

# 2017 WRITING CONTEST GRADUATE WINNER

## Physical Activity & People with Disabilities — A Qualitative Process and Outcome Pilot Evaluation of the Non-Profit Organization AccesSurf Hawai'i

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Her winning manuscript is entitled "Physical Activity & People with Disabilities — A Qualitative Process and Outcome Pilot Evaluation of the Non-Profit Organization AccesSurf Hawai'i." A growing number of studies suggest that physical activity can maintain and improve the physiological and psychological well-being of people with disabilities. However, there are only a limited number of studies that have tested interventions to increase physical activity for people with disabilities. This manuscript presents findings from

a qualitative process and outcome evaluation of the non-profit organization AccesSurf Hawai'i. The mission of AccesSurf Hawai'i is to provide ocean-based, sports activities to help children and adults with disabilities and to wounded veterans discover their abilities in the ocean.

### Abstract

Physical Activity (PA) is essential for the prevention of non-communicable diseases (NCD). The risk of developing NCDs is three times as high among people with disabilities than people without disabilities. In 2016, an estimated 158,570 people in Hawai'i had disabilities. So far, only limited studies have considered increasing PA opportunities for people with disabilities. AccesSurf is a non-profit organization empowering people with disabilities to perform adaptive swimming and surfing. The purpose of this study was to conduct qualitative process and pilot outcome evaluation of AccesSurf. A focus group was conducted to explore the perspectives of six AccesSurf participants on AccesSurf's process, participants' outcomes, and suggestions. Participants were individuals with neurological health conditions, aged between 30 to 64 years. The analysis followed a deductive-inductive approach. Focus group participants reported on process variables, such as the positive environment and the provision of a range of PA opportunities (eg, adaptive swimming & surfing, stand up/outrigger/va'a paddling, kayaking, and surf skiing). They recognized AccesSurf's positive contribution to their physical, mental, and social health. Participants not only felt empowered through AccesSurf, but also increased their PA frequency and built athletic identities. A comfortable environment and provision of a variety of opportunities for participants were identified as advantageous AccesSurf outputs, fostering progressive short- and long-term outcomes that result in life-changing effects. This research shows that AccesSurf may play an important role towards increasing PA among participants.

### Keywords

Physical Activity, People with Disabilities, Neurological Impairments, Spinal Cord Injury (SCI), Adaptive Sports, Aquatic Exercise, Focus Group, AccesSurf Hawai'i.

### Introduction

As physical activity (PA) is declining, the burden of non-communicable diseases (NCDs) increases.<sup>1</sup> It is predicted that by 2020, seven of ten deaths will be caused by NCDs.<sup>2</sup> PA improves well-being<sup>3</sup> and quality of life (QoL),<sup>4</sup> and hence can reduce the existing NCD health burden and its risk factors. Despite the increase in PA promotion and efforts for the general population, there are limited options for people with disabilities to be physically active.<sup>3</sup> The Centers for Disease Control and Prevention (CDC) emphasizes that the World Health Organization's (WHO) PA guidelines are for everyone, including people with disabilities.<sup>5,6</sup> The CDC defines adults with disabilities as those "with serious difficulty walking or climbing stairs; hearing; seeing; or concentrating, remembering, or making decisions."<sup>5</sup> The risk of developing NCDs is three times as high among people with a disability compared to people without a disability.<sup>5</sup> Worldwide, about 15% of the population have some sort of health condition causing disability.<sup>7</sup> Within the United States (U.S.), about 21 million adults aged 18-64 years (6% of the total U.S. adult population) have disabilities with nearly half of these (11 million) engaging in no leisure time PA (PA outside of school and work).<sup>5</sup> In 2014, about 9% of Hawai'i adults had a mobility disability, 2% reported a self-care disability, and 6% required a device.<sup>8</sup>

Community-based aquatic activities for people with disability amongst U.S. adults<sup>9</sup> showed an increase in their QoL.<sup>11</sup> Aquatic

activities provide moderate aerobic PA,<sup>10</sup> and improve motor skills in people with disability.<sup>11</sup> Adaptive Surfing is a type of aquatic exercise described as novel physiotherapy that increases both inclusion in society and disability awareness.<sup>12</sup> AccesSurf (described in following paragraph) uses the term “adaptive” to refer to the act of modifying equipment and/or the way in which a person surfs to accommodate the skills/ needs of a participant with disability. Only a few studies on aquatic adaptive sport are available,<sup>13-17</sup> with two pilot studies investigating adaptive surfing.<sup>13,17</sup> Surfing is a sport performed discontinuously, with about 50% of the time spent paddling.<sup>18</sup> However, there is a lack of research on the effectiveness of adaptive sports, especially adaptive surfing, providing PA for people with disabilities.

AccesSurf ([www.accessurf.org](http://www.accessurf.org)) is an established and experienced non-profit organization, based on O’ahu, whose mission has been to “empower people with physical and cognitive disabilities through accessible water programs” since 2006.<sup>19</sup> To fulfill their mission, AccesSurf has established several free programs for participants that are mainly volunteer-run including Day-at-the-Beach (DATB) and Wounded Warrior DATB. DATB is the main monthly program run at their base location, White Plains Beach Park, on O’ahu. Each event assists up to 140 participants to perform ocean activities, such as floating, swimming, and surfing. The Wounded Warrior DATB is limited to participants who are affiliated with the military. Since 2014, AccesSurf added swim and surf clinics to their programs, which are run at different local pools and beaches. AccesSurf established an adaptive surf team in 2016. Duke’s Oceanfest is an annual month-long fest that consists of many competition days for a variety of ocean sports, including surfing, paddling, swimming, and others to honor Duke Kahanamoku, the Hawaiian water legend. The Hawai’i Adaptive Surfing Championships is a program of AccesSurf that has been held yearly since 2007 in collaboration with the Duke’s Oceanfest (also known as “Duke’s”) to offer a week-long elite adaptive surfing competition that highlights the international, national, and local adaptive surfing community.”

In 2016, AccesSurf provided 50 formal events with 1315 registered participants (having one to multiple water experiences per event) and 2795 registered volunteers. The set-up of all programs is not permanent. AccesSurf stores and brings all needed equipment to the beach, thus creating their slogan—an “Ocean of Possibilities.”<sup>19</sup>

The objective of this study was to provide a programmatic evaluation of AccesSurf’s adaptive surf program by examining organizational outputs and participant level outcomes.

## Methods

This is a qualitative programmatic analysis using a focus group design to evaluate the aquatic program by AccesSurf.<sup>20,21</sup>

The recruitment criteria included participants who had a neurological health condition and were regularly involved with more than one type of AccesSurf event. A focus group (FG) of six people was desired to include a diversity of participants and information provided, yet small enough to create

an environment where participants feel comfortable sharing their thoughts, opinions, beliefs, and experiences. Purposive and snowball sampling<sup>22,23</sup> were used to over-recruit by at least 20% of intended minimum participant numbers. Therefore, we planned to recruit eight individuals to have at least six FG participants.<sup>24</sup> AccesSurf’s Executive Director facilitated the initial introductions with selected candidates. Email invitations were sent to selected AccesSurf participants during August 2015.

Two guiding questions creating a comprehensive structure suggested by Gläser and Laudel<sup>25</sup> were combined with the four steps “gather, review, sort, order” method by Helfferich<sup>26</sup> to develop the FG guide. The FG guide was adjusted in collaboration with AccesSurf’s Executive Director after piloting it with an AccesSurf volunteer.

The meeting room used for the focus group was chosen because of its relaxed atmosphere and wheelchair accessibility. The FG set-up was a circle and refreshments and snacks were available. The FG was facilitated in September 2015, lasted 120 minutes and was recorded by four devices. The FG was transcribed and de-identified.

FG participants gave written and oral consent. The University of Hawai’i at Manoa (UH) Institutional Review Board approved this project. The FG transcription was coded using MAX QDA 12 (VERBI GmbH; Berlin; Germany)<sup>27</sup> software following a deductive-inductive approach. A mix of deductive and inductive<sup>28</sup> analysis approaches were used, especially because of the study’s evaluative purpose to identify and possibly conceptualize program process and outcomes.<sup>29</sup> A deductive approach is relatively narrow and top-down, using and applying a code system, based on a theory to the content.<sup>30</sup> An inductive approach allows for codes beyond preset categories. Therefore, we used a mix of both approaches to maximize the advantages of both,<sup>29</sup> having categories for orientation in mind, but not limiting the analysis to those. Five deductive categories were identified prior to coding and inductive “free coding” was used while coding (unlimited initial coding).<sup>31</sup> This combination allows the analysis to be rather more “explorative” and “open-ended” than a pure deductive approach.<sup>30</sup>

## Results

Eight out of eight program participants agreed to be in the FG, however, due to time constraints only six were able to participate (Table 1). They ranged in age from 30 to 64 years; 50% were women, and they participated at AccesSurf between 12 months to 10 years. Four participants had Spinal Cord Injury (SCI) and two had other forms of neurological health conditions. Participants had their conditions either from birth (one), or between seven to 44 years (five) (Table 1). All participants participated at the main event DATB, one also at the Wounded Warrior DATB, five participated at AccesSurf swim clinics, three participated in surf clinics, and all competed at Duke’s.

The main results based on the emerging theme categories gave insight into key participants’ perceived AccesSurf’s process, participants’ outcomes, and suggestions for AccesSurf. Overall, there are 12 main themes, with six total themes for

Table 1. Description of 2015 Focus Group Participants			
Participant Number	Neurological Health Condition Resulting in Motor Impairment	How Long Participated	AccesSurf Activities
P-1	Spinal Cord Injury (SCI) incomplete**	1 year	Surfing, Swimming; Competition, Volunteer committee
P-2	Charcot-Marie-Tooth (CMT)*	1.5 years	Surfing, Swimming; Competition
P-3	Quadriplegic**	1.5 years	Surfing; Competition
P-4	SCI T-4**	10 years	Surfing, Swimming; Competition
P-5	Spinocerebellar ataxia type 6*	1 year	Surfing, Swimming; Competition
P-6	Paraplegic*	> 3 years	Surfing, Swimming; Competition

Table 2. AccesSurf's Process and Outputs
<p><b>1) Positive atmosphere – AccesSurf organization and first-timers</b></p> <ul style="list-style-type: none"> <li>- 'AccesSurf is all about the 'Ohana' (...) you belong to something, to somewhere'.</li> <li>- 'It's just people like you, or some people worse than you, but they have the best smile on their faces (laughs), because of AccesSurf'.</li> <li>- '(...) Now, we have this whole network of people that talk to each other through Facebook or whatever. (...) There is this whole community, here, that I am part of.</li> <li>- '(...) there is a whole culture of surfing that we are now part of, and that has something to do (...) [with] having to prove ourselves'. 'AccesSurf makes it pretty darn easy. You just show up and get in [the water, surf, swim]'.</li> <li>- '(...) I came from XY you know, where a disabled person, is very looked down, and there is (...), there is nothing like AccesSurf, back home, where you feel like you relate to someone (...) whole time (...) I was isolated. (...) I was ashamed, I did not want anybody to look at me'.</li> <li>- 'I was always active, tried to stay physically fit, tried to swim laps, I was a lap swimmer, it was a very solitary activity, I was by myself and, guess, I had stopped, going to the beach, because it was hard to get in'.</li> <li>- 'I took a picture of it (...) you never see the handy van at the beach'.</li> </ul>
<p><b>2) Opportunities</b></p> <ul style="list-style-type: none"> <li>- 'We [surfers and especially with disabilities] are in this little tiny niche, and unless we get a chance to get together somehow, and I know internet helps, Facebook helped a lot but, this is the opportunity to see somebody like yourself and get inspired by them, because every disability is different. Everybody with a disability has a unique case, but you can come close, and then you can learn, from each other, I am sure there are things I can teach XY, but, he's definitely taught me some stuff, (...) that is the type of thing, that I would not have the opportunity without AccesSurf'.</li> <li>- '(...) I would say that getting into the ocean, is, oh gosh, I would go once a year down to (...), because they had a special day, (...) now, it is at least one day a week, a month with DATB, and then there's chances to go, with this surf team, adaptive surf team, that adds about two to three days a month I guess, and then on our own, we are going (...) every morning (...)'.  <li>- 'I had an old beater of it, that I used as a spare. That is when I went out and I bought wide tires (...). It was really, it was a good suggestion, they explained it (...) you have to have something to get over the stretch of sand here, and this is what we do. So I, learned from other people'.</li> </li></ul>
<p><b>3) Enjoyment and excitement: Fun</b></p> <ul style="list-style-type: none"> <li>- 'When is the next day?'. '(...) it is always so fun'; afterwards it was (...) so much fun (...)'.  <li>- '(...) it is more fun (...) and I really, I am enjoying the social part of it, too'.</li> <li>- '(...) as much fun, as we do'.</li> </li></ul>
<p><b>4) AccesSurf volunteers</b></p> <ul style="list-style-type: none"> <li>- 'It is like, so wonderful, and even the volunteers feel like, like they are so happy, to be there, so happy to help you, it gives them joy to help you'.</li> <li>- '(...) I feel comfortable, and the volunteers are over the top. And that's why I think, they volunteer there. None of them are getting paid, they do not have to be there, if they do not want to, they all choose to be there, and they all want to be there'.</li> <li>- 'I remember, driving to Waikiki [I] was terrified, I kept saying: "There is volunteers there, nobody is going to let you drown"'.</li> </ul>
<p><b>5) Natural settings and type of activity: Surfing</b></p> <ul style="list-style-type: none"> <li>- 'I think the type of sport that was picked, makes a whole big difference, because there's a lot of adaptive sport programs, but surfing has something special about it'.</li> <li>- '(...) recreation or whatever, in natural settings is like one of the most desirable settings to be in, with a disability, but also the (...) hardest setting to be in'; '(...) the goal, to have choice in natural settings and AccesSurf provides that into surfing. Because surfing cannot, well I guess it could be simulated, but simulated in those wave pools (...) it is not the same in surfing, you can be on the biggest part, these levels, these waves, you can be on the biggest wave and it is not the same as being on the smallest wave in Hawai'i in natural settings, there is a difference about that'.</li> <li>- 'There is a big difference between going into a pool, swimming pool, and swimming laps, where you basically set your own pace, you can push yourself or not push yourself, you have that choice. When you get into surf at White Plains and those waves are coming at you, you don't have any more choice, you are, you are in nature and nature is in charge and it pushes you really hard'. (...) You have to. It is like being on a water treadmill, and you do not get to set the pace, so it is a totally different thing, than any form of exercising (...) nature, is very powerful, and you have to deal [with it]'.</li> </ul>
<p><b>6) Duke's Oceanfest</b></p> <ul style="list-style-type: none"> <li>- 'Dukes, this year, on the Thursday, cause all we adaptive(s) [athletes] had the whole Queens for, what, 8 hours?'</li> <li>- 'My favorite moment was the, at Duke's Fest, when they had the awards and when they had us all, in front of that stage, and XX took that photograph of all of us together. That to me was amazing, the feeling of 'Ohana and togetherness, and just, we had accomplished that'.</li> </ul>

Table 3. Participants' Outcomes and Effects
<p><b>1) Immediate outcome</b></p> <ul style="list-style-type: none"> <li>- 'I have more freedom, cause, when I am walking, I got to hold my crutches, use my crutches, but once I get to the water, (...), I get on my board and (...) I paddle out and it is like, I am free. I do not have to worry about my crutches, or wheelchair (...).'</li> </ul> <p>Participants also reported on their enjoyment while participating, such as having fun:</p> <ul style="list-style-type: none"> <li>- 'I get to have just fun with all my friends out there, and we're not worrying about any disabilities, we are just out there having fun, catching waves (...).'</li> </ul>
<p><b>2) Long-term outcome</b></p> <p><b>a) Physical outcomes</b></p> <ul style="list-style-type: none"> <li>- 'I was not going to the beach, because I could not get in the water by myself'.</li> <li>- It helps me with transfers, I can transfer out of my regular tub (...) transfer is one, has definitely changed, and cause, we are transferring off the ground, we are transferring into different chairs, into our boats (...) and surfboards, we are doing a lot of transferring, and we are getting good at it'.</li> <li>- I am not bed-ridden like the neurologist said. It is not curing me, but it is prolonging my disability, where I can move and still be active'.</li> </ul> <p><b>b) Mental outcomes</b></p> <ul style="list-style-type: none"> <li>- 'It helped me with my social anxiety. I used to be, like even in this group, I used to fear sitting here and speaking talking to everybody. But going there [to AccesSurf], I see everybody, and [I] talk to different people, it made it easier, to keep going.'</li> <li>- (...) problem solving, finding the minds, I mean a lot of things, you become trained in (...) adaptability' (...) that is a positive thing, (...) I am involved, in the waveski or swimming with AccesSurf, that gives me inner good health, to be honest I have never been so healthy. (...) stronger, too'.</li> <li>- 'I kind of take that, philosophy and kind of apply that in my life, like, pursuing a doctorate in occupational therapy, or living out[side] of county, or whatever, things that I did. It repeats itself in all my life through all of those things, and AccesSurf was kind of the platform for me to jump into that, (...) I was able to apply that to other aspects of life'.</li> <li>- 'a platform you can launch off to be more independent' (...) 'Going by ourselves'</li> </ul> <p><b>c) Social outcomes</b></p> <ul style="list-style-type: none"> <li>- 'I feel like I have a much healthier relationship with my kids, and even with my family, because I am not always at home, I have something to look forward to'.</li> <li>- '(...) being that auntie that I am, I want to take all my nieces and nephews, which I have six of them, to surf and AccesSurf (...) made that possible. I was able to bring my nephew four times now, and I hopped in the water with him surfing, (...) and even my nephew with autism, which I would not be able to handle alone, (...) and even with my other nephew, who is older, who helps carrying me into the water, I am out there in the water surfing with him. And he is like that is my auntie. And you know he is super proud. (...) AccesSurf has made it so much easier for me to pass that love of the ocean down to my nieces and nephews (...), and may be even kids.'</li> <li>- '(...) when you go out to Queens break and you want to catch your wave, you got people there, they know what they are doing, they have been there a long time, and you better learn how to deal with them, too. So, it's a lot of, becoming part of the community (...).'</li> </ul>
<p><b>3) Effects</b></p> <p><b>Change, empowerment</b></p> <ul style="list-style-type: none"> <li>- 'I have an adult daughter and she's - it's sweet - she is very proud of me'.</li> <li>- 'I got a lot of stuff on my Facebook page, from people who knew me before [the injury; surfing], (...), and now, they see my surfing pictures on my [Facebook page], I get comments all the time.'</li> <li>- 'In getting stronger, getting more confident, may be not doing the tandem, may be, going on their own, or trying a new piece of equipment, they are doing more, where they get their own board (...) or you can hear stories of them, going out on their own.'</li> </ul> <p><b>Life-changing</b></p> <ul style="list-style-type: none"> <li>- 'I know my life, well, 12 months ago, was completely different, to what it is now, I was (...) And then I started surfing, and now today (...). Surfing has taken over my life, it's taking over my life cause I surf, I compete, I have some sponsors, I travel, I surf (...).'</li> <li>- That was a barrier for me, to just overcome that barrier of what happened, and AccesSurf made it a lot easier, and it broke that barrier (...); 'For me, I am getting out more by myself, in the ocean, the waveski (...) I get the coolest, I get recognized, because of the board, because of what I am going in the water with. For people to ask, what is that, it makes you like be happy to share; besides the team training, I get out in the water, two to three times in the week. Because I'm in the Hawai'i Team, going to represent (...).'</li> <li>- 'The experience at Duke's Fest is a transformation because you see people from all over the world. And I saw a guy, I didn't really think I can do wave skis, till I met XX. And he has a high level injury like I do, and I always felt like, oh well, you have a high level injury, forget it. I'm not gonna have the trunk stability, you're not gonna be able to control the board while you are going out and to be able to catch the waves. He has this method that he just parks his paddle when he gets on the wave, he grabs the board and he just muscled it (...) I would think I can do this, I am looking ahead now, I see hills in the distance I can climb, because of Duke's Fest'.</li> </ul>

process and AccesSurf outputs (three for process and three for outputs; Table 2), three for outcomes and effects (Table 3), and three for suggestions referred to as a “wish list.”

FG participants observed AccesSurf as an “*organization pretty big for this island*” [P-1] and for example as “*the best program, I have ever been involved with*” [P-2], where they “*cannot wait for the next time*” [P-2] (Table 2). FG participants perceived certain activities, emerged in six themes, as important factors during AccesSurf events and process, which can be considered as AccesSurf output(s). As shown in Table 2, these themes are the following: (1) Positive atmosphere – AccesSurf organization and first-timers; (2) Opportunities; (3) Enjoyment of and excitement about AccesSurf: Fun; (4) AccesSurf volunteers; (5) Natural settings and type of activity: Surfing; and (6) Duke’s.

Half of the FG participants declared an experience at Duke’s as their favorite moment [P-1, P-2, P-5] and several participants especially liked that their activities were photographed, which was expressed in comments like “*we have a picture*” [P-6] and “*we documented it*” [P-1]. P-2 and P-1 emphasized that Duke’s is an event where you can meet idols of adaptive athletes. (Table 2; Figure 1).

Three main participant outcome themes emerged: (1) Immediate and (2) Long-term physical, mental, and social outcomes, and (3) Effects (Table 3). All participants felt immediate outcomes, from the first time they participated and each time they returned. Advantageous opportunities provided by AccesSurf are, for example, the option to participate, getting to the beach and into the water, support for water activities, to experience

freedom in the water versus the land environment, making equipment and expertise available beyond actual events, having fun, and relating to other participants and volunteers. There was agreement amongst all participants that they feel 'different' before and after they participate in an AccesSurf event, such as a DATB [P-1 to P-4]. This was very clearly expressed by the phrase 'Every time!' [P-4]. P-5 whose only way of moving around on land is using crutches, reported an instant feeling of "being free."

All six FG participants reported as long-term outcomes that their physical, mental, and social well-being and health, have improved since participating at AccesSurf (Table 3). FG participants reported that they improved their strength, endurance, and flexibility. Before participating at AccesSurf they were either unable to enter the water or had a very hard time to do so and now they can enter the water. Thus, AccesSurf not only provides the opportunities to help with water transfer at event days, it helped FG participants to learn to access the water outside of AccesSurf. They claimed that their participation also improved daily activities outside of AccesSurf, such as transfers, and walking with fewer walking aids. For example, P-6 stated "When I first joined AccesSurf I used two crutches (...)," but reported since participating at AccesSurf, she reduced her use of walking aids to one crutch instead of two. P-5 is also convinced that AccesSurf helped him to fight his diagnosis by delaying the worsening of disease symptoms. Beyond physi-

cal improvements, one participant [P-2] called AccesSurf her "mental health", while other participants described a decline in social anxiety [P-5] and stress [P-6], and an all participants agreed on increase in self-confidence and independence. For example, P-2 is no longer embarrassed to crawl into the water, stating "AccesSurf is giving me the courage to say "yes, I can do it (...)." The translation of this 'can-do-it' mindset and increased self-confidence in other areas of life was also conveyed by a participant who reported replacing her shower with a bathtub [P-4].

Participants explained how they implement what they learned at AccesSurf in their lifestyle. AccesSurf helped participants with their relationships within their families, friends, and among the community (social outcomes). Participants also reported changes that family or others observed in them as well as change they see in others. Participants reported that their families were proud of them (effects) and that "My life was the same, it's just now I'm including surfing, which is a life-changer" [P-4]. The comment, "It's like, every time you do it, it gets better, it gets easier" [P-2] can be considered for each sub-theme as well as collectively. Coming to an event, participating and the activity itself gets physically and mentally easier with each practice.

Long-term outcomes and effects, such as change, empowerment, and life changes including motivation requires a participant to be a returning participant (Table 3; Figure1).

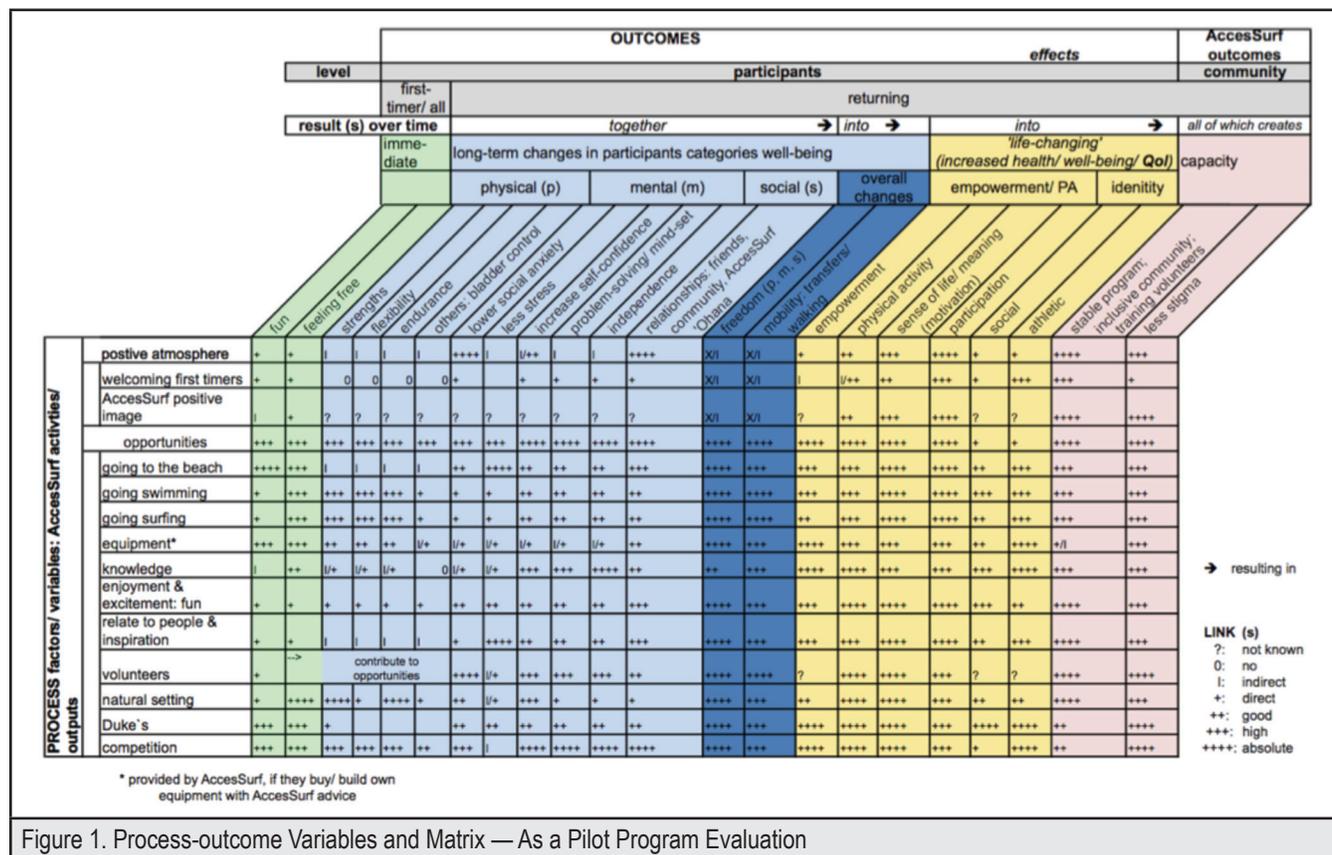


Figure 1. Process-outcome Variables and Matrix — As a Pilot Program Evaluation

The participants' wish list were divided into three categories: (1) Extension within existing programs for AccesSurf in general and in clinic (eg, training family members and caregivers), and DATB (eg, buddy-system, adding canoe); (2) Extension beyond existing programs, including location such as other beaches and islands; and (3) Outreach such as promotions about AccesSurf at schools.

While the intention was to present the process and outcome variables separately, they overlap. Figure 1 is a matrix of the reported process (vertical) (Table 1) and outcome (horizontal) variables (Table 3). It aims to visualize the relationship between both. Putting the variables of participants' perceived AccesSurf processes in relation to the outcomes (immediate and long-term) the following relationship(s) can be anticipated. There is either no direct link (0), there is an indirect (I) or a direct link (+) with different intensity: (++) good, (+++) high and (++++) absolute, or not given (?). Repeated participation can result (→) in overall changes (freedom and mobility) and effects that are life-changing: Empowerment/PA (empowerment, increase in PA, sense of life/meaning/participation), identity (social and athletic), and capacity (inclusive program and stigma reduction). Athletic identity was not considered in the original concept of this research question; it arose from the discussion as an important outcome and is therefore included here, and the same principle applies for stigma. Factors considered as AccesSurf outcomes are changes that participants mentioned relating to improvements within the community and not the individual participant level. This framework can help structuring and deepening future findings within the effects of adaptive surfing.

## Discussion

This study evaluated the process, outcomes, and recommendations of an aquatic program for individuals with disabilities in Hawai'i.

### Process and Outputs

Participants enjoyed being at AccesSurf events, spoke very highly of AccesSurf, were very appreciative of the service, and hesitant to voice any suggestions as it could be received as critique. Together, the atmosphere and opportunities for volunteer support and access to equipment, provided a positive experience for participants. The natural settings of AccesSurf venue(s) enhanced the benefits. For most participants, their first time at AccesSurf and Duke's were very meaningful events. Coming to AccesSurf has opened up a new world for participant where there are people like 'them', having fun and being happy, and wanting to return to AccesSurf. At Duke's, they not only related to others and became inspired by adaptive athletes, but they also competed and had a sense of belonging to AccesSurf and its 'Ohana (family). Duke's is strongly linked with the life-changing theme. The way participants presented both themes, Duke's and life-changing, underline an athletic identity as being salient to the participants.

## Outcomes and Effects

Participants also reported on their improved elements of well-being and overall changes through participating at AccesSurf. Having fun and "feeling free" are immediate participant outcomes, whereas physical, mental, and social long-term outcomes are experienced through repeated participation at AccesSurf. Participants reported physical improvements such as strength, endurance, flexibility, and bladder control. Mental improvements mentioned were lower anxiety and stress, greater self-confidence and independence. The feeling of greater independence could be due to improvements in all elements of well-being. Social well-being was described as having been increased through building and improving relationships. AccesSurf has helped participants to "fulfill" their social role as an aunt or mother, while building new friendships and becoming part of the AccesSurf 'Ohana. As a result of physical, mental, and social improvements, participants experience change(s) in themselves and others. Participants experience greater freedom in multiple ways and mobility improved by either enhanced transfer skills or walking ability, needing fewer walking aids.

Effects were outcomes that had a "life-changing" impact. Whereas some experiences might be fun and life-changing during the early stage of participating at AccesSurf, overall a participant needs to not only return to AccesSurf, but to become a regular and core participant to gain maximum benefit for their well-being and health. One perceived change and one effect are freedom and empowerment. Freedom is created by AccesSurf from lower to higher levels, for example, from the instant feeling of freedom on entering the water without a wheelchair or crutches, to a sense of freedom overall. The sensation of feeling free is reinforced by the increase in physical and mental strength, AccesSurf support, and they experience an enhanced sense of freedom through the feeling of empowerment. Empowerment is understood by Page & Czuba as a multi-dimensional social process helping to increase the control over their own life.<sup>32</sup> FG participants have the strong belief that they and others were empowered through AccesSurf, not only by participating in AccesSurf events but also by attending events outside of AccesSurf in groups or even by themselves, which provides freedom of choice. AccesSurf also provides knowledge through experienced staff, volunteers, and other participants on equipment and best sample practice on programming.

FG participants reported being more active and motivated than before their participation in AccesSurf. Surfing counts as a moderate physical activity.<sup>7</sup> Others argue that surfing is a vigorous physical activity due to the natural setting and to the heart rates achieved during paddling.<sup>33</sup> Frequent adaptive surfers meet the PA guidelines to be sufficiently active.<sup>34</sup> As reported by the FG participants, adaptive surfing helps them with their physical and mental well-being, and it may prevent secondary diseases, especially NCDs, which have a higher prevalence amongst people with disability due to lower activity.<sup>5</sup>

Our study design cannot answer which came first: the increased inclusion or the physical activities component. The fact is that they not only benefit each other, but also improve QoL.

McVeigh and colleagues<sup>35</sup> found that participation in sports after SCI significantly correlated with increased community integration and QoL. During AccesSurf events, participants can meet and relate to one another, and build friendships and support groups. AccesSurf strengthens community integration and improves QoL. Similar to our results, increased QoL was also found by two other studies not limited to SCI.<sup>10,16</sup> They found increased QoL within adults with disabilities participating in community-based aquatic activities and that adaptive sport programs positively improved family, social life, QoL, and overall health. Further research should investigate if the benefits are with QoL overall, or with sub-domains of QoL, namely environmental, psychological, and social relationship domains.<sup>14</sup>

The positive results were associated with reduced anxiety, which was also described by our FG participants. It was further reported that programs including family members increase the quality of family life. AccesSurf participants reported that family life improved not only for those whose family participated in the program, but also for those who participated by themselves. The results align with adaptive sport programs in general, and Lopes<sup>12</sup> who claimed that surfing helps with physical, mental and social rehabilitation, empowerment, and social integration. In the Lopes study, the limiting factor was the number of events per year, which was reported as five. AccesSurf provides more than twice as many events for everyone each year, with additional events for certain groups.

While Kissow<sup>35</sup> did not find any evidence that learned aspects of sport participation can be transferred to other contexts of life, FG participants reported that they were able to use what they learned through AccesSurf in their personal lives, such as a positive mind-set and self-confidence, allowing them to travel. One participant reported that she moved off island and out of the country for some time. Although surfing is an individual sport, participants reported the same benefits as team sports,<sup>37</sup> due to the setting of AccesSurf and its inclusive community counteracting stigma. Participants had been suffering from isolation and negative stigma, whereas now they felt part of the AccesSurf 'Ohana, where everyone is treated equally.

The high involvement of FG participants in AccesSurf, led to them discussing and mentioning aspects of the team, Duke's and life-changing, which led to the concept of identity, and ultimately athletic identity. All participants are returners and considered as not only regular but core participants, but this was not a recruitment criterion and happened by chance. It emerged within the analysis that all participants are athletes, as they all compete. AccesSurf enhances factors for building, regaining or strengthening identity, such as choice, freedom, and social inclusion.<sup>37</sup> Gill emphasizes the strong connection to integration within identity development.<sup>38</sup> Participants reported gaining freedom on different levels through participating at AccesSurf. Furthermore, it is a stable platform providing freedom and hope, which are important factors for identity. Overall participants reported that they gained their identity through activities such as performing sports, travelling, studying, and working. Ac-

cesSurf provides options for being physically active, and also for becoming an athlete. Individually or together, these options can be considered as giving participants a purpose. Athletic identity is an essential factor assisting in the adjustment and dealing process.<sup>37</sup> Hawkins also emphasized that rehabilitation and participation in sport should aim to directly build on, for example, a person's pre-injury athletic identity.<sup>37</sup> Thus, starting adaptive sports should be done as early as possible. However, with an acquired health condition such as SCI, trauma needs to be considered. Tasiemski and Brewer report on low and high athletic identity.<sup>39</sup> The trend towards an increased athletic identity through AccesSurf is evident in all participants, and is potential for further research. For example, participants acknowledged increased athletic identity by referring to themselves as adaptive (independent) surfers, their involvement with surf competitions (Duke's), the team, and the experience as life-changing events. It was important to them that their achievements and successes were documented by pictures, which was meaningful to all of them. All these elements help to build athletic identity.<sup>38</sup> The wish-list item of more coaching for themselves and others, shows how much they want to strengthen their own athletic identities and those of other AccesSurf participants. Tasiemski and colleagues<sup>40</sup> not only refer to athletic identity in people who perform sport on a competitive level, they also refer to it to people who participate in sport regularly. Therefore, athletic identity might be developed in more than the competitive participants. This needs further investigation within AccesSurf; it would be very beneficial to participants, as athletic identity is known to be more empowering than disability identity,<sup>36</sup> and can facilitate a life-long adjustment to disability.<sup>37,38</sup>

### Participants Wish List

Participants were reluctant to make suggestions for improving AccesSurf. It was only once the suggestions were called a "wish list" that participants slowly started to make recommendations.

One suggested *wish* was that AccesSurf facilitate more freedom and empowerment by going to different beaches or having a permanent location. Familiarization with a new beach within an AccesSurf event not only makes it accessible for one event, but "opens" that venue for independent usage. Having a permanent location such as a clubhouse or a storage facility close to the coastline where they could store equipment and go surfing independently without having to bring equipment, had immense meaning for participants, fulfilling the *wish* for a 'home base' would facilitate being amongst peers more often.

### Strengths and Limitations

A strength of this study is its qualitative approach which enabled the exploration of participants' perspectives. The use of the software MaxQDA allowed for a more thorough and systematic analysis. With six participants and a duration of two hours, the FG is considered well-designed.<sup>41,42</sup> A balance of heterogeneous and homogeneous elements is suggested for FGs<sup>24</sup>. The FG participants were a homogeneous group in terms of being AccesSurf participants and having a neurological health condition resulting

in disability, which may limit generalizability. However, they were heterogeneous regarding their age, gender and effects of the health condition on for example the type and level of motor impairments. The setting and environment were appropriate,<sup>43</sup> and multiple recording devices in different locations ensured accuracy of reporting the FG discussions.

Qualitative methods are specifically appropriate for evaluation where program processes and outcomes are general, or not defined.<sup>29</sup> This is the case for AccesSurf, where overall goals are unspecific, and detailed goals need to be determined for future evaluation purposes.

The collaboration with AccesSurf allowed additional insight into community-based adaptive aquatic sports. It also supported identification of and access to participants to describe their different perspectives. The involvement and attendance of the Executive Director was advantageous in accessing participants' perspectives. Researcher bias due to a pre-existing collaboration with AccesSurf and participants speaking "for their organization" also may have introduced social desirability and some researcher analysis bias. Generalizability is limited due to the small number of individuals participating and the characteristics of the participants who all became competitive surfers and the use of only one FG. Conducting additional FGs would have resulted in higher quality; however, personnel resources were limited. The results need to be treated with caution, and confirmed, especially for participants with recent onset of disability.

### Recommendations

Factors and areas emerged from this study are possible parameters for future evaluation purposes to not only identify, but also create and implement research-based outcome measures for adaptive sports and surfing, also as a tool for inclusion. Within research it is important to visualize the need for research and exchange between researchers and representatives of local communities with the focus on people with disabilities and adaptive program designers.

### Conclusion

A comfortable environment and provision of a variety of opportunities for participants were identified as advantageous AccesSurf outputs, fostering progressive short- and long-term outcomes that result in life-changing effects. There is a strong belief amongst FG participants that participating at AccesSurf has improved their mental, physical, and social well-being. The FG participants not only feel empowered through AccesSurf in multiple dimensions, but have also increased their PA level in terms of frequency and built athletic identities. The study shows that programs such as AccesSurf can play an important role towards improvement within PA for people with neurological health conditions resulting into disabilities in Hawai'i, while also creating an inclusive community and counteracting stigma.

### Conflict of Interest

None of the authors identify any conflict of interest.

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