

A scenic view of a coastline with a lighthouse on a cliff under a blue sky. The lighthouse is a small, cylindrical structure with a dark top and a white base, situated on a grassy cliff overlooking the ocean. The sky is a deep blue with some light clouds. The foreground shows a rocky coastline with some sparse vegetation.

INCLUSIVE RECREATION AND LEISURE
UMass Rural Health Scholars

OUTLINE

INTRODUCTION

SCOPE

BACKGROUND

METHODS

RECOMMENDATIONS

A wide, sandy beach with a path leading to the ocean under a cloudy sky. The path is made of sand and has some tracks on it. The ocean is on the right side of the image, and there are some trees and bushes on the left side. The sky is overcast with grey clouds.

INTRODUCTION

WHO ARE WE?

Rural Health Scholars UMass Medical and Nursing Students



Alex Cole
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Cathleen Cuddihy
NP Student
Rochester, MN



Wendy Haynes
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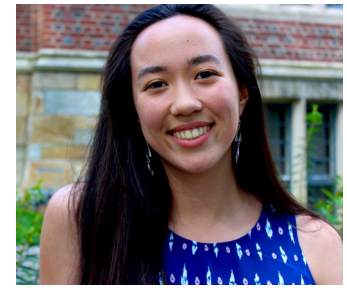
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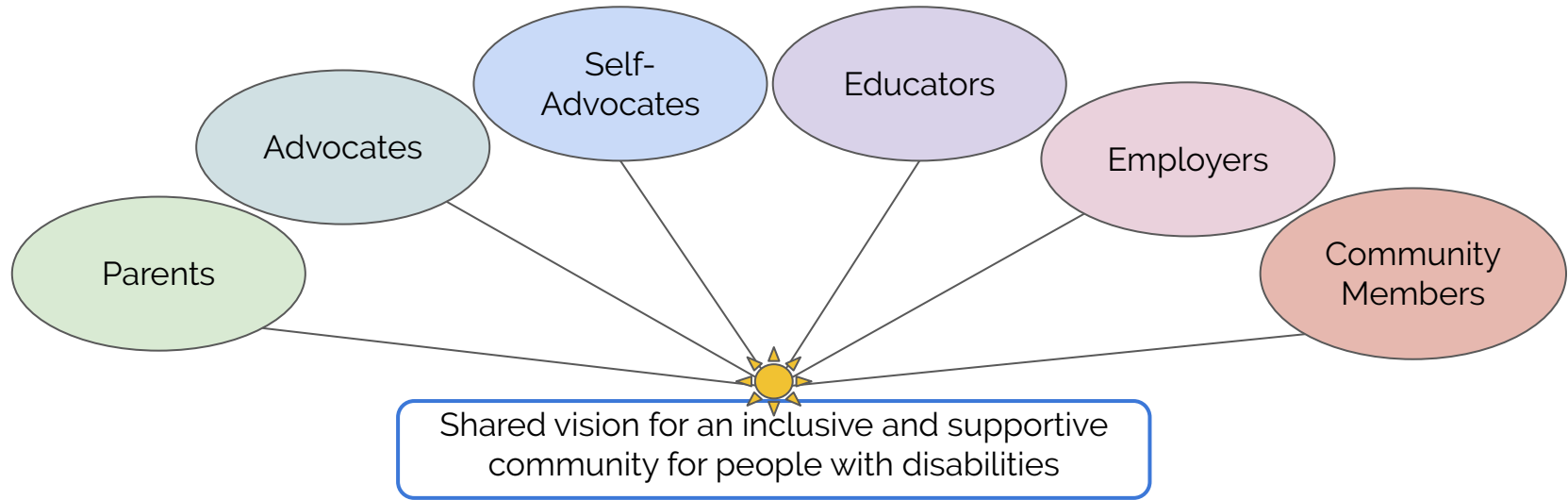


Alex Schryver
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Shrewsbury, MA

WHAT IS THE ISLAND DISABILITY COALITION (IDC)?



MISSION

The mission of the IDC is to bring together community members dedicated to promoting the full and equal participation of individuals with disabilities in all aspects of life. The Coalition will work to advocate and ensure that opportunities for self-determination, independence, empowerment, and inclusion exist in the areas including but not limited to education, housing, employment, transportation, civic engagement, socialization, and health care.



ISLAND DISABILITY
COALITION

JOIN THE CONVERSATION

IDC Membership Options

Be Part of the Solution

Organizational Members

- Join the conversation to become a more inclusive Martha's Vineyard.
- Organizational Members designate one or more representatives to attend monthly general IDC meetings.
- Participate in IDC activities to share your ideas, experiences and energy
- Participate in exploring creative solutions to complex issues
- Demonstrate your commitment to the mission of the IDC and our community

Get Involved

General Membership: Friends of the IDC

IDC's mission is to bring together community members dedicated to promoting the full and equal participation of individuals with disabilities in all aspects of life. Join our mailing list to learn of upcoming meetings, community events and resources available. Contact Beth Wike, idcmvy@gmail.com

Learn more at: www.idcmvy.org

SCOPE

A landscape photograph of a wetland area. In the foreground, there is a body of water with a narrow channel winding through it. The water is a pale, greyish-blue color. The banks are covered with tall, dry, golden-brown reeds or grasses. In the middle ground, there is a line of trees and shrubs, mostly in shades of green and brown. The background is a flat, greyish-blue sky. The word "SCOPE" is written in a large, bold, dark blue font, centered in the upper half of the image. It is enclosed in a white-bordered box.

POPULATION OF FOCUS

Youth with disabilities ages 3-22 (account for 15-20% currently enrolled in the Martha's Vineyard school system)

OBJECTIVES

- Identify and measure programs' current level of inclusivity, desire for change, and supports that would assist moving towards inclusion.
- Provide the IDC with recommended next steps in the process towards inclusion
- Continue and elevate the community conversation on inclusion

"I wish for a world that views disability, mental or physical, not as a hindrance but as unique attributes that can be seen as powerful assets if given the right opportunities."

-Oliver Sacks

DEFINITION OF DISABILITY

According to the WHO, disability has three dimensions:

- **Impairment** in a person's body structure or function, or mental functioning; examples of impairments include loss of a limb, loss of vision or memory loss.
- **Activity limitation**, such as difficulty seeing, hearing, walking, or problem solving.
- **Participation** restrictions in normal daily activities, such as working, engaging in social and recreational activities, and obtaining health care and preventive services.

Disabilities span a wide range

- Autism Spectrum Disorder
- Down Syndrome
- Cerebral Palsy
- Physical disabilities
- Emotional disabilities
- Mental health conditions
- Intellectual disabilities

A coastal landscape featuring a rocky beach in the foreground, waves crashing against the shore, and a clear blue sky. The scene is captured in a wide-angle shot, showing the ocean extending to the horizon. The rocks are dark and jagged, scattered along the shoreline. The water is a deep blue-grey color, with white foam from the waves. The sky is a uniform light blue. In the background, a low-lying coastline with some buildings is visible under the clear sky.

BACKGROUND

WORLD HEALTH ORGANIZATION: Redefining Disability

- **Disability** - an umbrella term
 - Impairments, activity limitations, participation restrictions
 - Not just a health problem, it is a complex phenomenon
 - Overcoming difficulties faced by people with disabilities requires interventions to remove environmental and social barriers

International Classification of Functioning, Disability, and Health (ICF)

- After extensive testing across the world, the ICF was approved for use by the World Health Assembly in 2001
 - A children & youth component was approved in 2007
- Shift from a medical classification to a broader **biopsychosocial model**

ICF - Disability and Functioning Framework

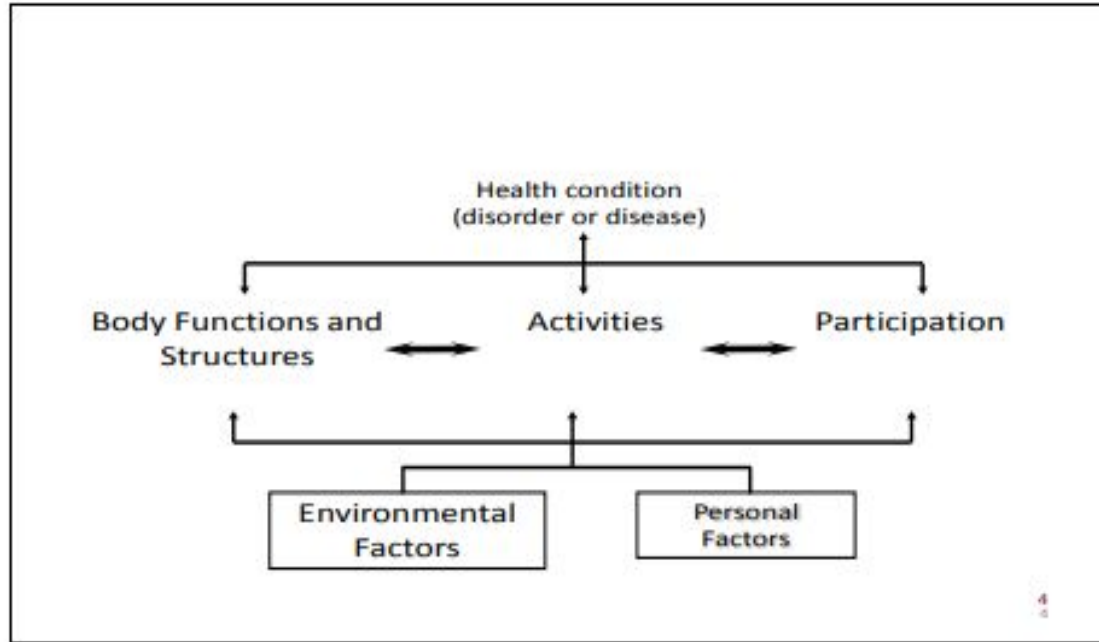
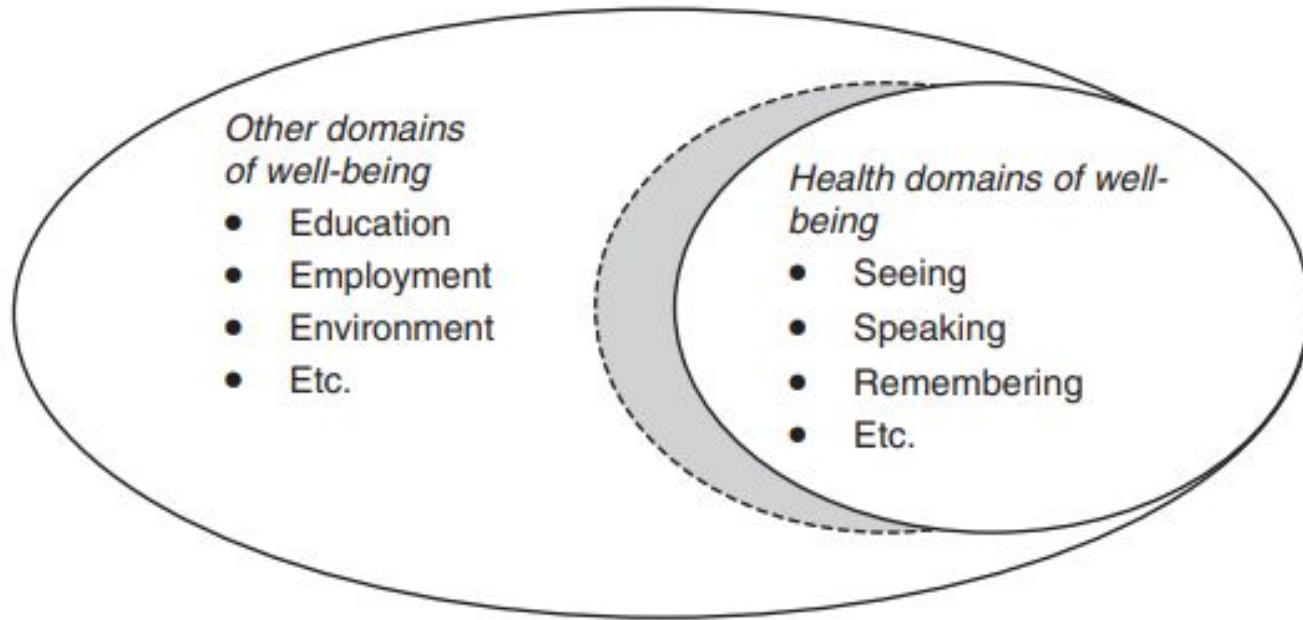


Figure 1: Interactions between the components of ICF (WHO 2001:18)

The Universe of Well-Being (ICF)

Fig. 1 The universe of well-being



(ICF-CY, 2007)

Facilitators

- Positive attitudes
- Relative assistive technology
- Recreation
- Work opportunities
- Advocacy & support from volunteer groups

Barriers

- Negative attitudes
- Lack of assistive technology
- Inaccessibility (via transportation, housing)
- Limited access to work
- Not enough advocacy and volunteer groups to meet their needs

PRINCIPLES OF UNIVERSAL DESIGN

- Equitable Use
- Flexibility in Use
- Simple and Intuitive Use
- Perceptible Information
- Tolerance for Error
- Low Physical Effort
- Size and Space for Approach and Use



PRINCIPLES OF INCLUSIVITY

- Responsive
- Flexible
- Convenient
- Accommodating
- Welcoming
- Realistic
- Understandable



INCLUSIVITY - WHAT DOES IT MEAN TO MARTHA'S VINEYARD



INCLUSION - RESEARCH OUTCOMES

Youth Perspective:

- Gaining entry to play
- Feeling like a legitimate participant
- Having **friends**
- Greater functional **independence**
- Positive attitude towards community

Caregiver Perspective:

- A **greater level of support** through additional **staffing** as well as additional **training** is the most important prerequisite to enable people with learning disabilities to access mainstream recreation and leisure
- Appropriate **equipment** was deemed to be an important requirement

IDC INCLUSIVE ACTION STRATEGIES

- **Provide current, accurate, and accessible information** to assist families and individuals to access services and support
- **Provide training and education** opportunities relevant to identified needs of individuals with disabilities to access inclusive opportunities and experience
- **Build the capacity of community partners, and the community in general,** to offer inclusive opportunities and experiences
- **Provide an environment that offers opportunities** for connection, networking, collaboration, and natural supports for community members working towards inclusions

WHY DO RECREATION AND LEISURE MATTER?

CHILDREN & TEENS WITH
DISABILITIES HAVE
**DISPROPORTIONATELY LOWER
LEVELS OF ACTIVITY & FITNESS**
COMPARED TO NON-DISABLED
PEERS.

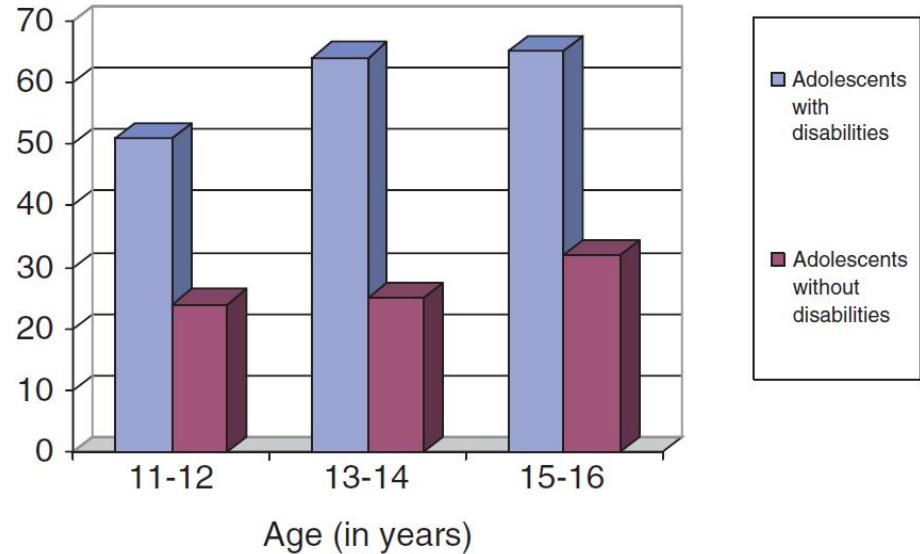


Figure 1. Physical activity levels of adolescents with and without disabilities who exercise once per week or less (OR: 4.50; 95% CI [3.55–5.72]) Steele et al. [8] Data from the Canadian WHO Cross-National Survey Health Behavior in School-Aged Children (HBSC).

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ADVERSE HEALTH
CONDITIONS**

WHY DO RECREATION AND LEISURE MATTER?

PHYSICAL ACTIVITY & EXERCISE PROGRAMS
FOR YOUTH ARE **BENEFICIAL IN IMPROVING:**



SOCIAL CONNECTION

Form friendships &
relationships
Reduction in social
stigma



PHYSICAL HEALTH

Cardiovascular Health
Strength

MENTAL HEALTH

Development of self-identity
Quality of life
Sense of meaning & purpose

WHAT ARE THE BARRIERS TO RECREATION AND LEISURE FOR YOUTH WITH DISABILITIES?

PHYSICAL BARRIERS

Playgrounds & Ball Fields that are inaccessible to youth who use wheelchairs

Grass surfaces

Climbing apparatus with no ramps

PROGRAMMATIC BARRIERS

Necessary staffing or support to accommodate the child during the activity

Not having knowledgeable staff who understand how to adapt the game or sport to meet child's needs

ATTITUDINAL BARRIERS

High level of competition and emphasis on winning

Protection of child from participating in competitive activities that may result in failure or verbal abuse from other children



METHODS

OUR TWO WEEKS HERE

Goal: To assess current inclusion levels and identify barriers for youth with disabilities across recreation/leisure providers through structured interviews, focus groups, research and observation.

The IDC identified 45+ organizations and groups for us to interview:

- ❑ Schools
- ❑ Libraries
- ❑ Local organizations
- ❑ Parent groups
- ❑ Local businesses

Interviews were conducted in groups of two

Questions:

- ❑ What is your personal experience with people with disabilities?
- ❑ What does inclusion mean to you?
- ❑ What are the strengths/challenges your organization has to serve those with a disability?

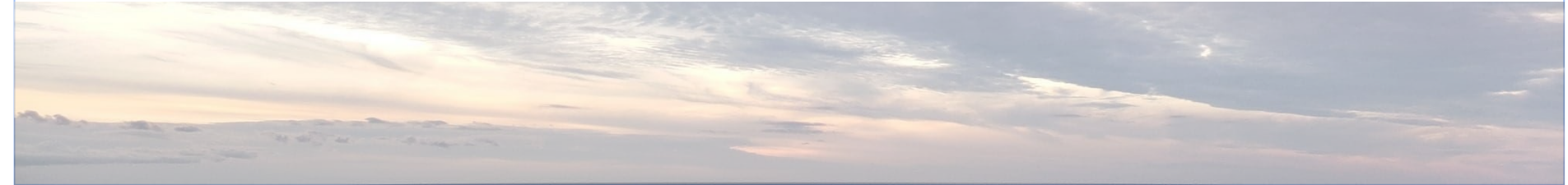
OUR TWO WEEKS HERE

Observation and Research:

- ❑ Clinical experience at Martha's Vineyard Health Care
- ❑ Making chocolate at Chilmark Chocolates
- ❑ Getting to know community members
- ❑ Exploring the island
- ❑ Literature review of methods for measuring inclusivity

Recommendations

- ❑ Short-term: 6 months
- ❑ Mid-term: 1 year
- ❑ Long-term: within 5 years



A serene beach scene at sunset. The sky is a mix of soft pinks, oranges, and blues. The ocean is calm with gentle waves, and a white-capped wave is breaking on the sandy shore in the foreground. The word "RECOMMENDATIONS" is centered in a white-bordered box.

RECOMMENDATIONS

I. INCREASE AWARENESS OF DISABILITY SERVICES AND PROGRAMS

Short-term Goal

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Short-term Goal

CURRENT STATE

- **Overlap** between organizations resulting in inefficiencies
- Parents of youth with disabilities have expressed that they **don't know** what resources are available
 - 69% of families report not receiving information
- Programs for people with disabilities are **cancelled due to low attendance** because parents don't know about them

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RECOMMENDATIONS

- Create a **centralized resource list** of all services and programs that support this population
- **Distribute** to organizations on the list, school counselors, and pediatricians working on the island
- Make it available on the **IDC website**

II. INCREASE SUPPORT FOR PARENTS OF A CHILD WITH A DISABILITY

Short-term Goal

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Short-term Goal

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- A new diagnosis is **overwhelming** for both parent and child, and the system is very confusing to navigate
- Parents of a child with a disability have a **wealth of knowledge** from their experiences
- There is **no centralized way to connect parents** who have gone through the process with those who are starting out
 - Based on whom you know
- 71% of parents believe that Martha's Vineyard needs **more places where their family member can meet others**

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RECOMMENDATIONS

- Create a **parent support referral list** to connect parents who can provide mentorship and support to each other
 - Connect based on child's diagnosis and/or school system
- Increase **awareness of the Support Group for Parents of Children with Disabilities** run by the Family Center
 - Add to IDC newsletter
 - Inform schools

III. EXPANSION OF PEER SUPPORT AND BUDDIES PROGRAM

Mid-term Goal

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Mid-term Goal

CURRENT STATE



What is the best buddies program?

- High school program where students from different grades are paired up together
- Inclusive for everyone who wants to be a part of the program
- Best Buddies get together during their flex period every Friday and they have different activities they can do each week
- The leaders are provided with training in Indiana
- The program has made the school more inclusive

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RECOMMENDATIONS

- Expand to more **outside of school activities**
- **Expand the program** to upper middle school aged children to make them feel more comfortable once they transition into high school
- Provide greater **financial support**
- Host a **school wide assembly** on inclusion
 - Having the nonprofit organization called Understanding Our Differences come to the elementary and middle schools

IV. INCREASE COLLABORATION BETWEEN THE IDC AND ORGANIZATIONS

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- Both the IDC and organizations have expressed a want and a need for **more collaboration**
- To promote collaboration the IDC, during its biweekly meetings, tries to get **different organizations** on the island to attend. Therefore, **increasing familiarity** with the **programs** that are offered on the island

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RECOMMENDATIONS

- **Publicize meeting dates**
 - Through email, facebook, text, and newsletters
- Create **monthly newsletters**
 - Detailing what the IDC is working on and what they may need help with
- Provide **support** when organizations come to them with questions
 - Having a list of organizations that are willing to collaborate with other organizations on the island

V. IMPROVED STAFF TRAINING

Mid-term Goal

CURRENT STATE

- Staff at the organizations interviewed have expressed **varying levels of knowledge** on inclusion and adaptive programming
- Local organization were **overwhelmingly positive about the benefits** of improved training on working with children with disabilities
- Some local organizations have been **unsuccessful in integrating adaptive programs**
- **Barriers:** Insufficient Funding, Staff Turnover, Knowledge Deficit, Lack of Coordination

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RECOMMENDATIONS

- Continue to identify and connect organizations that have expressed an interest to **appropriate services**
- Identify **new sources of training**
 - School department of special education
 - Organizations that are already successful in establishing inclusive programs
- Continue to promote **collaboration between Kids Included Together (KIT) and Organizations/Youth Programs/Clubs** on MV
- Create means of **continued support**
 - Online modules (already being offered by KIT)
 - Contact person
- Increase school collaboration/professional development

VI. SUPPORT LOCAL BUSINESSES IN HIRING PERSONS WITH DISABILITIES

Long-term Goal

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Long-term Goal

CURRENT STATE

- Youth with disabilities have **lessened support in highschool** and nearing the transitions phase (17-22 yrs old)
- The programs currently established need **more collaboration with local businesses and organisations**
- There is a **finite number of establishments that currently employ or provide internships** to those with disabilities



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RECOMMENDATIONS

- Create a **list of organizations** that are interested in more inclusive staffing
- Provide these organizations with the **appropriate supports, resources, training**
- Hire **job coach** or transition specialist
- **Allocate funds** to a skills building program or to continue support for the programs that currently exist
- **Modify programs currently in place** through feedback from all participating organizations and stakeholders

VII. SUSTAINABILITY AND FUNDING FOR AFTER SCHOOL PROGRAMMING

Long-term Goal

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Long-term Goal

CURRENT STATE

- Some of the successful afterschool programs for youth in the community with disabilities have expressed a need for **increased support/funding**
 - Fun Club
 - Island Autism Group
 - Boys and Girls Club
 - Inclusive after school recreation and sports
- There are **disproportionately more programs for children under 12** with disability

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RECOMMENDATIONS

- Identify a **means of funding for the Island Autism Group**
 - This program has been undeniably successful and provides a necessary service that is not currently provided elsewhere
- **Increase attendance** within these programs
 - Refer to the MV disability resource list and MV Parent Mentoring Group
- Increase **access to recreation for youth with disabilities over the age of 12 yr** between 2pm-6pm year round
 - Skill building and internship opportunities

VIII. FUNDING SUPPORT FOR ORGANIZATIONS AROUND THE ISLAND

Long-term Goal

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Long-term Goal

CURRENT STATE

- Many organizations **rely on grant funding** to support programming, including programs that are inclusive and supportive of youth with disabilities
- Grant funding has a **limited time frame**.
- Organizations have to **decide** whether:
 - To incorporate grant-supported programming into budget
 - To renew or find alternative grants to continue to support these programs
 - To fizzle the program out
- Reliance on grants leads to **decreased sustainability**

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RECOMMENDATIONS

- Inclusion of a **sustainability plan** when applying for grants as start-up funding for programming
- Provide **sustainability planning resources** on IDC or Community Services website to guide organizations in developing a plan
- Identification of **grant-writing partnerships** to decrease competition between organizations for similar grants, including partnerships with IDC
- Development of a **grant database** to help organizations identify sources of funding
- Increased **networking** of IDC with grant organizations that support inclusive programming to increase likelihood of funding.

IX. IMPROVING ACCESSIBILITY TO RECREATION

Long-term Goal

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Long-term Goal

CURRENT STATE

- Only 33% of adolescents and adults with disabilities drive
- 78% of adolescents and adults with disabilities use public transportation
- 24% of parents and 53% of community members said that accessible transportation was one of the most important factors for daily activities, leisure and recreation
- Lower levels of participation in the Wampanoag and Brazilian communities

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RECOMMENDATIONS

- Increase **public transportation** to and from Aquinnah and Chilmark, especially routes to the YMCA
- Expand awareness of the **Lift program** and how to use it
- Provide resources on the IDC website for **ADA Compliance** and suggestions for structural adjustments to make spaces more accessible
- Provide **beach-friendly wheelchairs** that community members and visitors can sign out to use
- Increased IDC **advocacy** for accessible spaces
- Provide an **audio message in Portuguese** when possible to increase reach of promotional materials

A scenic view of a coastline with a large body of water and a cliffside. The sky is a mix of light blue and white, suggesting a clear or slightly overcast day. The water is a deep blue-grey, and the cliffside is a mix of brown and tan, with some sparse vegetation. The overall mood is calm and serene.

ACKNOWLEDGEMENTS & REFERENCES

ACKNOWLEDGEMENTS



Island Disability Coalition

- Beth Wike, Coordinator
- Julie Lively, Steering Committee
- Cecilia Brennan, Steering Committee
- Hope Macleod, Steering Committee
- Nancy Dugan, Steering Committee
- Dick Cohen, Steering Committee
- Catherine Flynn, Steering Committee



University of Massachusetts Medical School Faculty

- Suzanne Cashman, ScD



Martha's Vineyard Hospital

- Dan Pesch, MD

ACKNOWLEDGEMENTS

Schools:

- MV Regional High School
- West Tisbury School
- Tisbury School
- Edgartown School
- Oak Bluffs School
- Chilmark School
- MV Public Charter School
- Organized School Sports
- Special Education

Libraries:

- Edgartown Library
- West Tisbury Library
- Chilmark Public Library
- Vineyard Haven Library

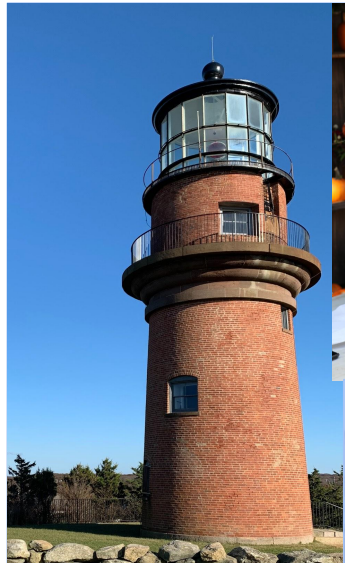
Businesses & Organizations:

- Daybreak Clubhouse
- Sail MV
- Camp Jabberwocky
- Boys and Girls Club
- Head Start
- Chilmark Chocolates

- MV YMCA for Wellness & Youth
- Kids Included Together
- Vineyard Transit Authority
- MV Museum
- Special Olympics
- Unified Sports
- Center for Living
- Misty Meadows Equine Learning Center
- Seven Hills
- Trusteed for Land and Property
- MV Learn to Skate Figure Skating
- Island Autism Group
- Best Buddies
- RISE Dance Studio
- Family Centers of MVCS
- Trustees Educational Program
- The Vineyard Playhouse
- The Yard
- Sassafra's Earth Education
- Vineyard Family Tennis
- Felix Neck
- MVH Social Work

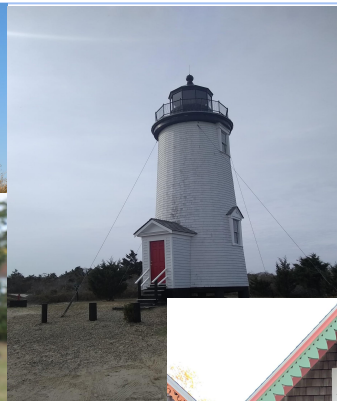



- Island Parents Advisory Council
- Primary Care MV Hospital Staff
- Island Health Care Staff
- Juli Vanderhoop
- David Vigneault
- MV Little League



Let me win.
But if I cannot win
let me be brave
in the attempt

Special Olympics Athlete Oath


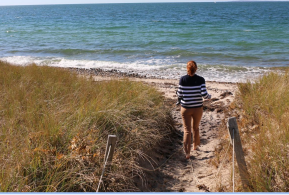
Alex's Place

Alexandra MM Gagnon, an aggressive downhill skier, is a student of life and a woman who never ceases in all that she achieves. Alex was also a student of life and a woman who never ceases in all that she achieves. Alex was also a student of life and a woman who never ceases in all that she achieves. Alex was also a student of life and a woman who never ceases in all that she achieves.

Alex also enjoys three languages, loved to cook, to dance, to sing, to read, enjoyed music, being to show things, sports and virtually all sports. She was a natural leader, organizing any type and could almost always organize. Alex had a radiant smile, was fun, compassionate, loyal to her friends, loved life, traveled extensively and spent most of her teenage years with many of her friends.

Alex's life was not short because she did not always have a safe place to explore her talents, passions and enthusiasm for life. The Alexandra Gagnon Home Center did open at Alex's Place, honors Alex's spirit and is dedicated to helping those develop their talents, enhance mind, body and spirit and build friendships. Alex would be very proud that her legacy makes this possible on her beloved Island.

Alexandra MM Gagnon
November 1, 1994 - June 3, 1998

THANK YOU



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