injury. *Arch Phys Med Rehabil.* 1999;80(11):1411–9.
20. Sezer N, Akkus S, Ugurlu FG. Chronic complications of spinal cord injury. *World J Orthop.* 2015;6(1):24–33.
21. McKinley WO, Jackson JB, Cardenas DD, DeVivo MJ. Long-Term Medical Complications After Traumatic Spinal Cord Injury: A Regional Model Systems Analysis. *Arch Phys Med Rehabil.* 1999;80(11):1402–10.
22. Krause JS, Saunders LL. Health, Secondary Conditions, and Life Expectancy after Spinal Cord Injury. *Arch Phys Med Rehabil.* 2011;92(11):1770–5.
23. Maynard F, Karunas R, Waring W. Epidemiology of spasticity following traumatic spinal cord injury. *Arch Phys Med Rehabil.* 1990;71(8):566–9.
24. Burns S. Acute respiratory infections in persons with spinal cord injury. *Phys Med Rehabil Clin N Am.* 2007;18(2):203–16, v–vi.
25. Rimmer JH, Chen M-D, McCubbin JA, Drum C, Peterson j. Exercise Interventions Research on Person with Disabilities: What We Know and Where We need to Go. 2010;
26. Devillard X, Rimaud D, Calmels P. Effects of training programs for spinal cord injury. *Ann Readapt Med Phys.* 2007;50(6):480–9.
27. Kloosterman MG, Snoek GJ, Jannink MJ. Systematic review of the effects of exercise therapy on the upper extremity of patients with spinal-cord injury. *Spinal Cord.* 2009 Mar;47(3):196–203.

28. Sheel A, Reid W, Townson A, Ayas N, Konnyu K, The Spinal Cord Rehabilitation Evidence (SCIRE) Research Team. Effects of Exercise Training and Inspiratory Muscle Training in Spinal Cord Injury: A Systematic Review. *J Spinal Cord Med.* 2008;31(5):500–8.
29. Hicks AL, Martin Ginis KA, Peltier CA, Ditor DS, Foulun B, Wolfe DL. The effects of exercise training on physical capacity, strength, body composition and functional performance among adults with spinal cord injury: a systematic review. *Spinal Cord.* 2011;49(11):1103–27.
30. Gorter JW, Currie SJ. Aquatic Exercise Programs for Children and Adolescents with Cerebral Palsy: What Do We Know and Where Do We Go? *Int J Pediatr [Internet]*. 2011 [cited 2020 May 19];2011. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3228376/>
31. Chunxiao Li, Selina Khoo, Adnan A. Effects of aquatic exercise on physical function and fitness among people with spinal cord injury A systematic review. *Medicine (Baltimore).* 2017;96(11):1–6.
32. Schmid S. Effects of Aquatic Exercise for Adults with Spinal Cord Injury -A Systematic Literature Review -Unpublished PhD Qualifying Paper. University of Hawai'i. 2016;
33. Herold B, Stanley A, Oltrogge K, Alberto T, Shackelford P, Hunter E, et al. Post-Traumatic Stress Disorder, Sensory Integration, and Aquatic Therapy: A Scoping Review. *Occup Ther Ment Health.* 2016 Oct;32(4):392–9.
34. Davidson CL, Babson KA, Bonn-Miller MO, Souter T, Vannoy S. The Impact of Exercise on Suicide Risk: Examining Pathways through Depression, PTSD, and Sleep in an Inpatient Sample of Veterans. *Suicide Life Threat Behav.* 2013;43(3):279–89.
35. Reinders NJ, Branco A, Wright K, Fletcher PC, Bryden PJ. Scoping Review: Physical Activity and Social Functioning in Young People With Autism Spectrum Disorder. *Front Psychol [Internet]*. 2019 Feb 13 [cited 2020 May 19];10. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6381857/>
36. Mische Lawson L, D'Adamo J, Campbell K, Hermreck B, Holz S, Moxley J, et al. A Qualitative Investigation of Swimming Experiences of Children With Autism Spectrum Disorders and Their Families. *Clin Med Insights Pediatr.* 2019 Jan 1;13:1179556519872214.
37. Baumgardner DJ. Social Isolation Among Families Caring for Children With Disabilities. *J Patient-Centered Res Rev.* 2019 Oct 28;6(4):229–32.
38. Armitano CN, Clapham Emily, Lamont LS, Audette JG. Surfing for children with disabilities pilot study. *Benefits of a Surfing Program: A Pilot Study.*

39. Lopes JT. Adapted Surfing as a Tool to Promote Inclusion and Rising Disability Awareness in Portugal. *J Sport Dev.* 2015;3(5).
40. Bond, Gregory. *An Adaptive Surfing Apparatus.* 1975;
41. Lopes JT, Masdemont M, Cruz GMV. Adaptive surfing: leisure, competition or therapy? *Cad Educ Tecnol E Soc.* 2018 Mar 31;11(1):148.
42. Fleischmann D, Michalewicz B, Stedje-Larsen E, Neff J, Murphy J, Browning K, et al. Surf Medicine: Surfing as a Means of Therapy for Combat-Related Polytrauma: *JPO J Prosthet Orthot.* 2011 Jan;23(1):27–9.
43. Gregor V. Sarkisian, Kristien H. Walter, Giovanni Martinez, Philip B. Ward. Introduction to the Special Issue on Surf Therapy Around the Globe. Vol. 11 Issue 2 [Internet]. 2020 [cited 2020 May 5]. Available from: <https://www.gjcopp.org/en/article.php?issue=36&article=216>
44. Khasnabis C, Motsch KH, Achu K, Jubah KA, Brodtkorb S, Chervin P, et al. Prevention [Internet]. *Community-Based Rehabilitation: CBR Guidelines.* World Health Organization; 2010 [cited 2020 Apr 9]. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK310943/>
45. Grandisson M, Hébert M, Thibeault R. A systematic review on how to conduct evaluations in community-based rehabilitation. *Disabil Rehabil.* 2014 Feb;36(4):265–75.
46. Israel B, Schulz A, Parker E, Becker A, Allen A, JR G. Critical issues in developing and following community based participatory principles. In: Minkler M, Wallerstein N, editors. *Community-based participatory research for health.* San Francisco, CA: Jossey-Bass/Wiley; 2003. p. 53–76.
47. Israel BA, et al. *Methods for community-based participatory research for health* (2nd edition). San Francisco: Jossey-Bass.; 2012.
48. AccesSurf Hawaii [Internet]. 2020. Available from: <https://www.accessurf.org/missionandvision/>
49. Schmid S. McNerny Foundation. Bank of Hawai'i. Grant Application. AccesSurf. (Unpublished work. Approved by Executive Director). AccesSurf. HI, USA. 2016;
50. Schmid SM, Short CT, Nigg CR. Physical Activity & People with Disabilities — A Qualitative Process and Outcome Pilot Evaluation of the Non-Profit Organization AccesSurf Hawai'i. *Hawaii J Med Public Health.* 2019 Feb;78(2):52–60.
51. Hawaii's 1st case of coronavirus confirmed, Gov. David Ige announces | Honolulu Star-Advertiser [Internet]. [cited 2020 Sep 2]. Available from: <https://www.staradvertiser.com/2020/03/06/breaking-news/cruise-ship-that-tested-positive-for-coronavirus-increases-likelihood-of-infection-in-hawaii-lt-gov-josh-green-says/>

52. WHO declares the coronavirus outbreak a pandemic - STAT [Internet]. [cited 2020 Sep 2]. Available from: <https://www.statnews.com/2020/03/11/who-declares-the-coronavirus-outbreak-a-pandemic/>
53. Cucinotta D, Vanelli M. WHO Declares COVID-19 a Pandemic. *Acta Bio-Medica Atenei Parm.* 2020 19;91(1):157–60.
54. CDC. Coronavirus Disease 2019 (COVID-19) People with disabilities [Internet]. Centers for Disease Control and Prevention. 2020 [cited 2020 Nov 4]. Available from: <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-disabilities.html>
55. Horesh D, Brown AD. Traumatic stress in the age of COVID-19: A call to close critical gaps and adapt to new realities. [Internet]. [cited 2020 Oct 27]. Available from: <https://psycnet.apa.org/fulltext/2020-25108-001.html>
56. Campbell L. The World Is Experiencing Mass Trauma from COVID-19: What You Can Do [Internet]. *Community Psychiatry.* 2020 [cited 2020 Oct 27]. Available from: <https://www.communitypsychiatry.com/the-world-is-experiencing-mass-trauma-from-covid-19-what-you-can-do/>
57. Macdonald SJ, Deacon L, Nixon J, Akintola A, Gillingham A, Kent J, et al. 'The invisible enemy': Disability, loneliness and isolation. *Disabil Soc.* 2018;33(7):1138–59.
58. Schuengel C, Tummers J, Embregts PJCM, Leusink GL. Impact of the initial response to COVID-19 on long-term care for people with intellectual disability: an interrupted time series analysis of incident reports. *J Intellect Disabil Res.* 2020;64(11):817–24.
59. Scheirer MA. Is Sustainability Possible? A Review and Commentary on Empirical Studies of Program Sustainability. In 2005.
60. Steinberg M, Hutchinson K. Literature Review of Program Sustainability Assessment Tools. 2010;26.
61. Schell SF, Luke DA, Schooley MW, Elliott MB, Herbers SH, Mueller NB, et al. Public health program capacity for sustainability: a new framework. *Implement Sci.* 2013 Feb 1;8(1):15.
62. Luke DA, Calhoun A, Robichaux CB, Elliott MB, Moreland-Russell S. The Program Sustainability Assessment Tool: A New Instrument for Public Health Programs. *Prev Chronic Dis* [Internet]. 2014 Jan 23 [cited 2020 Mar 5];11. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3900326/>
63. Center for Public Health Systems Science, Brown School at Washington University in St. Louis. Program Sustainability Assessment Tool [Internet]. PSAT Program Sustainability Assessment Tool. 2020. Available from: <https://sustaintool.org/psat/>

64. Assess | PSAT | Sustaintool [Internet]. PSAT/CSAT. [cited 2020 Nov 5]. Available from:  
<https://sustaintool.org/psat/assess/>
65. CDC. PSAT questionnaires and probes [Internet]. CDC; Available from:  
[http://www.cdc.gov/pcd/issues/2015/docs/15\\_0133\\_Appendix.docxword](http://www.cdc.gov/pcd/issues/2015/docs/15_0133_Appendix.docxword)
66. CDC. CDC Evaluation Framework [Internet]. 2020 [cited 2020 Dec 6]. Available from:  
<http://www.cdc.gov/eval/>
67. U.S. Department of Health and Human Services CDC. Introduction to Program Evaluation for Public Health Programs" A Self-Study Guide. 2011;
68. Susan B. Utilizing the Logic Model for Program Design and Evaluation [Internet]. 2002 [cited 2020 Apr 8]. Available from:  
<http://www.humanserviceresearch.com/youthlifefskillsevaluation/LogicModel.pdf>
69. Matsunaga DS, Enos R, Gotay CC, Banner RO, DeCambra H, Hammond OW, et al. Participatory Research in a Hawaiian Community. The Wai'anae Cancer Research Project. 1995;
70. Fong M, Braun KL, Tsark JU. Improving Native Hawaiian Health Through Community-Based Participatory Research. *Californian J Health Promot*. 2003 Dec 31;1(SI):136–48.
71. Stack E, McDonald KE. Nothing About Us Without Us: Does Action Research in Developmental Disabilities Research Measure Up? *J Policy Pract Intellect Disabil*. 2014 Jun;11(2):83–91.
72. McDonald KE, Stack E. You say you want a revolution: An empirical study of community-based participatory research with people with developmental disabilities. *Disabil Health J*. 2016 Apr 1;9(2):201–7.
73. Nicolaidis C, Raymaker D, Katz M, Oschwald M, Goe R, Leotti S, et al. Community-Based Participatory Research to Adapt Health Measures for Use by People With Developmental Disabilities. *Prog Community Health Partnersh Res Educ Action*. 2015;9(2):157–70.
74. Hassounah D, Alcala-Moss A, McNeff E. Practical Strategies for Promoting Full Inclusion of Individuals with Disabilities in Community-Based Participatory Intervention Research. *Res Nurs Health*. 2011 Jun;34(3):253–65.
75. Balcazar F, Keys C, Kaplan D. Participatory Action Research and People with Disabilities: Principles and Challenges. *Can J Rehabil*. 2006 Jan 1;12.
76. Okoro CA, Hollis N, Griffing-Blake S. Prevalence of Disabilities and Health Care Access by Disability Status and Type Among Adults — United States, 2016. *MMWR Morb Mortal Wkly Rep* [Internet]. 2018 [cited 2021 Jan 13];67. Available from:  
<https://www.cdc.gov/mmwr/volumes/67/wr/mm6732a3.htm>

77. Bize R, Johnson JA, Plotnikoff RC. Physical activity level and health-related quality of life in the general adult population: A systematic review. *Prev Med*. 2012;45(6):401–15.
78. Adamson BC, Ensari I, Motl RW. Effect of exercise on depressive symptoms in adults with neurologic disorders: a systematic review and meta-analysis. *Arch Phys Med Rehabil*. 2015 Jul;96(7):1329–38.
79. Bond, Gregory. *An Adaptive Surfing Apparatus*. 1975;
80. Armitano CN, Lamont LS, Clapham ED, Audette JG. Benefits of Surfing for Children with Disabilities: A Pilot Study. *Palaest Macomb Ill*. 2015;29(3):31-.
81. Wirz S, Thomas M. Evaluation of community-based rehabilitation programmes: a search for appropriate indicators: *Int J Rehabil Res*. 2002 Sep;25(3):163–71.
82. Scheff SW. *Fundamental Statistical Principles for the Neurobiologist: A Survival Guide* [Internet]. San Diego, UNITED STATES: Elsevier Science & Technology; 2016 [cited 2021 Jan 13]. Available from: <http://ebookcentral.proquest.com/lib/uhm/detail.action?docID=4412744>
83. Nederhof AJ. Methods of coping with social desirability bias: A review. *Eur J Soc Psychol*. 1985;15(3):263–80.
84. Farley O. *Competitive Surfing: A Physiological Profile of Athletes and Determinants of Performance*.
85. Ivbijaro G, Brooks C, Kolkiewicz L, Sunkel C, Long A. Psychological impact and psychosocial consequences of the COVID 19 pandemic Resilience, mental well-being, and the coronavirus pandemic. *Indian J Psychiatry*. 2020 Sep 2;62:S395–403.
86. Diamant M. COVID-19 Disproportionately Impacting Those With Developmental Disabilities [Internet]. *Disability Scoop*. 2020 [cited 2020 Oct 26]. Available from: <https://www.disabilityscoop.com/2020/09/08/covid-19-disproportionately-impacting-developmental-disabilities/28909/>
87. Altschuld JW, Watkins R. *A Primer on Needs Assessment: More Than 40 Years of Research and Practice*. *New Dir Eval*. 2014;2014(144):5–18.
88. Framework Step 2 Checklist | Program Evaluation | CDC [Internet]. 2019 [cited 2021 Jan 14]. Available from: <https://www.cdc.gov/eval/steps/step2/index.htm>
89. Witkin BR. *Planning and conducting needs assessments: a practical guide*. Thousand Oaks: Sage Publications; 1995.
90. Sleezer CM, Russ-Eft DF, Gupta K. *A Practical Guide to Needs Assessment* [Internet]. Somerset, UNITED STATES: Center for Creative Leadership; 2014 [cited 2020 Nov 29]. Available from: <http://ebookcentral.proquest.com/lib/uhm/detail.action?docID=1599317>

91. SAMSHA. U.S. Department of Health and Human Services Substance Abuse and Mental Health Services Administration Center for Substance Abuse Treatment.
92. Mitra M, Clifford C, Smith L, Landers B, Tanenhaus R, May G. Health Needs Assessment of People with Disabilities in Massachusetts, 2013 Executive Summary. 2013.
93. Wilder Research. Types of evaluation. 2009;6.
94. Australian Government. SHUT OUT: The Experience of People with Disabilities and their Families in Australia | Department of Social Services, Australian Government [Internet]. 2009 [cited 2021 Jan 4]. Available from: <https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/shut-out-the-experience-of-people-with-disabilities-and-their-families-in-australia?HTML>
95. Mye SC, Moracco KE. "Compassion, pleasantry, and hope": A process evaluation of a volunteer-based nonprofit. *Eval Program Plann*. 2015 Jun;50:18–25.
96. Kirkpatrick JD, Kirkpatrick WK. Kirkpatrick's Four Levels of Training Evaluation. Association for Talent Development; 2016. 341 p.
97. Revilla MA, Saris WE, Krosnick JA. Choosing the Number of Categories in Agree–Disagree Scales. *Sociol Methods Res*. 2014 Feb 1;43(1):73–97.
98. Capella ME, Turner RC. Development of an Instrument to Measure Consumer Satisfaction in Vocational Rehabilitation. *Rehabil Couns Bull*. 2004 Jan 1;47(2):76–85.
99. CDC. Community Needs Assessment. Participant Workbook. 2013;Community Needs Assessment. Atlanta, GA: Centers for Disease Control and Prevention (CDC), 2013.:79.
100. Chapter 3. Assessing Community Needs and Resources | Section 7. Conducting Needs Assessment Surveys | Main Section | Community Tool Box [Internet]. [cited 2020 Nov 29]. Available from: <https://ctb.ku.edu/en/table-of-contents/assessment/assessing-community-needs-and-resources/conducting-needs-assessment-surveys/main>
101. Office of Migrant Education. Comprehensive Needs Assessment. [Internet]. 2001 [cited 2020 Sep 1]. Available from: <https://www2.ed.gov/admins/lead/account/compneedsassessment.pdf>
102. Altschuld J. The Needs Assessment Kit. 2010.
103. About CHANGE | DNPAO | CDC [Internet]. 2019 [cited 2020 Nov 29]. Available from: <https://www.cdc.gov/nccdphp/dnpao/state-local-programs/change-tool/about.html>
104. Meissner H, Creswell J, Klassen AC, Plano V, Smith KC. Best Practices for Mixed Methods Research in the Health Sciences. :39.

105. My Byline Media. Automatic Readability Checker, a Free Readability Formula Consensus Calculator [Internet]. [cited 2020 Dec 1]. Available from:  
<https://readabilityformulas.com/free-readability-formula-tests.php>
106. Thomas DR. A General Inductive Approach for Analyzing Qualitative Evaluation Data. *Am J Eval*. 2006;27(2):237–46.
107. Beatty PW, Richmond GW, Tepper S, DeJong G. Personal assistance for people with physical disabilities: consumer-direction and satisfaction with services. *Arch Phys Med Rehabil*. 1998 Jun;79(6):674–7.
108. OHCHR. COVID-19 and the rights of persons with disabilities: Guidance [Internet]. [cited 2020 Jan 29]. Available from: [https://www.ohchr.org/Documents/Issues/Disability/COVID-19\\_and\\_The\\_Rights\\_of\\_Persons\\_with\\_Disabilities.pdf](https://www.ohchr.org/Documents/Issues/Disability/COVID-19_and_The_Rights_of_Persons_with_Disabilities.pdf)
109. Short C. Discussion of 2020 needs assessment findings. 2020.
110. Yahr E. The pandemic forced live events to go virtual. It may change access to entertainment forever. *Washington Post* [Internet]. [cited 2021 Feb 4]; Available from:  
<https://www.washingtonpost.com/road-to-recovery/2021/01/12/pandemic-entertainment-changes/>
111. Dunham J. Will people ever feel comfortable in large crowds again? [Internet]. CTVNews. 2020 [cited 2021 Feb 4]. Available from: <https://www.ctvnews.ca/canada/will-people-ever-feel-comfortable-in-large-crowds-again-1.5128513>
112. MacCarthy S, Izenberg M, Barreras JL, Brooks RA, Gonzalez A, Linnemayr S. Rapid mixed-methods assessment of COVID-19 impact on Latinx sexual minority men and Latinx transgender women. *PLOS ONE*. 2020 Dec 31;15(12):e0244421.
113. Yu JC, McIntyre M, Dow H, Robinson L, Winston P. Changes to rehabilitation service delivery and the associated physician perspectives during the COVID-19 pandemic: A mixed methods needs assessment study. *Am J Phys Med Rehabil* [Internet]. 2020 Jul 6 [cited 2021 Jan 30]; Available from:  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7363393/>
114. Morton SMB, Bandara DK, Robinson EM, Carr PEA. In the 21st Century, what is an acceptable response rate? *Aust N Z J Public Health*. 2012;36(2):106–8.
115. Baruch Y, Holtom BC. Survey response rate levels and trends in organizational research. *Hum Relat*. 2008 Aug 1;61(8):1139–60.
116. Batan M, Butterfoss FD, Jaffe A, LaPier T. Sustainability Planning Guide. 2017;120.
117. Scheirer MA, Dearing JW. An Agenda for Research on the Sustainability of Public Health Programs. *Am J Public Health*. 2011 Nov;101(11):2059–67.

118. Ross C. Brownson, Graham A. Colditz, and Enola K. Proctor. Dissemination and Implementation Research in Health: Translating Science to Practice [Internet]. Dissemination and Implementation Research in Health. Oxford University Press; [cited 2020 Apr 5]. Available from: <https://www.oxfordscholarship.com/view/10.1093/acprof:oso/9780199751877.001.0001/acprof-9780199751877>
119. Calhoun A, Mainor A, Moreland-Russell S, Maier RC, Brossart L, Luke DA. Using the Program Sustainability Assessment Tool to Assess and Plan for Sustainability. *Prev Chronic Dis* [Internet]. 2014 Jan 23 [cited 2020 Mar 5];11. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3900327/>
120. Video Conferencing, Web Conferencing, Webinars, Screen Sharing [Internet]. Zoom Video. [cited 2020 Oct 12]. Available from: <https://zoom.us/>
121. Professional Online Meetings with HD Video Conferencing | GoToMeeting | GoToMeeting [Internet]. [cited 2020 Oct 12]. Available from: [https://www.gotomeeting.com/lp/sem?cid=g2m\\_noam\\_ggs\\_cpc\\_71700000060694846\\_58700005664692144\\_p51588954265&gclid=EAlaIqObChMIm\\_7T5Luw7AIVhT6tBh1fwgoUEAAAYASAAEgJobvD\\_BwE&gclidsrc=aw.ds](https://www.gotomeeting.com/lp/sem?cid=g2m_noam_ggs_cpc_71700000060694846_58700005664692144_p51588954265&gclid=EAlaIqObChMIm_7T5Luw7AIVhT6tBh1fwgoUEAAAYASAAEgJobvD_BwE&gclidsrc=aw.ds)
122. Green J, Thorogood N. *Qualitative Methods for Health Research*. London, California, India, Singapore: Sage; 2008.
123. Audio to Text Automatic Transcription Service & App | temi.com [Internet]. temi. [cited 2020 Oct 12]. Available from: <https://www.temi.com/>
124. MAXQDA. MAXQDA. *The Art of Data Analysis. Professional Software for Qualitative & Mixed Methods Research* [Internet]. 2020 [cited 2020 Aug 1]. Available from: <http://www.maxqda.com>
125. Kuckartz. *Qualitative Inhaltsanalyse. Methode, Praxis, Computerunterstützung* (3rd ed.). Weinheim: Beltz Juventa; 2016.
126. Saldana J. *The Coding Manual for Qualitative Researchers*. Los Angeles, London, New Dehli, Singapore, Washington DC: Sage; 2013.
127. Krefting L. Rigor in Qualitative Research: The Assessment of Trustworthiness. *Am J Occup Ther*. 1991 Mar 1;45(3):214–22.
128. Sarah Vicary, Alys Young, Hicks S. A reflective journal as learning process and contribution to quality and validity in Interpretative Phenomenological Analysis. *Qual Soc Work*. 2017;16(4):550–65.

129. About Us | Section508.gov [Internet]. [cited 2020 Nov 3]. Available from:  
<https://www.section508.gov/about-us>
130. Stoll S, Janevic M, Lara M, Ramos-Valencia G, Stephens TB, Persky V, et al. A Mixed-Method Application of the Program Sustainability Assessment Tool to Evaluate the Sustainability of 4 Pediatric Asthma Care Coordination Programs. *Prev Chronic Dis*. 2015 Dec 3;12:150133.
131. Develop Your Plan | PSAT | Sustaintool [Internet]. PSAT/CSAT. [cited 2020 Nov 2]. Available from: <https://sustaintool.org/psat/plan-for-sustainability/>
132. Scheirer MA, Hartling G, Hagerman D. Defining sustainability outcomes of health programs: Illustrations from an on-line survey. *Eval Program Plann*. 2008 Nov;31(4):335–46.
133. Nederhof AJ. Methods of coping with social desirability bias: a review. *Eur J Soc Psychol*. 1985;15(3):263–80.
134. Home [Internet]. Hawaii Alliance of Nonprofit Organizations. [cited 2020 Nov 2]. Available from: <https://hano-hawaii.org/>
135. Write your Plan | PSAT | Sustaintool [Internet]. [cited 2020 Nov 2]. Available from: <https://sustaintool.org/psat/write-your-plan/>
136. Free Management Library. All About Strategic Planning [Internet]. [cited 2021 Apr 5]. Available from: <https://managementhelp.org/strategicplanning/index.htm>
137. Crystal Foster C, Louie J. Grassroots Action and Learning for Social Change: Evaluating Community Organizing. *San Franc CA Bluepr Res Des*. 2005;16.
138. International Surfing Association | A Better World Through Surfing [Internet]. [cited 2021 Feb 9]. Available from: <https://www.isasurf.org/>

## **APPENDICES**

### **Appendix I: Literature Review**

#### **Effects of Aquatic Physical Activity for Adults with Spinal Cord Injury: A Systematic Review**

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**Conflict of interest statement: None**

**Effects of Aquatic Physical Activity for Adults with Spinal Cord Injury:  
A Systematic Review**

**ABSTRACT**

**Study Design.** Systematic review.

**Objective.** To identify and evaluate the benefits of the variety of PA options developed for people with SCI.

**Methods.** This review used PICOS to guide the article search and selection process and followed the *Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA)* guidelines. PubMed, PsycINFO, PsycCRITIQUES, PsycEXTRA, PsycARTICLES, and Web of Science were searched through November 2016. Because of limited research in the area, all study designs were included. Articles were categorized into the six levels of evidence as suggested by the SCI-Research-Evidence-Team. The quality of all articles was assessed by 10 items of the Downs and Black scale.

**Results.** Out of 527 articles identified, 16 articles representing 14 different studies met the inclusion criteria. The level of evidence for included articles ranged from 1b (highest) to 5 (lowest). The studies examined a wider range of aquatic interventions, such as aquatic immersion and walking, hydrotherapy, swimming, scuba-diving, and kayaking. Most commonly measured were pulmonary and cardiovascular function, and elements of mobility.

**Conclusion.** There is weak to fair evidence that aquatic PA is effective in increasing pulmonary and cardiovascular function among people with SCI. It appears, but there is insufficient evidence to conclude, that aquatic PA improves mobility (spasticity, strength, balance, and gait), body composition, activity of daily living, and mental health. Future studies should replicate existing and evaluate effects of aquatic PA on physical and psychological outcomes through more rigorous research designs, utilizing standardized measures, within build and natural settings (e.g., river, lake, ocean).

**Key Words:** aquatic exercise, water based activity, Spinal Cord Injury (SCI), rehabilitation, adults, paraplegia

## INTRODUCTION

A growing number of studies suggest that physical activity (PA) can maintain and improve the physiological and psychological well-being of people with spinal cord injury (SCI) (1) and that aquatic PA is a beneficial option for people with disabilities (2-4) and SCI (5). However, no systematic review on the benefits of aquatic PA for adults with SCI was found.

Despite the need for PA (6), people with SCI are less active in comparison to their peers without disabilities (7). Among a sample of people with SCI in a Canadian province only 12% met the SCI-specific PA guidelines, and 44% reported zero PA (8). Physical inactivity among people with SCI contributes to their higher prevalence of chronic conditions compared to people without disabilities (9). Secondary conditions common in people with SCI are pulmonary (10) and cardiovascular conditions (both linked to PA), as well as spasticity (experienced by 78% of individuals with SCI (11)), pain, and depressive disorders (12-14). Respiratory conditions, especially infections such as pneumonia, are the leading cause of death among people with SCI (15). Gait is more painful and stiff-legged, and gait speed (velocity) is usually slowed (16).

Devillard and colleagues analyzed the effects of training and reconditioning programs for people with SCI in 2008. They found these programs to offer a variety of benefits, including improvements in cardiorespiratory, cardiovascular, cardiac, metabolic, bone, biomechanical, strength, Quality of Life (QoL) outcomes, mechanical efficiency, and wheelchair handling (17). Kloosterman's 2009 review of the effects of exercise therapy for people with SCI found benefits to physical function (18). Sheel and colleagues reviewed 13 articles on exercise training and inspiratory muscle training of patients with SCI in 2008; they found good evidence that PA enhances respiratory strength and endurance and suggestive evidence that PA enhances resting and exercising respiratory function (19). Hicks and colleagues analyzed 69 articles testing PA in the chronic SCI population and concluded that there was strong evidence that moderate-to-vigorous exercise, performed two to three times weekly, increases physical capacity and strength (1). However, none of the 85 studies in the Devillard, Kloosterman, and Sheel reviews, and only one of the 69 studies in Hick's review, examined water-based PA in people with SCI.

It is important to examine aquatic-based interventions for people with SCI. Being emerged in water holds advantages to land training, including buoyancy, lower impact, and increased resistance for movement. Although a 2002 review about people with neurological disease concluded that there was insufficient evidence that aquatic exercise was superior to land-based therapy (20), aquatic exercise has been shown to be an effective PA option for people with other disabilities or in general, but not for SCI (2, 4). Aquatic-based PA encompasses a range of activities from hydrotherapy to adaptive swimming, kayaking and surfing (21). Qualitative research with Hawai'i residents with neurological health conditions, including SCI, revealed high praise for an ocean-based adaptive swim and surf program. Participants noted the positive impact of the program on their mental, physical, and social well-being

(22). However, little is known about the benefits of aquatic PA for people with SCI. Thus, we conducted a systematic review of benefits of aquatic PA options for people with SCI.

## **METHODS**

A review protocol for this research was not published. PICOS (participants, intervention, comparison, outcomes, study design) guided the article search and selection process (Appendix I). The reporting of this review followed PRISMA, the *Preferred Reporting Items for Systematic Reviews and Meta-Analysis* (23) (Appendix II).

### **Electronic bibliographic searches**

Electronic bibliographic databases searched between August and November 2016, included PubMed (Medline; from 1951 and selectively earlier), PsycNet (from 1967; including PsycINFO, PsycEXTRA, PsycARTICLES) and Web of Science (from 1945). Search terms included (Spinal cord injury OR paraplegic OR paraplegia OR tetraplegia OR quadriplegic OR quadriplegia) AND "aquatic activity" OR aquatic therapy OR aquatic exercise OR aquatic sports OR aquatic training OR "water based activity" OR aquatic leisure OR aquatic rehabilitation OR aqua fitness OR "water aerobics" OR "water gymnastics" OR "water recreation" OR "water based therapy" OR hydrotherapy OR pool therapy OR surfing sport. Asterisks were used for words with multiple options for endings, e.g., activit\* for activities and activity. We adjusted the search strategy for each database, per its specifications regarding key word and search algorithms. Additionally, the references sections of identified reviews and articles were searched, and experts in the field of adaptive PA were asked to identify relevant articles.

### **Inclusion and exclusion criteria**

Given the expected scarcity of articles on the topic, we included all published qualitative and quantitative studies from peer-reviewed journals evaluating any type of aquatic PA in people, aged 17 or older, with SCI. Articles written in English and German were included. Articles may have included participants with other disabilities, as long as the results were presented separately for people with SCI. Articles describing an exercise regime with water and non-water-based components were included, as long as results were presented separately for the aquatic component. Studies with land-based control groups were included. For the purpose of this literature review, aquatic PA was defined as any activity performed in or on water, such as aquatic immersion, hydrotherapy (immersion with active component), swimming and diving, or on the water, such as kayaking, canoeing and surfing. All physiological, psychological, and social outcomes were considered. No limitations were placed on location of the research or year (Appendix II, PICOS).

### **Study selection**

After identifying the articles and removing duplicates, study selection followed a three-stage process. First, article titles were screened and articles with a different focus than aquatic PA and people with SCI were excluded. Next, abstracts were reviewed and clearly irrelevant articles eliminated. The

remaining articles were read in full. If a clear determination could not be made at an early stage, the article was forwarded to the next level of review, as done by Hall and colleagues (24).

### Data extraction and analysis

Location and purpose of the intervention, study design, participants, intervention and control conditions, measures, and outcomes were extracted from included articles. We classified each study design by the six levels of evidence (LoE) suggested by the SCI-Research-Evidence-Team (Table 1) (25). The LoE instructed to rate the RCT(randomized controlled trials)-quality utilizing the 11-item Physiotherapy Evidence Database score (PEDro) (26).

Table 1: The levels of evidence-scaling criteria (Version 4.0) suggested by Spinal Cord Injury

| Rehabilitation Evidence |                                   |                                                                                                                                                               |
|-------------------------|-----------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Level (LOE)             | Research Design                   | Description/ PEDro scale                                                                                                                                      |
| Level 1a                | Randomized Controlled Trial (RCT) | More than 1 higher RCT, PEDro score $\geq 6$ . Includes within subjects comparison with randomized conditions and cross-over designs                          |
| Level 1b                | RCT                               | 1 higher RCT, PEDro score $\geq 6$                                                                                                                            |
| Level 2                 | RCT                               | Lower RCT, PEDro score $< 6$ .                                                                                                                                |
|                         | Prospective controlled trial      | Prospective controlled trial (not randomized)                                                                                                                 |
|                         | Cohort                            | Prospective longitudinal study using at least 2 similar groups with one exposed to a particular condition.                                                    |
| Level 3                 | Case control                      | A retrospective study comparing conditions, including historical controls                                                                                     |
| Level 4                 | Pre-post                          | A prospective trial with a baseline measure, intervention, and a post-test using a single group of subjects.                                                  |
|                         | Post-test                         | A prospective post-test with two or more groups (intervention followed by post-test and no re-test or baseline measurement) using a single group of subjects. |
|                         | Case Series                       | A retrospective study usually collecting variables from a chart review.                                                                                       |
| Level 5                 | Observational                     | Study using cross-sectional analysis to interpret relations.                                                                                                  |
|                         | Case Report                       | Pre-post or case series involving one subject                                                                                                                 |

Reprinted from [25], eliminated Clinical Consensus (Level 5) as not included in review.

Because non-RCT studies were included, the methodological quality of studies was evaluated using a modified 10-item Downs and Black (D&B) scale (27). In its original, the D&B scale includes 27 items (28). Due to limitations in study design, questions selected from the D&B quality assessment instrument were those relevant to all study designs, not just RCTs. The ten chosen items related to the quality of reporting (6 items), external validity (2 items) and internal validity/risk of bias (2 items) (Appendix III) (27). Items were scored as “yes” (1) or “no/unable to determine” (0), and the sum of item scores were calculated (Table 2). Interrater reliability was conducted across two coders (SMS and CRN), resulting in 90% agreement, which is above accepted levels ( $> 80\%$ ). Treatment effects of studies including the mean and SD for baseline and post-intervention for both, experimental and control, groups were calculated using the standardized difference based on pooled Standard Deviation (SD). A further quantitative synthesis was not possible. Rather this synthesis is qualitative, with study findings organized by outcome. Conclusions are, when available, based on effect sizes between groups. More weighting

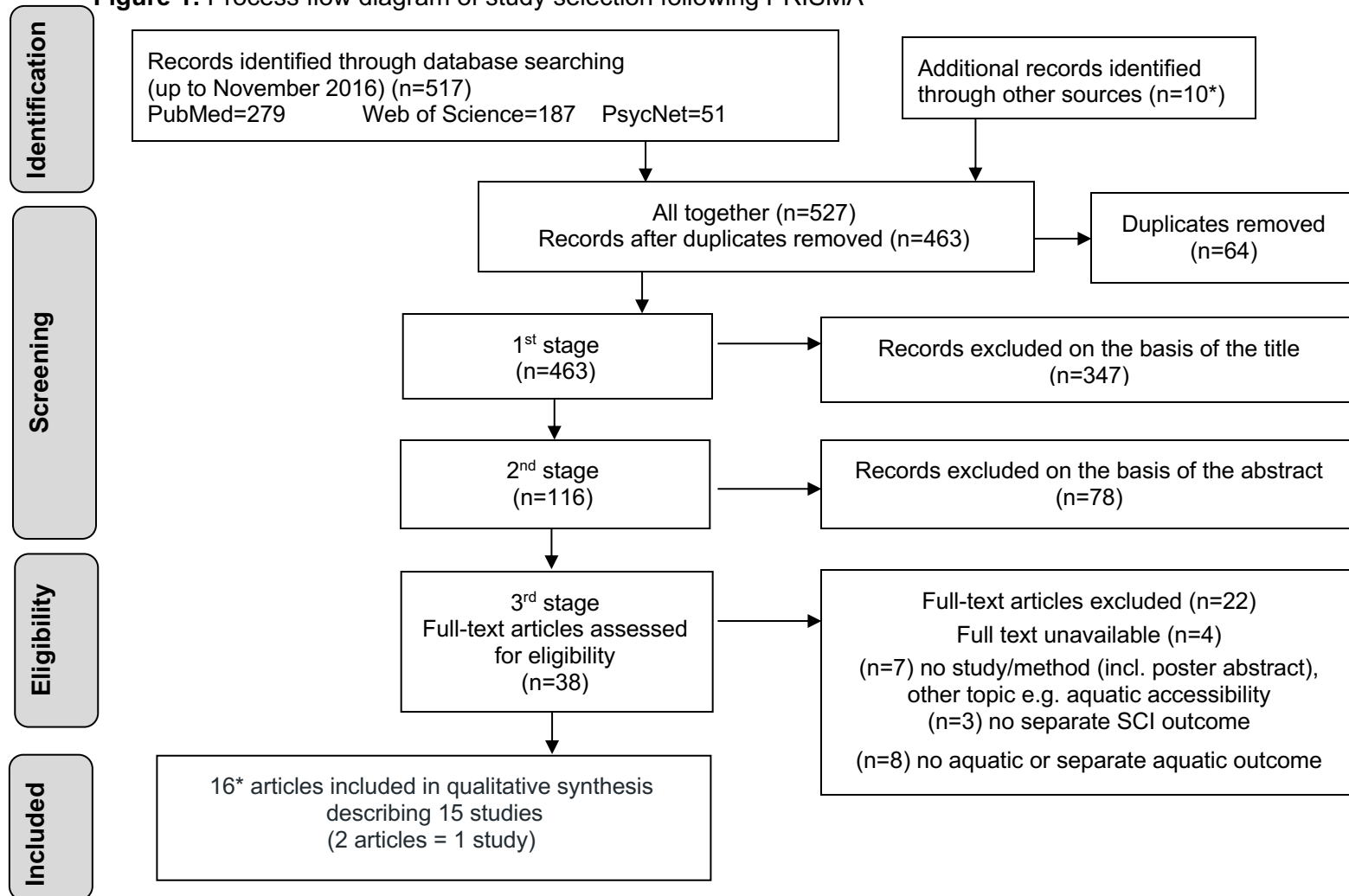
was also given to studies presenting statistically significant changes between pre- and post treatment measures. Significant level is at 0.05, with highly significant at 0.001.

## **RESULTS**

### **Result of the search**

PRISMA was used to report the results (Appendix II). The search yielded 527 articles, 517 through databases and ten through other sources, including citation tracking and consultation with experts in the field (Figure 1; PRISMA diagram). We removed 64 duplicates, and further excluded 447 articles based upon the title, abstract, and reading of articles in full. Eleven of 38 studies read in full were excluded because they mixed findings of people with SCI and participants with other disabilities, or they mixed results from aquatic and non-aquatic PA. Remaining were 16 articles reporting on 15 studies. One article was written in German (29), the rest in English (5, 29-43).

**Figure 1:** Process flow diagram of study selection following PRISMA



\*2 of the articles (1 of the studies) included were identified through the additional resources (one was a reference of a reference, one was identified by an expert who is working on a review); SCI= Spinal Cord Injury; Process flow based on [37], PsycNet includes PsycINFO, PsycEXTRA, PsycARTICLES.

## **Included studies**

### **Study and intervention characteristics**

The 15 studies (described in 16 articles) were conducted between 1980 and 2016, across eight countries, including 303 adults, aged 17 to 69 years, with 73.0% male (221), 26.7% female (81) and 0.3% unknown (1), examining a swimming intervention (4 studies), immersion in water (3), kayaking (2), walking in water (2), hydrotherapy (1), aquatic exercise, (1), underwater treadmill (1) and scuba-diving (1) (Table 2). Two intervention (kayaking) were facilitated outdoors (on fjord), eleven in indoor pools, and one unknown (scuba-diving). Eleven out of 16 studies used control groups, with five either using people with or without SCI and one using both. They either received no training, conventional care, land training or the same as the experimental group.

### **Study type and level of evidence**

One intervention was examined using a RCT design (Level 1b), four were examined using a non-randomized, prospective, controlled design (Level 2), two were examined using a single-group, pre-post design (Level 4), two were case studies (Level 5), and six studies were cross-sectional (Level 5).

### **Quality assessment of execution of the studies described in the articles**

None of the articles met all ten quality-criteria of the 10 items of the D&B scale (Table 2) (Appendix III) (30). One article met 9 out of 10 criteria; nine scored 7 to 8, and six scored less than 7. Most studies met criteria related to reporting (Q1-6) and internal validity (Q9/10). Across articles, the objective, hypothesis or purpose was well stated (Q1), while 15 had their main outcomes clearly stated (Q2), and 13 had their inclusion and exclusion criteria described (Q3). The two external validity criteria were least met (Q7/8).

Table 2: Characteristics of included articles grouped by type of study (level of evidence (LoE)), within type of study alphabetic order and belonging to other article (articles N=16)

| Article                                                                            |                                       |      |                   | Study |                             |                                                                                    | Intervention                                            |                                                           |  | Participants |                |                                     |                         | Treatment                                 |    | Control                               |                 |
|------------------------------------------------------------------------------------|---------------------------------------|------|-------------------|-------|-----------------------------|------------------------------------------------------------------------------------|---------------------------------------------------------|-----------------------------------------------------------|--|--------------|----------------|-------------------------------------|-------------------------|-------------------------------------------|----|---------------------------------------|-----------------|
| #                                                                                  | Reference                             | Year | Country           | Type  | Method. Quality 10-item D&B | Type                                                                               | Control                                                 | Dose                                                      |  | n: all       | Male: Female   | Age range in years: M±SD            | Level of lesion         | All chronic/ complete SCI (unless stated) | n  | All chronic/ complete (unless stated) | n               |
| Interventions [repeated]                                                           |                                       |      |                   |       |                             |                                                                                    |                                                         |                                                           |  |              |                |                                     |                         |                                           |    |                                       |                 |
| [RCT (1a or 1b), Prospective controlled trials (2), Pre-post (4), Case Report (5)] |                                       |      |                   |       |                             |                                                                                    |                                                         |                                                           |  |              |                |                                     |                         |                                           |    |                                       |                 |
| 1                                                                                  | Jung et. al [31]                      | 2014 | Republic of Korea | 1b    | 8                           | Aquatic Exercise                                                                   | On Land Exercise                                        | 8 wks, 3/wk, 60 min                                       |  | 20           | 12 m, 8 f      | 42.1±10.6/<br>Control 51.1±8.7      | C8-L5                   | SCI                                       | 10 | SCI                                   | 10              |
| 2                                                                                  | Grigorenko et. al [32]                | 2004 | Sweden            | 2     | 8                           | Kayak (outdoors)                                                                   | No training                                             | 8 wks, 2-3/wk, 60 min                                     |  | (25-1) 24    | 18 m, 6 f      | 22-57: 40±11                        | T2-6,9-11               | SCI                                       | 12 | Able-body                             | 12              |
| 3                                                                                  | Kesiktas et. al [33]                  | 2004 | Turkey            | 2     | 7                           | Hydrotherapy [underwater exercise] (plus: passive range of motion & oral baclofen) | Passive range of motion & oral baclofen                 | all: 10 wks, 3/wk<br>Hydrotherapy: 10 wks, 3/ wks, 20 min |  | 20           | 15 m, 5 f      | 32.13±8.34/<br>Control: 33.10±10.71 | C5-6, T8-9              | SCI                                       | 10 | SCI                                   | 10              |
| 4                                                                                  | Novak & Ladurner [34]                 | 1999 | Austria           | 2     | 8                           | Scuba-diving (n.g. in-/outdoors)                                                   | Sailing (SCI control): No training (people without SCI) | up to 8 dives ~ 20 min / 10 sails                         |  | (36-4) 32    | 25 m, 11 f     | 17-41: 28                           | C, T, L                 | SCI: paraplegic                           | 9  | SCI: paraplegic/ able-body            | 8 sailor/ 15 no |
| 5                                                                                  | Pachalski & Mekarski [35]             | 1980 | Poland            | 2     | 6                           | Swimming                                                                           | Conventional Rehabilitation                             | 36 mths, 2-3/wk, 2.5hrs                                   |  | 60           | 34 m, 26 f     | 18-27                               | T1 & below              | SCI: paraplegic                           | 30 | SCI: paraplegic                       | 30              |
| 6                                                                                  | Broach, Groff & Dattilo [36]          | 1997 | US                | 4     | 5                           | Swimming (n.g. in-/outdoors)                                                       |                                                         | 10-15 wks, 3/wk, 60 min                                   |  | 4            | 3 m, 1 f       | 30-63                               | T7, T10, T-6, T-23/L1   | SCI: paraplegic                           | 4  |                                       |                 |
| 7                                                                                  | Stevens et. al [5]                    | 2014 | US                | 4     | 9                           | Underwater Treadmill                                                               |                                                         | 8 wks, 3/wk, (5-10) min (3 walks)                         |  | (12-1) 11    | 7 m, (5-1) 4 f | 23-62: 48±13                        | C2,3, 4, C6, T5,6,8, L2 | iSCI                                      | 11 |                                       |                 |
| 8                                                                                  | Stevens & Morgan [37]                 | 2015 | *                 | *     | 8                           | *                                                                                  |                                                         | *                                                         |  | *            | *              | *                                   | *                       | *                                         | *  |                                       |                 |
| 9                                                                                  | Sorg [38]                             | 1993 | US                | 5     | 5                           | Swimming                                                                           |                                                         | 72 mths, 3-4/wks, 60 min                                  |  | 1            | 1 m            | 41                                  | T11-12/ L4              | SCI: paraplegic                           | 1  |                                       |                 |
| 10                                                                                 | Taylor & McGruder [39]                | 1996 | US                | 5     | 5                           | Sea Kayaking (n.g. but assumed outdoors)                                           |                                                         | length not given (45 min interviews)                      |  | 3            | 2 m, 1 f       | 23-38                               | C6, C7 (plus one T1)    | iSCI: quadriplegia                        | 3  |                                       |                 |
| Cross-sectional [one-time]                                                         |                                       |      |                   |       |                             |                                                                                    |                                                         |                                                           |  |              |                |                                     |                         |                                           |    |                                       |                 |
| 11                                                                                 | DiRocco et. al [40]                   | 1985 | US                | 5     | 6                           | Tethered swimming plus arm workout on land and water                               | Tethered swimming plus arm workout on land and water    | 30-40 min (with 5-10 min breaks)                          |  | 12           | 9 m, 3 f       | 21-47: 33.3/<br>Control: 32.8       | C7, T8, T12             | Spinal Cord Impaired                      | 6  | Able-body                             | 6               |
| 12                                                                                 | Gass, Gass & Pitetti [41]             | 2002 | US                | 5     | 6                           | Water immersion                                                                    | Land training                                           | 60 min                                                    |  | 4            | 4 m            | 33-44                               | C5-7                    | SCI: tetraplegia                          | 4  | (SCI: tetraplegia)                    | (4)             |
| 13                                                                                 | lucksch et. al [42]                   | 2013 | Brazil            | 5     | 8                           | Walking in water                                                                   | Walking in water                                        | self-selected speed                                       |  | 19           | 18 m, 1 f      | 39±14.2                             | C4 - L1                 | iSCI                                      | 9  | Able-body                             | 10              |
| 14                                                                                 | Leal et. al [43]                      | 2010 | Brazil            | 5     | 7                           | Water immersion                                                                    | Water immersion                                         | 15 min                                                    |  | 23           | 23 m           | 22-40: 30.4±6.0                     | C4-7                    | SCI: tetraplegia                          | 11 | Able-body                             | 12              |
| 15                                                                                 | Thomaz et. al [44]                    | 2005 | Brazil            | 5     | 8                           | Isothermic immersion                                                               | Isothermic immersion                                    | 15 min                                                    |  | 34           | 34 m           | 25:27:00                            | C4-8                    | SCI: tetraplegia                          | 23 | Able-body                             | 11              |
| 16                                                                                 | Tamburella, Cosentino & Molinari [45] | 2013 | Italy             | 5     | 8                           | Walking in water                                                                   | Land                                                    |                                                           |  | 30           | 16 m, 14 f     | 23-69: 43.53±17.43                  | C, T, L                 | (Chronic & sub-acute) iSCI                | 15 | Able-body                             | 15              |

\* Shows the belonging to the article above: same information since it is same study, but different article; type of study: we looked at procedures not necessarily how author classified their study; Symbols: n=number (after drop outs, actual participants), mean=M, SD= Standard Deviation, mth(s)= month(s), wk(s)=week(s), min=minutes, m=male, f=female; SCI=Spinal Cord Injury, iSCI=incomplete SCI, chronic (> 1 year), acute (< 1 year: included studies participants between 7 to 9 mths after injury), (-# drop out): sum: n=303 (-6), male: 221, female: 81, not listed:1; Hydrotherapy, water/isothermic immersion: we kept the naming of the original articles. Hydrotherapy is understood as water immersion including exercise or jets, while water/isothermic immersion is the simple immersion in water at certain temperature (more passive). Able-body control(s): person/people without disabilities; within interventionn: italic=on the water; (control group) used same participants for treatment and control.

### **Type of outcome measures and outcomes**

Mainly physiological, measures related to physical fitness, mobility, activities of daily living and body composition, and psychological outcomes were reported, including some but minimal cognitive measures (part of functional independence measures) and factors of social well-being (Table 3). A variety of measures were used. Fourteen out of 15 studies used objective measures (marked with 1). One study was solely qualitative (3a self-reported), whereas two of the quantitative studies used next to the objective measures, scales or endurance tests as outcome measures (marked as 2), four self-reported measures, and one included additional observation of spasticity, however, not using an established scale (marked with 3b). Out of the six cross-sectional studies, four examined physical fitness (all pulmonary measures, plus three cardiovascular) and two examined gait.

Table 3: Study outcome and measures

|                                                                                                                |                              |                                            | Outcomes                                         |                           |                                  |                    |                 |                  |                         |                            |           |                                                                                             | Measurements<br>(experimental: control group)                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |                                                                |
|----------------------------------------------------------------------------------------------------------------|------------------------------|--------------------------------------------|--------------------------------------------------|---------------------------|----------------------------------|--------------------|-----------------|------------------|-------------------------|----------------------------|-----------|---------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------|
| Article                                                                                                        |                              | Study                                      | Intervention                                     | Physiological             |                                  |                    |                 |                  |                         |                            |           | Psychological                                                                               | Mix                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            | Fitness: Aerobic: Pulmonary/ Cardiovascular Measures<br>Mobility: Strength/ Gait/Range of Motion/ Balance/ Spasticity/ Other gait characteristics<br>Activities of daily living: FIM<br>Gait speed: Velocity<br>Body: Fat/Mass<br>Mental<br>Other                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               | Effect Size                                                    |
| #                                                                                                              | Reference<br>Author [Ref. #] | Type<br>Method, Quality 10-item D&B<br>LoE | Type<br>(in water unless italic = on the water ) | Fitness: Aerobic capacity |                                  | Mobility           |                 |                  |                         | Activities of daily living | Body      |                                                                                             |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |                                                                |
|                                                                                                                |                              |                                            |                                                  | Pulmonary                 | Cardio-vascular                  | Muscular: Strength | Balance         | Spasticity       | Walking characteristics | Functional Indep. Measure  | Fat/ Mass | Mental                                                                                      | Other                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |                                                                |
| Interventions [repeated]<br>[RCT (1a or 1b), Prospective controlled trials (2), Pre-post (4), Case Report (5)] |                              |                                            |                                                  |                           |                                  |                    |                 |                  |                         |                            |           |                                                                                             |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |                                                                |
| 1                                                                                                              | Jung et. al [31]             | 1b 8                                       | Aquatic Exercise                                 | 1<br>++/+++               |                                  |                    |                 |                  |                         |                            |           |                                                                                             |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                | (1) Pulmonary function measured by Forced:<br>Vital Capacity (FVC) (+++:+)<br>Expiratory flow rate (FER) (++:++)<br>Expiratory volume at one second (FEV1) (++:+)<br>Expiratory flow rate at one second (FER1: (FEV1/FVC) (+++:+)<br>(1) Biomechanical variables: <b>balance</b> (sitting): center of pressure acceleration (CoP):<br>CoP: mean velocity (=) & median frequency : a significant training effect was seen only as a lowering of median frequency (+)<br>Fmed: sagittal opposite to more "normal" (-:=-), Fmed: frontal (=)<br>(3a) Questionnaires: <b>increase in shoulder strength &amp; stability of the upper body</b> : 8 subjects (+); <b>Balance</b> : 9 subjects; <b>Spasticity</b> : 5 subjects (+); <b>Well-being</b> : 11 subjects<br>(2) Ashworthscores ( <b>Spasticity</b> ) (+++:++)<br>(2) <b>Spasm</b> severity (+++:++)<br>(1/3b) Oral baclofen intake (++/=) [mild fatigue in 2 subjects]<br>(2) <b>Functional Independence Measure (FIM)</b> (+++:++)<br>(1) Spirometer: VC/ FEV1: ++ (significant not defined at which level)= (both control groups: sailing & land);<br>(3a/b) <b>Spasticity</b> (during water immersion & onset delayed after being back on land: +)<br>(3a) Final report: Physical and mental well-being (+)<br>(1) Skibinski's <b>cardio-respiratory index (SCRI)</b> ++ (significant not defined at which level):+ [SCRI 4* CG]<br>(includes Vital Capacity (+), Apnoe time (+), HR (+)) | FVC: 1.26<br>FER: 0.27^<br>FEV1: 0.90<br>FER1: FEV1/FVC: 0.53^ |
| 2                                                                                                              | Grigorenko et. al [32]       | 2 8                                        | Kayak                                            |                           |                                  | 3a<br>+            | 1//3a<br>=/-+/+ | 3a<br>+          |                         |                            | 3a<br>+   | 3a Well-being, upper body stability +                                                       |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                | -                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |                                                                |
| 3                                                                                                              | Kesiktas et. al [33]         | 2 7                                        | Hydrotherapy                                     |                           |                                  |                    |                 | 2<br>++/+++      | 2<br>++                 |                            |           | 1 Lower medication + [mild fatigue in 2 subjects]                                           |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                | -                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |                                                                |
| 4                                                                                                              | Novak & Ladurner [34]        | 2 8                                        | Scuba-diving                                     | 1<br>++                   |                                  |                    |                 | 3a/b<br>+        |                         |                            | 3a<br>+   | 3a Physical and mental well-being                                                           |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                | FEV1<br>TG/Healthy CG: 0.29<br>TG/Sailing CG: 0.37<br>VC<br>TG/Healthy CG: 0.25                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |                                                                |
| 5                                                                                                              | Pachalski & Mekarski [35]    | 2 6                                        | Swimming                                         | 1<br>+                    | 1+                               |                    |                 |                  |                         |                            |           | [1 Cardio-respiratory test ++]                                                              |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                | SCRI 2.26                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |                                                                |
| 6                                                                                                              | Broach, Groff & Dattilo [36] | 4 5                                        | Swimming                                         | 1<br>+                    | 1<br>(HR, BP: n.g.)<br>2/3b<br>+ | 3a<br>+            | 3a<br>+         | 3a/b<br>+/(n.g.) |                         | 1<br>+                     | 3a<br>+   | 3b Pain<br>3a Social Validity: well-being, leisure participation (environment), stability + | (1/3a) Forced VC (+)<br>(1) <b>Cooper 12 Minute Swim Test</b> (+), HR, Blood Pressure (BP) (n.g.)<br>(1) % of Weight=Fat (+)<br>(3b) <b>Muscle tone, pain (n.g)</b><br>(3a) <b>Perceived exertion (RPE)</b> (n.g.)<br>(3a) <b>Social Validity Interviews</b> : individuals reported (+) in one one more of the following: Endurance, Shoulder strength, Sitting balance in wheelchair, Upper body strength, Stability, Balance & postural stability (+)<br>(1) Endurance: <b>6-minute walk distance (6MWD)</b> (++)<br>(1) Lower-extremity <b>strength (LS)</b> : handheld dynameters: Jtech Commander Power Track (++)<br>(2) <b>Balance (BL)</b> : Berg-Balance Scale (++)<br>(1) Preferred (PWS) & Rapid <b>Speed (RWS)</b> : 10-Meter Walk Test (both: ++)<br>(1) Daily step activity (DSA (1-leg)): Orthocare Step Activity Monitor (SAM) (++)<br>(1) <b>HR</b> (++) [same walking speed] | -                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |                                                                |
| 7                                                                                                              | Stevens et. al [5]           | 4 9                                        | Underwater Treadmill                             |                           | 2<br>++                          | 1<br>++            | 2<br>++         |                  | 1 Speed, Activity<br>++ |                            |           |                                                                                             |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                | [Pre-post: one group:<br>Partial η2<br>Leg Strength: 0.84<br>Balance: 0.65<br>P/RWS: 0.64<br>6-min/DSA: 0.51]                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |                                                                |
| 8                                                                                                              | Stevens & Morgan [37]        | * 8                                        | *                                                | 1<br>++                   |                                  |                    |                 |                  |                         |                            |           |                                                                                             |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                | -                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |                                                                |
| 9                                                                                                              | Sorg [38]                    | 5 5                                        | Swimming                                         |                           |                                  |                    |                 |                  |                         | 1+                         |           | 1 HDL-Cholesterol, Cholesterol, Triglycerides (+)<br>LDL Cholesterol (=)                    | (1) <b>Bodyweight</b> (overall +)<br>(1) <b>Lipid Makers</b> :<br>HDL Cholesterol (+), Cholesterol (+), LDL Cholesterol (=), Triglycerides (+)<br><b>Mental</b> : (3a) Interviews: Enjoyment & Quality of Life, Identity construction (+) novelty, challenge, safety, sociability, natural environment aspects of sea kayaking; perceptions of the self as able in the eyes of others and the need for support in pursuit of outdoor, leisure activities                                                                                                                                                                                                                                                                                                                                                                                                                                       | -                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |                                                                |
| 10                                                                                                             | Taylor & McGruder [39]       | 5 5                                        | Sea Kayaking                                     |                           |                                  |                    |                 |                  |                         |                            | 3a<br>+   |                                                                                             |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                | -                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |                                                                |

| Cross-sectional [one-time] |                                       |   |   |                      |         |        |                           |   |   |                               |   |     |
|----------------------------|---------------------------------------|---|---|----------------------|---------|--------|---------------------------|---|---|-------------------------------|---|-----|
| 11                         | DiRocco et. al [40]                   | 5 | 6 | Tethered swimming    | 1<br>+  | 1<br>+ |                           |   |   |                               |   |     |
| 12                         | Gass, Gass & Pitetti [41]             | 5 | 6 | Hydrotherapy         | 1<br>+  | 1<br>+ |                           |   |   |                               |   |     |
| 13                         | lucksch et. al [42]                   | 5 | 8 | Walking in water     |         |        | 1<br>Gait/Range of Motion |   |   |                               |   |     |
| 14                         | Leal et. al [43]                      | 5 | 7 | Isothermic immersion | 1<br>++ | 1<br>+ |                           |   |   |                               |   |     |
| 15                         | Thomaz et. al [44]                    | * | 8 | Isothermic           | 1<br>++ |        |                           |   |   |                               |   |     |
| 16                         | Tamburella, Cosentino & Molinari [45] | 5 | 8 | Walking in water     |         |        | 1<br>+<br>Gait            |   |   |                               |   |     |
|                            |                                       |   |   |                      | 7 (8)   | 5 (6)  | 3                         | 3 | 4 | 1 Speed/ Activity<br>2 x Gait | 1 | 2 4 |
|                            |                                       |   |   |                      |         |        |                           |   |   | 4                             |   |     |

\*1 Objective Measures, 2 Measurement using a scale or an endurance test, 3: Subjective Measures: 3a Self reported, 3b Observation (no scale); e.g. 1/3a means it was measured with both: Objective and Self reported measures; + improvement (without judgment on significance), ++ significant improvement at 0.05 level, +++ significant at 0.001 level; - negative effect, -- negative effect at 0.05 level, = no change, \*attention SD> 2, n.g. not given; #(# studies (articles) e.g. 8 studies (9 articles), Method. Methodological; italic within intervention means on the water; VC Vital Capacity, HR Heart Rate

## Physiological outcomes

Eight studies measured the **pulmonary function** (Table 3). Different measures were used, but six studies measured (forced) vital capacity ((F)VC) with two additionally measuring forced expiratory volume at one second (FEV1) and two measured VO2max with one measuring additionally ventilation. Interventions with evidence level 1 and 2 found that pulmonary function of people with SCI was statistically highly (VC, forced expiratory flow rate (FER1)) and statistically significantly increased by aquatic PA and scuba-diving. Effect sizes for FVC and FEV1 were large (1.26/ 0.90) in the scuba-divers compared to the on land control group (without SCI), and compared to the sailing control (with SCI) small to medium (0.29/0.37 to 0.25/0.44). One level 4 study reported positive FVC changes between pre- and post of a 15-week swimming intervention. Four additional cross-sectional studies used tethered swimming, hydrotherapy and aquatic immersion to measure pulmonary function before and during the activity. Two reported significant improvement in VC at 0.05, with the function of individuals with higher degrees of SCI improving more.

Six studies measured **cardiovascular functions**, four through heart rate, one additionally and one solely through endurance tests, respectively 6-minute walk test and Cooper 12 minute swim test, and one additional and one solely through plasma volume (Level 2, 4 and 5). A level 4 study measured statistically significant cardiovascular improvements from underwater treadmill training by two measures, heart rate and endurance test (Level 4). The 6-minute walk test also showed a large effect size ( $\eta^2=0.51$ ). The level 2 study found improvements in heart rate, however, not statistically significant. The Cooper 12-minute swim test showed that participants were able to swim an increased amount of pool lengths after 15 weeks (2-3 sessions/week) with a median of at least one length (Level 4). Three cross-sectional studies found cardiovascular improvements associated with the activity, either through heart rate and/or plasma volume. Skibinski's cardio-respiratory index improved statistically between pre-post of a level 2 swimming study (Effect size: 2.26).

Seven studies examined outcomes in relation to **mobility** (spasticity, strength, balance, walking characteristics (speed, activity, gait/range of motion), six in-water and one on-water PA interventions. Four studies measured the effects of aquatic PA on **spasticity** with, three using self-report or observation, and one using an established measure, the Ashworth's scale. People participating in hydrotherapy, kayaking, scuba-diving and swimming demonstrated reduced levels of spasticity; within hydrotherapy the changes were statistically significant and highly significant. **Balance** and **strength** were evaluated by three studies using objective, scale and self-report measures (Level 2 and 4). Two studies reported improvement in shoulder, whereas one study reported statistically significant improvement in lower-extremity, strength. Two studies reported improvement in balance (one self-reported and one assessed through the Berg-Balance scale, with a statistically significant change), and the centre of pressure acceleration showed either no or negative change. **Gait speed, gait activity, and range of motion** were included in three studies, one examining the underwater treadmill and two examining

walking-in-water interventions. Findings showed that gait speed and daily step activity were statistically significant improved (one level 4 study) and that gait of people with SCI in water approached the gait of able-bodied controls on land (two level 4 studies).

One level 2 study reported statistically significant improvements in **Functional Independence Measures**, two studies, level 4 and 5, reported improved **body** composition, via either reduced body fat percentage or body weight.

### **Psychological outcomes**

Four studies (28 people with SCI) found improved **mental well-being**, facilitated by enjoyment, improved stamina, and better quality of life. Mental well-being was either assessed through questionnaires (1 study) or interviews (3 studies).

### **Adverse events**

Measures on sagittal and frontal balance showed opposite to “more normal” results after one intervention, which was explained by the authors as coping strategy for balance control by training (31). The control group in one study experienced mild fatigue, which authors claimed on their intake of oral baclofen to control spasticity (32).

## **DISCUSSION**

This systematic review of 15 eligible studies (16 articles) is the first to summarize the evidence of effects of aquatic PA for adults with SCI, with a single RCT and eight level 5, including six cross-sectional, studies, with scores 5 to 9 out of a modified 10-item Downs and Black scale. As such, overall, evidence regarding the effects of aquatic PA on physiological and psychological outcomes is characterized as low quality. Despite the variety of aquatic interventions examined, the findings suggest that aquatic PA improves areas of physical and psychological well-being. While there is weak to fair evidence to draw conclusions for few physical outcomes, there is insufficient evidence for the majority of the outcomes investigated by included studies.

### **Pulmonary and cardiovascular outcomes**

Cross-sectional studies suggest that **pulmonary** function is improved for people with SCI while being either solely immersed into water or performing aquatic exercise. These findings are expanded by a single RCT, two control trials and a pre-post study, showing the effectiveness of exercise in improving pulmonary function. Although the RCT demonstrated strong evidence that aquatic PA is superior to land-based PA in improving pulmonary function in people with SCI, it did not specify the aquatic exercise in detail. No matter whether the control groups received no training, sailing or on-land training, all comparisons showed a positive effect for aquatic exercise and scuba-diving on FVC and FER. Within all (F)VC results, aquatic exercise and scuba-diving showed better outcomes than swimming. As respiratory conditions are the leading cause of death amongst people with SCI (10), aquatic PA can help maintain and improve pulmonary function in people with SCI. One level 2 study and two level 4 studies measured **cardiovascular** effects, all finding positive improvement with the later being statistically significant.

Temporary improved cardiovascular measures were also reported in three cross-sectional studies through heart rate and plasma volume, benefiting people with SCI more the higher their degree of injury. Combining pulmonary and cardiovascular improvements, this review suggests that aquatic PA improves physical fitness. The Skibinski's cardio-respiratory index improved statistically between pre-post of a level 2 swimming study (Effect size: 2.26). It is also noteworthy that no study reported any decreased pulmonary and cardiovascular outcomes. Hicks and colleagues suggest that the maintenance and/or absence of significant fitness losses could be interpreted as a positive result since people acquiring a SCI experience immense deconditioning (1).

### **Mobility**

Findings suggest that a variety of aquatic PA, in and on the water, improved **spasticity** (level 2 and 4). There is a lack of valid and reliable measures for spasticity, and clinical measures of spasticity do not correlate well with perceptions of improved function (44). Three of the four studies measuring spasticity in this review used self-report. Level 4 evidence suggests, that underwater treadmill improves lower-extremity **strength**, while people participating in a kayak and swimming intervention reported improved upper body or shoulder strength. Two studies (level 2 and 4) reported improvement in **balance** (one self-reported and one assessed through the Berg-Balance scale, with a statistically significant change), however, one study's measure, the centre of pressure acceleration showed either no or negative change. **Gait** speed and gait activity were only described by one level 4 study. Cross-sectional studies showed that gait of people with SCI in water approached the gait of able-bodied controls on land (two level 4 studies). While the finding improved gait within the water environment is consistent with a review of aquatic therapy of individuals with neurological diseases, the effect of improved gait through water interventions needs to be confirmed by non-cross-sectional studies in people with SCI. These encouraging findings on benefits of aquatic PA on mobility require replication in high-quality studies.

### **Activities of daily living and body composition**

While both showing positive trends, there is insufficient evidence to conclude that aquatic PA can affect Activities of Daily Living and body composition in people with SCI, as activities of daily living was only evaluated by one level 2 study (however, measuring a statistical significant results), and body composition by two studies (level 4 and 5).

### **Mental Outcomes**

Although depressive disorders are one of the major reasons for reduced life expectancy in the SCI population (14), there was very limited evidence related to mental health. PsycNet was included among the searched databases in hopes of finding studies focusing on mental outcomes. However, only one study measured mental health as primary outcome, while included psychological well-being as a secondary outcome. One study excluded people with SCI with mental impairment (31). PA is known to be positively associated with health-related quality of life, decreased anxiety in adults (45), and reduced

depressive symptoms in people with neurological impairments (46). Future studies should include mental health measures.

### **Limitations**

There was a small number of aquatic studies, together examining a variety of aquatic PA and measurement tools, with generally small sample sizes, explained by limited access to pools (47), lakes, rivers, and ocean, and relatively low number of people with SCI in any given community (48, 49). Only one study used RCT-design. Other researchers have suggested that a RCT, the gold standard of evidence, is not always realistic in testing PA interventions with people with SCI because of limited sample and the need for vast amounts of human resources (50). Hence, interventions using any study design were included, however, decreasing the overall quality of studies, not allowing for more advanced quantitative analysis, upon which to base conclusions. While most articles did well in reporting their purpose, intervention, and recruitment criteria, and used valid and reliable measures, internal validity was low because so few studies used controlled designs. When controlled, studies were not consistent in their use of controls, with some using SCI controls, others using able-body controls, one study using both, and control conditions (e.g., water or land-based or no interventions).

Only two studies were facilitated in open water, however, using a kayak so participants were actually “on” the water. Aquatic interventions cannot only be a task of rehabilitation centres: a) they often lack the equipment to offer for example underwater treadmill training, b) have a high staff-to-patient ratio requirements off at least 3-to-1 (51), c) are inaccessible for non-patients, and d) are often not near open water. Public pool facilities are also inaccessible for people with disabilities due to physical, social and emotional barriers (47, 52). Community providers might have more flexibility to offer programs in the outdoors. The outdoors is also known to improve vitality, and this improvement seems to be to independent to other factors such as levels of PA or social interaction (53). For example, participants with neurological impairments in an adaptive surfing program in Hawai'i associated the unpredictable component of an ocean with physical and mental health improvements (22).

### **Future implication**

Aquatic environments, such as pools, lakes, and ocean need to become accessible to people with SCI, not only for rehabilitation centres but also for community interventions. This includes accessible ramps or elevators, bathrooms, and “water lifts” in pools, as well as wheelchair accessibility mats on a beach and water-transfer chairs. Using trained volunteers and family members may help address the high need for paid staff of water-based programs for the indoor, but especially for outdoor open waters. More studies of outdoor aquatic interventions are needed.

Future studies should replicate existing and evaluate effects of aquatic PA on physical and psychological outcomes through more rigorous research designs, utilizing standardized measures, within build and natural settings (e.g., river, lake, ocean). The difference between aquatic PA within and “on” the water needs further study and analysis. It is also highly recommended to evaluate social outcomes,

and include details on aquatic PA, especially the frequency and intensity.

### **CONCLUSION**

There is weak to fair evidence that aquatic PA is effective in increasing cardiovascular and pulmonary function among people with chronic SCI. Studies suggest, but there is insufficient evidence to conclude, that aquatic PA improves mobility (spasticity, balance, strength and gait), body composition, activities of daily living and mental health. Findings require replication in high-quality studies, incorporating larger sample sizes and controlled designs that compare people with SCI in aquatic versus land-based intervention. It is recommended that both psychological as well as physiological effects be measured. Additionally, the value added by a natural setting--such as the ocean, rivers, and lakes--should be investigated.

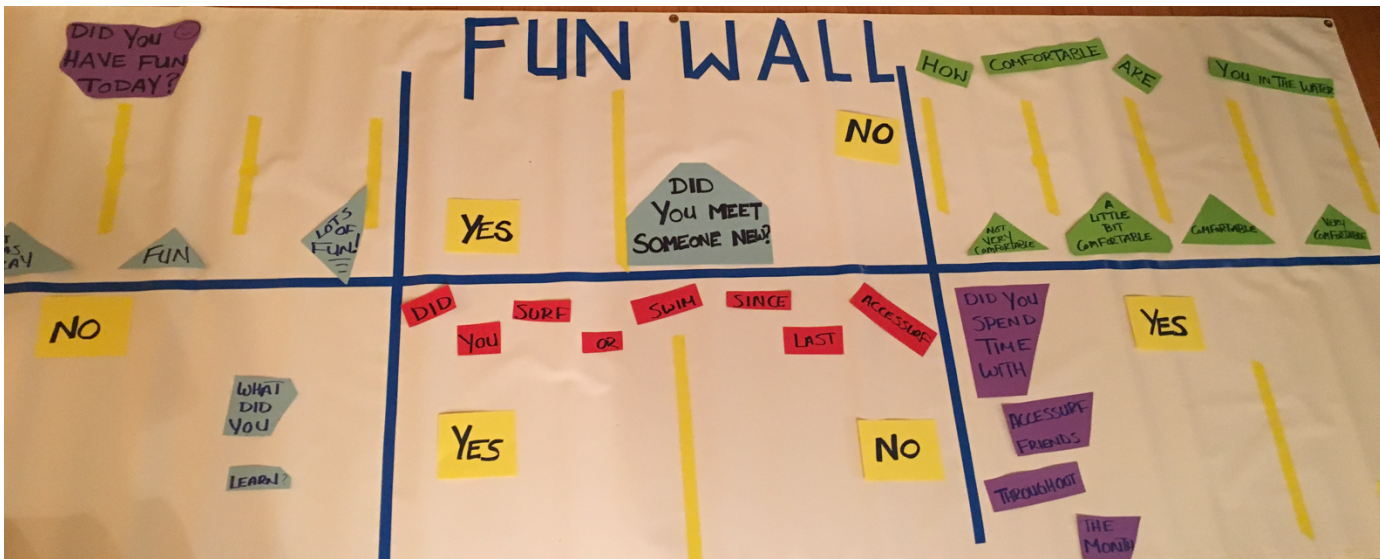
## REFERENCES

1. Hicks AL, Martin Ginis KA, Peltier CA, Ditor DS, Foulun B, Wolfe DL. The effects of exercise training on physical capacity, strength, body composition and functional performance among adults with spinal cord injury: a systematic review. *Spinal Cord* 2011; **49**(11): 1103-1127.
2. Cadmus L, Patrick MB, Maciejewski ML, Topolski T, Belza B, Patrick DL. Community-based aquatic exercise and quality of life in persons with osteoarthritis. *Med Sci Sports Exerc* 2010; **42**(1): 8-15.
3. Bartels EM, Juhl CB, Christensen R, Hagen KB, Danneskiold-Samsøe B, Dagfinrud H, *et al.* Aquatic exercise for the treatment of knee and hip osteoarthritis (Review). *Cochrane Database of Systematic Reviews* 2016; (3): 1-69.
4. Stan E. The benefits of participation in aquatic activities for people with disabilities. *Romanian Sports Medicine Society* 2012; **8**(1): 1737-1742.
5. Stevens SL, Caputo JL, Fuller DK, Morgan DW. Effects of underwater treadmill training on leg strength, balance, and walking performance in adults with incomplete spinal cord injury. *The Journal of Spinal Cord Medicine* 2014; **38**(1): 91-101.
6. WHO. World Report on Disability. Malta: World Health Organization 2011 [Accessed: 07.11.2016]. Available from: [http://www.who.int/disabilities/world\\_report/2011/report/en/](http://www.who.int/disabilities/world_report/2011/report/en/)
7. US Health and Human Services. 2008 Physical Activity Guidelines for American. Be Active, Healthy and Happy! 2008 [Accessed: 10.10.2016]. Available from: <http://health.gov/paguidelines/pdf/paguide.pdf>.
8. Rochi M, Routier F, Latimer-Cheung A, Ginis K, Noreau L, Sweet S. Are adults with spinal cord injury meeting the spinal cord injury-specific activity guidelines? A look at a sample from a Canadian province *Spinal Cord* 2017; **55**(5): 454-459.
9. CDC. Disability and Health. Increasing Physical Activity among Adults with Disabilities 2016 [Accessed: 05.10.2016]. Available from: <http://www.cdc.gov/ncbddd/disabilityandhealth/pa.html>.
10. Burns S. Acute respiratory infections in persons with spinal cord injury. *Phys Med Rehabil Clin N Am* 2007; **18**(2): 203-216, v-vi.
11. Maynard F, Karunas R, Waring W. Epidemiology of spasticity following traumatic spinal cord injury. *Arch Phys Med Rehabil* 1990; **71**(8): 566–569.
12. Sezer N, Akkus S, Ugurlu FG. Chronic complications of spinal cord injury. *World J Orthop* 2015; **6**(1): 24-33.
13. McKinley WO, Jackson JB, Cardenas DD, DeVivo MJ. Long-Term Medical Complications After Traumatic Spinal Cord Injury: A Regional Model Systems Analysis. *Arch Phys Med Rehabil* 1999; **80**(11): 1402–1410.
14. Krause JS, Saunders LL. Health, Secondary Conditions, and Life Expectancy after Spinal Cord Injury. *Arch Phys Med Rehabil* 2011; **92**(11): 1770–1775.
15. DeVivo MJ, Krause JS, Lammertse DP. Recent trends in mortality and causes of death among persons with spinal cord injury. *Arch Phys Med Rehabil* 1999; **80**(11): 1411-1419.
16. McGee S. *Stance and Gait*. 3rd ed. Elsevier Saunders: Seattle, Washington, 2012.
17. Devillard X, Rimaud D, Calmels P. Effects of training programs for spinal cord injury. *Ann Readapt Med Phys* 2007; **50**(6): 480-489.
18. Kloosterman MG, Snoek GJ, Jannink MJ. Systematic review of the effects of exercise therapy on the upper extremity of patients with spinal-cord injury. *Spinal Cord* 2009; **47**(3): 196-203.

19. Sheel A, Reid W, Townson A, Ayas N, Konnyu K, The Spinal Cord Rehabilitation Evidence (SCIRE) Research Team. Effects of Exercise Training and Inspiratory Muscle Training in Spinal Cord Injury: A Systematic Review. *J Spinal Cord Med* 2008; **31**(5): 500–508.
20. Marinho-Buzelli AR, Bonnyman AM, Verrier MC. The effect of aquatic therapy on mobility of individuals with neurological diseases: a systematic review. *Clinical Rehabilitation* 2015; **29**(8): 741-751.
21. Clapham E. Ocean Surfing as a Novel Physiotherapy Environment: A Commentary. *Journal of Novel Physiotherapies* 2014; **04**(02).
22. Schmid S. Physical Activity & People with Disabilities. A Pilot for a Qualitative Process- and Outcome Evaluation Through a Focus Group of the Non-Profit Organization AccesSurf Hawai'i. [Evaluation / Thesis]. In press 2016.
23. Moher D, Liberati A, Tetzlaff J, Altman DG, Group. TP. Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLoS Med* 2009; **6**(7): e1000097.
24. Hall J, Swinkels A, Bridson J, McCabe CS. Does Aquatic Exercise Relieve Pain in Adults With Neurologic or Musculoskeletal Disease? A Systematic Review and Meta-Analysis of Randomized Controlled Trials. *Arch Phys Med Rehabil* 2008; **89**(5): 873-883.
25. CEBP. Centre of Evidence-Based Physiotherapy. About SCIRE (Spinal Cord Injury Research Evidence). Methods of Systematic Review. Determining Levels of Evidence and Formulating Conclusions 2016 [Accessed: 21.10.2016]. Available from: <http://scireproject.com/about-scire/methods-of-systematic-review/determining-levels-of-evidence-and-formulating-conclusions>.
26. CEBP. Centre of Evidence-Based Physiotherapy PEDro. Physiotherapy Evidence Database. PEDro scale 2016 [Accessed: 21.10.2016]. Available from: <http://www.pedro.org.au/english/downloads/pedro-scale/>.
27. Muthuri SK, Francis CE, Wachira LM, LeBlanc AG, Sampson M, Onywera VO, *et al.* Evidence of an Overweight/Obesity Transition among School-Aged Children and Youth in Sub-Saharan Africa: A Systematic Review. *PLoS One* 2014; **9** e92846(3).
28. Downs SH, Black N. The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and non-randomised studies of health care interventions. *J Epidemiol Community Health* 1998; **52**(6): 377-384.
29. Novak HF, Ladurner G. Scuba diving as a rehabilitation approach in paraplegia. *Rehabilitation (Stuttg)* 1999; **38**(3): 181-184.
30. Jung J, Chung E, Kim K, Lee BH, Lee J. The effects of aquatic exercise on pulmonary function in patients with spinal cord injury. *J Phys Ther Sci* 2014; **26**(5): 707-709.
31. Grigorenko A, Bjerkefors A, Rosdahl H, Hultling C, Alm M, Thorstensson A. Sitting balance and effects of kayak training in paraplegics. *J Rehabil Med* 2004; **36**(3): 110-116.
32. Kesiktas N, Paker N, Erdogan N, Gülsen G, Biçki D, Yilmaz H. The Use of Hydrotherapy for the Management of Spasticity. *Neurorehabil Neural Repair* 2004; **18**(4): 268-273.
33. Pachalski A, Mekarski T. Effect of swimming on increasing of cardio-respiratory capacity in paraplegics. *Paraplegia* 1980; **18**(3): 190-196.
34. Broach E, Groff D, Dattilo J. Effects of an Aquatic Therapy Swimming Program on Adults with Spinal Cord Injury. *Therapeutic Recreational Journal* 1997; **31**(3): 160-173.
35. Stevens SL, Morgan DW. Proffered Paper. Heart Rate Response During Underwater Treadmill Training in Adults with Incomplete Spinal Cord Injury. *Top Spinal Cord Inj Rehabil* 2015; **21**(1): 40-48.
36. Sorg RJ. HDL-cholesterol: exercise formula. Results of long-term (6-year) strenuous swimming exercise in a middle-aged male with paraplegia. *J Orthop Sports Phys Ther* 1993; **17**(4): 195-199.

37. Taylor LPS, McGruder JE. The meaning of sea kayaking for persons with spinal cord injuries. *Am J Occup Ther* 1996; **50**(1): 39-46.
38. DiRocco P, Hashimoto A, Daskalovic I, Langbein E. Cardiopulmonary responses during arm work on land and in a water environment of nonambulatory, spinal cord impaired individuals. *Paraplegia* 1985; **23**(2): 90-99.
39. Gass EM, Gass GC, Pitetti K. Thermoregulatory responses to exercise and warm water immersion in physically trained men with tetraplegia. *Spinal Cord* 2002; **40**(9): 474-480.
40. Iucksch DD, Israel VL, Ribas DIR, Manffra EF. Gait characteristics of persons with incomplete spinal cord injury in shallow water. *J Rehabil Med* 2013; **45**(9): 860-865.
41. Leal JC, Mateus SRM, Horan TA, Beraldo PSS. Effect of graded water immersion on vital capacity and plasma volume in patients with cervical spinal cord injury. *Spinal Cord* 2010; **48**(5): 375-379.
42. Thomaz S, Beraldo P, Mateus S, Horan T, Leal JC. Effects of partial isothermic immersion on the spirometry parameters of tetraplegic patients. *Chest* 2005; **128**(1): 184-189.
43. Tamburella F, Scivoletto G, Cosentino E, Molinari M. Walking in water and on land after an incomplete spinal cord injury. *Am J Phys Med Rehabil* 2013; **92**(10 Suppl 2).
44. Priebe MM, Sherwood AM, Thornby JI, Kharas NF, Markowski J. Clinical assessment of spasticity in spinal cord injury: a multidimensional problem. *Arch Phys Med Rehabil* 1996; **77**(7): 713-716.
45. Bize R, Johnson JA, Plotnikoff RC. Physical activity level and health-related quality of life in the general adult population: A systematic review. *Prev Med* 2007; **45**(6): 401-415.
46. Adamson BC, Ensari I, Motl RW. Effect of exercise on depressive symptoms in adults with neurologic disorders: a systematic review and meta-analysis. *Arch Phys Med Rehabil* 2015; **96**(7): 1329-1338.
47. Arbour-Nicitopoulos KP, Martin Ginis KA. Universal Accessibility of "Accessible" Fitness and Recreational Facilities for Persons With Mobility Disabilities. *Adapted Physical Activity Quarterly* 2011; **28**(1): 1-15.
48. Craven BC, Baliouss C, Hitzig SL, Moore C, Verrier MC, Giangregorio M, *et al.* Use of screening to recruitment ratios as a tool for planning and implementing spinal cord injury rehabilitation research. *Spinal Cord* 2014; **52**(10): 764-768.
49. Martin Ginis KA, Hicks AL. Exercise Research Issues in the Spinal Cord Injured Population *Exerc Sport Sci Rev* 2005; **33**(1): 49-53.
50. Barnett SD, Heinemann AW, Libin A, Houts AC, Gassaway J, Sen-Gupta S, *et al.* Small N designs for rehabilitation research. *J Rehabil Res Dev* 2012; **49**(1): 175-186.
51. Dolbow DR, Gorgey AS, Recio AC, Stiens SA, Curry AC, Sadowsky CL, *et al.* Activity-Based Restorative Therapies after Spinal Cord Injury: Inter-institutional conceptions and perceptions. *Aging and Disease* 2015; **6**(4): 254-261.
52. Hilda Mulligan, Polkinghorne A. Community use of a hospital pool by people with disabilities. *Disability and Health Journal* 2013; **6**: 385-390.
53. Ryan RM, Weinstein N, Bernstein J, Brown KW, Mistretta L, Gagné M. Vitalizing effects of being outdoors and in nature. *Journal of Environmental Psychology* 2010; **30**(2): 159-168.

## Appendix II: Study 1 Part I: Fun Wall



## Appendix III: Study 1 Part II: Skills Tool to Evaluate Participants

<https://www.accessurf.org/observation-questionnaire-surfing>

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### OBSERVATION QUESTIONNAIRE SURFING

Volunteer Name(s): \*

AccessSurfer Name: \*

Date of Most Recent Activity:

(Referred to as: "Today" in fields below) \*

How long has the AccessSurfer been surfing with AccessSurf? month/year (if known)

How many times have you worked with the AccessSurfer? (estimate)

What type of board did the AccessSurfer use to surf?

#### 1. Where did you and the AccessSurfer surf?

When they first joined AccessSurf:

- ☐ White Plains Beach AccessSurf Day at the Beach  
☐ Other

Today:

- ☐ White Plains Beach AccessSurf Day at the Beach  
☐ Other

#### 2. How was the access to the water?

When they first joined AccessSurf:

- ☐ Beginner ☐ Intermediate ☐ Advanced

Today:

- ☐ Beginner ☐ Intermediate ☐ Advanced

#### 3. How were the environmental conditions? (Water, wind, current, waves, crowds):

When they first joined AccessSurf:

- ☐ Beginner ☐ Intermediate ☐ Advanced

Today:

- ☐ Beginner ☐ Intermediate ☐ Advanced

#### 4. What is the surfing style of the AccessSurfer?

When they first joined AccessSurf:

- ☐ Prone (on their stomach)  
☐ Sitting  
☐ Kneeling  
☐ Standing  
☐ Other

Today:

- ☐ Prone (on their stomach)  
☐ Sitting  
☐ Kneeling  
☐ Standing  
☐ Other

#### 5. How much assistance in the water did the AccessSurfer need?

When they first joined AccessSurf:

- ☐ Independent (surfing on their own with minimal assistance in the water)  
☐ Assisted (surfing on their own with instructor close by for assistance)  
☐ Dependent (surfing tandem with an instructor)

Today:

- ☐ Independent (surfing on their own with minimal assistance in the water)  
☐ Assisted (surfing on their own with instructor close by for assistance)  
☐ Dependent (surfing tandem with an instructor)

## 6. How does the AccesSurfer access the water?

When they first joined AccesSurf:

- ☐ Walking unassisted
- ☐ Walking assisted
- ☐ Crawling
- ☐ Beach Wheel-Chair
- ☐ Carried (fireman's, princess, backpack, etc.)
- ☐ Other

Today:

- ☐ Walking unassisted
- ☐ Walking assisted
- ☐ Crawling
- ☐ Beach Wheel-Chair
- ☐ Carried (fireman's, princess, backpack, etc.)
- ☐ Other

## Comfort Level Scale

VERY UNCOMFORTABLE

UNCOMFORTABLE

NEUTRAL (OK, ALRIGHT)

COMFORTABLE

VERY COMFORTABLE

1

2

3

4

5

## 7. How comfortable is the AccesSurfer talking to new people at AccesSurf?

When they first joined AccesSurf:

- ○ ○ ○ ○  
1 2 3 4 5

Today:

- ○ ○ ○ ○  
1 2 3 4 5

## 8. How comfortable is the AccesSurfer entering the water?

When they first joined AccesSurf:

- ○ ○ ○ ○  
1 2 3 4 5

Today:

- ○ ○ ○ ○  
1 2 3 4 5

## 9. How comfortable is the AccesSurfer in the water (on a surfboard)?

When they first joined AccesSurf:

- ○ ○ ○ ○  
1 2 3 4 5

Today:

- ○ ○ ○ ○  
1 2 3 4 5

## 10. How comfortable is the AccesSurfer when falling or wiping out?

When they first joined AccesSurf:

- ○ ○ ○ ○  
1 2 3 4 5

Today:

- ○ ○ ○ ○  
1 2 3 4 5

## Level of Communication and Dependency

TOTALLY DEPENDENT

MAX ASSIST

MIN ASSIST

VERBAL ASSIST

SELF DIRECT

TOTALLY INDEPENDENT

1

2

3

4

5

6

## 11. How does the AccesSurfer prepare for surfing? (sun protection, hydration, equipment, meds, leash, wax, leg straps, fins, etc.)

When they first joined AccesSurf:

- ○ ○ ○ ○ ○  
1 2 3 4 5 6

Today:

- ○ ○ ○ ○ ○  
1 2 3 4 5 6

12. How does the AccesSurfer choose the path to enter the water?

When they first joined AccesSurf:

☐ ☐ ☐ ☐ ☐ ☐

1 2 3 4 5 6

Today:

☐ ☐ ☐ ☐ ☐ ☐

1 2 3 4 5 6

13. How does the AccesSurfer paddle out to surf?

When they first joined AccesSurf:

☐ ☐ ☐ ☐ ☐ ☐

1 2 3 4 5 6

Today:

☐ ☐ ☐ ☐ ☐ ☐

1 2 3 4 5 6

14. How does the AccesSurfer select surfable waves?

When they first joined AccesSurf:

☐ ☐ ☐ ☐ ☐ ☐

1 2 3 4 5 6

Today:

☐ ☐ ☐ ☐ ☐ ☐

1 2 3 4 5 6

15. How does the AccesSurfer catch waves?

When they first joined AccesSurf:

☐ ☐ ☐ ☐ ☐ ☐

1 2 3 4 5 6

Today:

☐ ☐ ☐ ☐ ☐ ☐

1 2 3 4 5 6

16. How does the AccesSurfer ride waves?

When they first joined AccesSurf:

☐ ☐ ☐ ☐ ☐ ☐

1 2 3 4 5 6

Today:

☐ ☐ ☐ ☐ ☐ ☐

1 2 3 4 5 6

17. How does the AccesSurfer recover after wiping out?

When they first joined AccesSurf:

☐ ☐ ☐ ☐ ☐ ☐

1 2 3 4 5 6

Today:

☐ ☐ ☐ ☐ ☐ ☐

1 2 3 4 5 6

18. How does the AccesSurfer manage underwater situations?

When they first joined AccesSurf:

☐ ☐ ☐ ☐ ☐ ☐

1 2 3 4 5 6

Today:

☐ ☐ ☐ ☐ ☐ ☐

1 2 3 4 5 6

19. How does the AccesSurfer direct needs and wants to surf? (e.g. selection of waves, white water, lost equipment, etc.)

When they first joined AccesSurf:

☐ ☐ ☐ ☐ ☐ ☐

1 2 3 4 5 6

Today:

☐ ☐ ☐ ☐ ☐ ☐

1 2 3 4 5 6

Intensity Level

LOW

MEDIUM

HIGH

1

2

3

20. What level of intensity was the surfing session?

When they first joined AccesSurf:

☐ ☐ ☐

1 2 3

Today:

☐ ☐ ☐

1 2 3

21. How long can the AccesSurfer endure a surfing session at the intensity stated in question #20?

When they first joined AccesSurf:

- ☐ less than 20 minutes
- ☐ 20 minutes
- ☐ 40 minutes
- ☐ 1 hour
- ☐ 1.5 hours
- ☐ 2 hours
- ☐ More than 2 hours
- ☐ Other

Today:

- ☐ less than 20 minutes
- ☐ 20 minutes
- ☐ 40 minutes
- ☐ 1 hour
- ☐ 1.5 hours
- ☐ 2 hours
- ☐ More than 2 hours
- ☐ Other

### Community Integration Scale

ALWAYS DISAGREE

SOMETIMES DISAGREE

NEUTRAL

SOMETIMES AGREE

ALWAYS AGREE

1

2

3

4

5

22. The AccesSurfer knows a number of people in AccesSurf to initiate a greeting and a receive a greeting in return.

When they first joined AccesSurf:

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

Today:

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

23. The AccesSurfer has developed a support system at AccesSurf events.

When they first joined AccesSurf:

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

Today:

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

24. The AccesSurfer is able to access new locations in the community.

When they first joined AccesSurf:

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

Today:

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

25. Does the AccesSurfer participate in water activities outside of AccesSurf events and how often?

When they first joined AccesSurf:

- ☐ None  
☐ Only AccesSurf Events  
☐ Once a month  
☐ Twice a month  
☐ Once a week  
☐ More than once a week

Today:

- ☐ None  
☐ Only AccesSurf Events  
☐ Once a month  
☐ Twice a month  
☐ Once a week  
☐ More than once a week

Do you recall any other changes/improvements you've observed since working with this AccesSurfer?

Comments:

Thank you very much!

Submit

## Appendix IV: Study 2 Part I: Info Graph of Results



## Concerns due to Covid19

71 comments

- ✓ 41% have no concern
- ✓ 21% some concerns, but trust AccesSurf safety measures
- ✗ 38% have concerns
- 59% Covid-19 as a problem

Social emotional benefits out-weigh the risk [1]

### Concerns

Vulnerable population [10]  
Social distancing [8]  
PPE/mask and water [6]  
Size of event [3]  
State guidelines [1]  
Reduced volunteer numbers [1]  
Plan for the worst case [1]

### Programming & Covid

60 comments

#### Prior to event:

Screening & Testing [6]  
Education [5]



#### At events:

Smaller events [7]  
Timeslots [5]  
Masks [7]  
No food [2]  
Hand wash station [2]  
Bleach & papertowels [1]  
Gloves for food [1]



## Suggested Improvements

### EVENTS

- Smaller more & frequent events
- Shorter circle announcements
- Increase 1-1 opportunity
- DATB: Increase local health care students
- DATB: Increase services, e.g. massages
- DATB: Assistance in parking lot
- DATB: Choice in surf instructor
- DATB: Opportunities to connect outside of events
- DATB: Keep to the Time Slots
- WW: Incorporate Weekend day
- Swim Clinic: Categorize by condition
- Canoe Day: Have regular/ monthly opportunities
- Diffrent locations
- HASC: Accommodation package, assistance for equipment to hotel/car
- Mau: Events
- Scheduling
- Choice of instructor
- Adeehering to time slots
- Schedule before events for instructors



### Location/Frequency

Vary locations  
Increased frequency  
Public Transportation challenges  
Wheelchair accessible bathrooms  
Make Shaded area for lunch



### Training

- More formal training PRIOR to event
- More training for new volunteers
- More sports specific training
- Media increase
- Commercial sponsorships
- Publicity e.g. build relationships with pro athletes
- Partnerships with other non-profits
- Quality and accessibility of media (photos)



## Other common themes:

MERCHANDISE: from people who want to sell again and people who want to get some

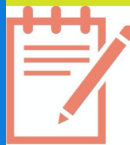
COMMENTS ON SURVEY/ MISSING COMMUNITY (more than 10) : such as

"Thank you for listening to our voices through this survey. I really miss all of you and being in the water."

### APPRECIATION:

"(...) there are females who go out with us as that helps to lower my anxiety (I am female)."

## How can we change to address this? YOUR NOTES



thank you

for sharing your thoughts

## NEW NORMAL SURVEY 2

NEW NORMAL SURVEY 2

I am a(n): ☆

- ☐ Volunteer (including LC and BOD members) ☐ AccesSurfer (Participant) ☐ Family Member/Caregiver
- ☐ Other

Gender \*

- ☐ Female ☐ Male ☐ Other

Age <sup>☆</sup>

- ☐ Child 0-12   ☐ Adolescent 13-19   ☐ Adult 20-64   ☐ Senior 65+

**Directions: Rate the following questions; all questions are for everyone taking the survey.**

**Satisfaction: Overall**

**How satisfied are you with your AccesSurf experiences?**



**In-Person Programs (Overall before April 2020):**

- ☐ Did Not Know About Program  
☐ Did Not Attend  
☐ ★★★★★  
☐ ★★★★☆  
☐ ★★★☆☆  
☐ ★★☆☆☆  
☐ ★☆☆☆☆  
☐ ★☆☆☆☆

### May Move Challenge:

- ☐ Did Not Know About Program  
☐ Did Not Attend  
☐ ★★★★★  
☐ ★★★★☆  
☐ ★★★☆☆  
☐ ★★☆☆☆  
☐ ★☆☆☆☆  
☐ ★☆☆☆☆

**Talk Story Tuesdays:**

- ☐ Did Not Know About Program  
☐ Did Not Attend  
☐ ★★★★★  
☐ ★★★★☆  
☐ ★★★☆☆  
☐ ★★☆☆☆  
☐ ★☆☆☆☆  
☐ ★☆☆☆☆

**Weekly Virtual Meetings:**

- ☐ Did Not Know About Program  
☐ Did Not Attend  
☐ ★★★★★  
☐ ★★★★☆  
☐ ★★★☆☆  
☐ ★★☆☆☆  
☐ ★☆☆☆☆

### Online Adaptive Surf Contest:

- ☐ Did Not Know About Program  
☐ Did Not Attend  
☐ ★★★★★  
☐ ★★★★☆  
☐ ★★★☆☆  
☐ ★★☆☆☆  
☐ ★☆☆☆☆  
☐ ★☆☆☆☆

---

## Programs

What type of programs would you like to see in the next six months?

- ☐ In-Person Programs Only ☐ Virtual Programs Only ☐ Both

How often would you like to attend AccesSurf Events?

- ☐ Daily ☐ Multiple times per week ☐ Weekly ☐ Every other week ☐ Monthly ☐ Other
- 

### Programs: In-Person

Would you prefer programs in groups or one on one?

- ☐ Groups ☐ Individual ☐ Both

When would you prefer events to be held? (Select all that apply)

- ☐ Weekend ☐ Weekdays ☐ Morning ☐ Afternoon/Evening

How long would you prefer the in-person event last?

- ☐ 1 hour ☐ 2 hours ☐ More than 2 hours

Where would you prefer events be held? (Select all that apply)

- ☐ South Shore ☐ North Shore ☐ West Shore ☐ East Shore

What types of event do you prefer be hosted?

- ☐ Clinics with specific goals ☐ Leisurely water experiences ☐ Other

### Programs: Virtual

What type of virtual program would you prefer?

- ☐ Interactive (able to ask questions in real time)  
☐ Passive (previously recorded video)

How long would you prefer virtual events to last?

- ☐ 30 minutes ☐ 1 hour ☐ 2 hours ☐ More than 2 hours ☐ Other

What video/social media platform do you prefer? (Select all that apply)

- |                                    |                                   |                                  |
|------------------------------------|-----------------------------------|----------------------------------|
| <input type="checkbox"/> Instagram | <input type="checkbox"/> FaceBook | <input type="checkbox"/> YouTube |
| <input type="checkbox"/> Zoom      | <input type="checkbox"/> Webinar  | <input type="checkbox"/> Twitter |
| <input type="checkbox"/> Other     |                                   |                                  |

What types of virtual programs would you like to experience? (Select all that apply)

- |                                                                  |                                                                           |                                                         |
|------------------------------------------------------------------|---------------------------------------------------------------------------|---------------------------------------------------------|
| <input type="checkbox"/> Educational/Training                    | <input type="checkbox"/> Social Calls                                     | <input type="checkbox"/> Interviews/Talk Story Tuesdays |
| <input type="checkbox"/> Adventures with the AccesSurf Community | <input type="checkbox"/> Learning new things with the AccesSurf Community | <input type="checkbox"/> Exercise/Workout               |
| <input type="checkbox"/> Ocean Safety                            | <input type="checkbox"/> Advanced Volunteer Training                      | <input type="checkbox"/> Other                          |
-

## Communication

How do you prefer to hear about updates from AccesSurf? (Select all that apply)

- |                                             |                                             |                                                                   |
|---------------------------------------------|---------------------------------------------|-------------------------------------------------------------------|
| <input type="checkbox"/> Media/TV/Newspaper | <input type="checkbox"/> Emails             | <input type="checkbox"/> Social Media (FaceBook, Instagram, etc.) |
| <input type="checkbox"/> Phone (Text/Call)  | <input type="checkbox"/> Letter in the Mail | <input type="checkbox"/> In Person Communication                  |
| <input type="checkbox"/> AccesSurf Website  | <input type="checkbox"/> Other              |                                                                   |

Do you like the amount of communication?

- ☐ Too little ☐ Just right ☐ Too much ☐ Other

Which partnerships/outreach activities do you believe AccesSurf should develop? (Select all the apply)

- ☐ Schools ☐ Non-Profit Organizations ☐ Hospitals ☐ Media ☐ Other

I feel that AccesSurf's media communications encourages me to participate in water activities.

- ☐ ★★★★★★  
☐ ★★★★★★  
☐ ★★★★★★  
☐ ★★★★★★  
☐ ★★★★★★  
☐ ★★★★★★  
☐ Don't Know

I feel included in AccesSurf's community because of its communication.

- ☐ ★★★★★★  
☐ ★★★★★★  
☐ ★★★★★★  
☐ ★★★★★★  
☐ ★★★★★★  
☐ ★★★★★★  
☐ Don't Know

I feel that AccesSurf creates positive representation of people with disabilities in the local news and media.

- ☐ ★★★★★★  
☐ ★★★★★★  
☐ ★★★★★★  
☐ ★★★★★★  
☐ ★★★★★★  
☐ ★★★★★★  
☐ Don't Know

I feel that AccesSurf's language is appropriate.

- ☐ ★★★★★★  
☐ ★★★★★★  
☐ ★★★★★★  
☐ ★★★★★★  
☐ ★★★★★★  
☐ Don't Know

I feel that AccesSurf's communication is easily accessible for people with disabilities.

- ☐ ★★★★★★  
☐ ★★★★★★  
☐ ★★★★★★  
☐ ★★★★★★  
☐ ★★★★★★  
☐ Don't Know

I feel that there is enough information about AccesSurf events and activities available to me.

- ☐ ★★★★★★  
☐ ★★★★★★  
☐ ★★★★★★  
☐ ★★★★★★  
☐ ★★★★★★  
☐ Don't Know

I feel that COVID-19 and its effects have made me feel more isolated and unable to access ocean activities.

- ☐ ★★★★★★  
☐ ★★★★★★  
☐ ★★★★★★  
☐ ★★★★★★  
☐ ★★★★★★  
☐ Don't Know

## Inclusion

Which of the following statements apply to you:

- ☐ I have a network of friends and have plenty of opportunity to participate in ocean activities.
- ☐ I have a network of friends and would like more opportunity to participate in ocean activities.
- ☐ I would like to increase my network of friends and would like more opportunities to participate in ocean activities.

Which of the following statements apply to you: (Select all that apply)

- ☐ I feel connected and included in the community of my preferred water sport. (surf, swim, paddle community)
- ☐ I feel like I am able to access water activities through AccesSurf.
- ☐ I feel included in the AccesSurf community.
- ☐ I feel included in the community that I live in.
- ☐ I feel isolated and would appreciate more opportunities to socialize with other AccesSurf people.
- ☐ I need help to get out and socialize.

Feedback, remarks, or questions:

Was anything in this survey too difficult to answer?

If you would like to be entered to win a prize, please complete the information below:

Name:

Email:

–or–

Phone:

Submit

## Appendix VI: Study 3: PSAT Questionnaire and Probes

### Program Sustainability Assessment Tool

**Note:** The Program Sustainability Assessment Tool (PSAT), a set of 40 quantitative items, was developed by the Washington University, St Louis, Missouri. If you would like more information about the original framework or the PSAT, visit

(12). This work is licensed under a Creative Commons Attribution-Non Commercial Share Alike License.

This document contains the original PSAT items, plus open-ended probes that were developed by evaluators at the Center for Managing Chronic Disease, University of Michigan (10). *The instructions to respondents were tailored to the organization, AccesSurf Hawai'i, and the domain Political Supported updated to Environmental Support (as found in the literature).*

### You are assessing AccesSurf programs for people with disabilities.

In the following questions, you will rate your program across a range of specific factors that affect sustainability. Please respond to as many items as possible. If you truly feel you are not able to answer an item, you may select 'NA.' **For each statement, circle the number that best indicates the extent to which your program has or does the following things.**

| Environmental Support: Internal and external political environments that support your program | Response Categories    |   |   |   |   |   |                        |                    |
|-----------------------------------------------------------------------------------------------|------------------------|---|---|---|---|---|------------------------|--------------------|
|                                                                                               | To little or no extent | 2 | 3 | 4 | 5 | 6 | To a very great extent | Not able to answer |
| 1. Champions advocate for the program.                                                        | 1                      | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |
| 2. The program has strong champions with the ability to garner resources.                     | 1                      | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |
| 3. The program has leadership support within the larger organization.                         | 1                      | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |
| 4. The program has leadership support from outside of the organization.                       | 1                      | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |
| 5. The program has strong public support.                                                     | 1                      | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |

Probes:

- Who are your champions or advocates? In what ways do they advocate for the program (or have they advocated, or you hope they will do)? Can you provide an example?
- Describe the environmental/political support—or lack thereof—that exists within the organization. Include internal existing policies or recent or impending internal policy changes that support or impede the program's sustainability.
- Describe the environmental/political support—or lack thereof—that exists *beyond* the organization. Include *external* existing policies or recent or impending external policy changes that support or impede the program's sustainability.

| <b>Funding Stability:</b> Establishing a consistent financial base for your program | <b>Response Categories</b> |   |   |   |   |   |                        |                    |
|-------------------------------------------------------------------------------------|----------------------------|---|---|---|---|---|------------------------|--------------------|
|                                                                                     | To little or no extent     | 2 | 3 | 4 | 5 | 6 | To a very great extent | Not able to answer |
| 1. The program exists in a supportive state economic climate.                       | 1                          | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |
| 2. The program implements policies to help ensure sustained funding.                | 1                          | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |
| 3. The program is funded through a variety of sources.                              | 1                          | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |
| 4. The program has a combination of stable and flexible funding.                    | 1                          | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |
| 5. The program has sustained funding.                                               | 1                          | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |

Probes:

- Describe the current funding situation
- How will the program be funded after GIA funding ends?
- Describe your efforts to obtain funding, past and future.

| <b>Partnerships:</b> Cultivating connections between your program and its stakeholders | <b>Response categories</b> |   |   |   |   |   |                        |                    |
|----------------------------------------------------------------------------------------|----------------------------|---|---|---|---|---|------------------------|--------------------|
|                                                                                        | To little or no extent     | 2 | 3 | 4 | 5 | 6 | To a very great extent | Not able to answer |
| 1. Diverse community organizations are invested in the success of the program.         | 1                          | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |
| 2. Community leaders are involved with the program.                                    | 1                          | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |
| 3. Community members are passionately committed to the program.                        | 1                          | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |
| 4. The program communicates with the community leaders                                 | 1                          | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |
| 5. The community is engaged in the development of program goals.                       | 1                          | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |

Probes:

- What organizations or individuals are invested in the success of the program? Why?
- How do you see partner organizations or community members contributing to the sustainability of your efforts to improve care coordination?
- How important is it to have community leaders involved with or committed to the program?
- Are there partnership structures such as coalitions or networks created by the project that may be sustained beyond the GIA funding? If so, describe them.

| <b>Organizational Capacity: Having the internal support and resources needed to effectively manage your program and its activities</b> | <b>Response categories</b> |   |   |   |   |   |                        |                    |
|----------------------------------------------------------------------------------------------------------------------------------------|----------------------------|---|---|---|---|---|------------------------|--------------------|
|                                                                                                                                        | To little or no extent     | 2 | 3 | 4 | 5 | 6 | To a very great extent | Not able to answer |
| 1. The program is well integrated into the operations of the organization.                                                             | 1                          | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |
| 2. Organizational systems are in place to support the various program needs.                                                           | 1                          | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |
| 3. Leadership effectively articulates the vision of the program to external partners.                                                  | 1                          | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |

| <b>Organizational Capacity: Having the internal support and resources needed to effectively manage your program and its activities</b> | <b>Response categories</b> |   |   |   |   |   |                        |                    |
|----------------------------------------------------------------------------------------------------------------------------------------|----------------------------|---|---|---|---|---|------------------------|--------------------|
|                                                                                                                                        | To little or no extent     | 2 | 3 | 4 | 5 | 6 | To a very great extent | Not able to answer |
| 4. Leadership efficiently manages staff and other resources.                                                                           | 1                          | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |
| 5. The program has adequate staff to complete the program's goals.                                                                     | 1                          | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |

Probes:

- Describe the internal support and resources you currently have for this program, and how this will change after GIA funding ends
- Describe the strengths and weaknesses you see in terms of the organizational capacity to maintain this program

| <b>Program Evaluation: Assessing your program to inform planning and document results</b>              | <b>Response categories</b> |   |   |   |   |   |                        |                    |
|--------------------------------------------------------------------------------------------------------|----------------------------|---|---|---|---|---|------------------------|--------------------|
|                                                                                                        | To little or no extent     | 2 | 3 | 4 | 5 | 6 | To a very great extent | Not able to answer |
| 1. The program has the capacity for quality program evaluation.                                        | 1                          | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |
| 2. The program reports short term and intermediate outcomes.                                           | 1                          | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |
| 3. Evaluation results inform program planning and implementation.                                      | 1                          | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |
| 4. Program evaluation results are used to demonstrate successes to funders and other key stakeholders. | 1                          | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |
| 5. The program provides strong evidence to the public that the program works.                          | 1                          | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |

Probes:

- Describe how the program has used evaluation findings to strengthen the program and its sustainability
- Describe how you foresee the role of evaluation after GIA funding ends
- Who have you shared your evaluation results with?

| <b>Program Adaptation: Taking actions that adapt your program to ensure its ongoing effectiveness</b> | <b>Response categories</b> |   |   |   |   |   |                        |                    |
|-------------------------------------------------------------------------------------------------------|----------------------------|---|---|---|---|---|------------------------|--------------------|
|                                                                                                       | To little or no extent     | 2 | 3 | 4 | 5 | 6 | To a very great extent | Not able to answer |
| 1. The program periodically reviews the evidence base.                                                | 1                          | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |
| 2. The program adapts strategies as needed.                                                           | 1                          | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |
| 3. The program adapts to new science.                                                                 | 1                          | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |
| 4. The program proactively adapts to changes in the environment.                                      | 1                          | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |
| 5. The program makes decisions about which components are ineffective and should not continue.        | 1                          | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |

Probes:

- The questions above refer to the program as you have implemented it. Provide an example or two that demonstrates adaptability of your program.

- Did the EBIs you implemented (Yes We Can and/or ICAS) allow for adaptability? Please describe.
- How do you think the EBI's level of adaptability affects sustainability of your program?

| <b>Communications: Strategic communication with stakeholders and the public about your program</b> | <b>Response categories</b> |   |   |   |   |   |                        |                    |
|----------------------------------------------------------------------------------------------------|----------------------------|---|---|---|---|---|------------------------|--------------------|
|                                                                                                    | To little or no extent     | 2 | 3 | 4 | 5 | 6 | To a very great extent | Not able to answer |
| 1. The program has communication strategies to secure and maintain public support.                 | 1                          | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |
| 2. Program staff communicate the need for the program to the public.                               | 1                          | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |
| 3. The program is marketed in a way that generates interest.                                       | 1                          | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |
| 4. The program increases community awareness of the issue.                                         | 1                          | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |
| 5. The program demonstrates its value to the public.                                               | 1                          | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |

Probes:

- Describe your communication tools and strategies
- How important is it that the program demonstrates its value to the public?

| <b>Strategic Planning: Using processes that guide your program's direction, goals, and strategies</b> | <b>Response categories</b> |   |   |   |   |   |                        |                    |
|-------------------------------------------------------------------------------------------------------|----------------------------|---|---|---|---|---|------------------------|--------------------|
|                                                                                                       | To little or no extent     | 2 | 3 | 4 | 5 | 6 | To a very great extent | Not able to answer |
| 1. The program plans for future resource needs.                                                       | 1                          | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |
| 2. The program has a long-term financial plan.                                                        | 1                          | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |
| 3. The program has a sustainability plan.                                                             | 1                          | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |
| 4. The program's goals are understood by all stakeholders.                                            | 1                          | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |
| 5. The program clearly outlines roles and responsibilities for all stakeholders.                      | 1                          | 2 | 3 | 4 | 5 | 6 | 7                      | NA                 |

Probes:

- Describe the program's sustainability plan
  - How was it developed?
  - What does the plan entail?
  - Is the plan formalized in writing?
- Describe how you foresee the work of this program continuing after GIA funding.

## Final Questions

- How does the fact that you did not adapted an EBI (or EBIs), versus creating your own program from scratch, affect the sustainability of the work? When answering, consider the following factors that affect sustainability:
  - Political support
  - Funding stability
  - Partnerships

- Organizational capacity
    - Program evaluation
    - Program adaptation
    - Communications
    - Strategic planning
  - What practices, procedures, or social norms have changed due to the program? How will they be sustained after GIA funding?
  - This question is more reflective in nature. Overall, what have you learned (or done) about creating sustainable care coordination programs or improvements?
- Auhor (S.Schmid) ADDED
- 'Do you think you answers would have been different if weren't facing the COVID-19 pandemic?