



**INCLUSIVE RECREATION AND LEISURE**  
UMass Rural Health Scholars

# WHO ARE WE?

**Rural Health Scholars** UMass Medical and Nursing Students



**Alex Cole**  
NP Student  
Salem, NH



**Cathleen Cuddihy**  
NP Student  
Rochester, MN



**Wendy Haynes**  
NP Student  
Washington D.C.



**Jessica Kahan**  
Medical Student  
Wayland, MA



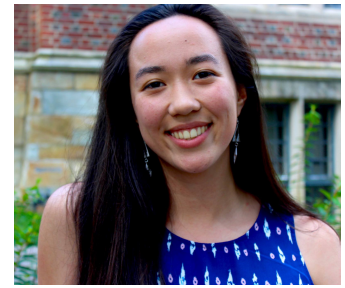
**Arden Marin**  
Medical Student  
Needham, MA



**Meghan Parrett**  
NP Student  
Mansfield, MA



**Alex Schryver**  
Medical Student  
Lancaster, MA



**Filia Van Dessel**  
Medical Student  
Shrewsbury, MA

# OUTLINE

PART 1: Definition of the population of focus

PART 2: Exploring interprofessional teams of care

PART 3: Health advocacy

PART 4: Service and experiential learning

PART 5: Acknowledgements



# **PART 1**

**Definition of the population of focus**



# POPULATION OF FOCUS: Key Definitions

## Youth with disabilities ages 3-22 on Martha's Vineyard

(account for 15-20% currently enrolled in the Martha's Vineyard school system)

### 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

# POPULATION OF FOCUS: Key Demographics

## Youth with disabilities ages 3-22 on Martha's Vineyard

(account for 15-20% currently enrolled in the Martha's Vineyard school system)

### MARTHA'S VINEYARD:

- **6 Towns:** Oak Bluffs, Tisbury, West Tisbury, Edgartown, Chilmark, Aquinnah
- **Year round population:** 17,325
- **Age:** 18+ y.o. (82%), >18 y.o. (18%)
- **Racial & Ethnic diversity:** White (88%), African American (4%), American Indian (2%), Hispanic (2%), mixed (4%)
- **Language:** English, Portuguese
- **U.S. Citizenship:** 96%

### OUR POPULATION OF INTEREST:

- **3-22 years old**
- **Diagnosed/self-identified as having a disability**



# POPULATION OF FOCUS: Clinically Relevant Needs or Trends

## Youth with disabilities ages 3-22 on Martha's Vineyard

(account for 15-20% currently enrolled in the Martha's Vineyard school system)

### MEDICAL RISK EXPOSURES AND INCIDENCE RATES:

- **Lyme Disease:** bacterial infection from tick bite (100-200 new cases/year)
- **Tularemia:** bacterial infection from deer flies

### SOCIAL RISK EXPOSURES AND INCIDENT RATES:

- **Unemployment (3%)**
- **Poverty (8%)**
- **Accessibility to Off-Island Resources**

### SPOTLIGHT:

- **Disparities:** Accessibility to opportunities for youth with disabilities
- **Strengths:** Involvement of community members in coalitions and initiatives



# WHY IS THIS A POPULATION THAT WE SHOULD KNOW MORE ABOUT AS FUTURE PROVIDERS?

## Youth with disabilities ages 3-22 on Martha's Vineyard

(account for 15-20% currently enrolled in the Martha's Vineyard school system)

### **RURAL COMMUNITIES:**

A community that is geographically farther and more isolated from industrialized areas.

**MARTHA'S VINEYARD:** Martha's Vineyard is deemed a **rural community** due to the restricted access. During the winter months the population greatly decreases and with it the island sees a reduction in available services. The population on the Island swells from approx. **17,000** to nearly **150,000** between May and August.

**YOUTH WITH DISABILITIES:** Impairments, activity limitations, participation restrictions

*"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

A coastal scene with waves crashing against a rocky shore under a clear blue sky. The foreground is filled with large, dark rocks, and the ocean extends to the horizon. The sky is a uniform light blue.

# **PART 2**

**Exploring interprofessional teams of care**



# INTERPROFESSIONAL TEAMS: Our Team

**We were a team of 4 medical students and 4 nurse practitioner students!**

**Interdisciplinary Team:** Each interview team was made up of 1 MS2 and 1 NP student. We each entered the project with varying levels of knowledge and experience on the population of focus.

## **WHAT ARE THE STRENGTHS AND LIMITATIONS OF THE TEAM?**

The unique experiences that each team member brought to the project guided the interview questions and contributed to the depth of information gathered. Our team was most limited by the scope of recommendations we were making.

### **Island Limitations:**

- Housing Crisis
- Funding
- High Staff turnover/Lack of retention

# INTERPROFESSIONAL TEAMS: Professions Across the Island

## PROFESSIONS, QUALIFICATIONS & SCOPE OF PRACTICE:

- Schools
- Libraries
- Community Services
- YMCA
- Youth sports
- Boys and Girls Club
- Summer Camps
- Non-profit organizations
- Local businesses
- Island Autism Group

**RELATIONSHIPS:** Coordination through school system and local organizations

## COORDINATED VS. STAND-ALONE CARE:

Due to the lack of accessibility many youth with disabilities living on MV seek specialty care off island. Some groups have been founded by parents on the island to provide the necessary skill building for their children.

## HOW & WHERE DO THEY PROVIDE CARE FOR THE POPULATION MEMBERS?

- Island Health Care (Federally-funded CHC)
- Martha's Vineyard Hospital
- Community Organizations

## WHAT ARE THE STRENGTHS AND LIMITATIONS OF THE TEAM?

**Strengths:** Many non-profits, committed advocates, community involvement

**Limitations:** Funding, transportation, coordination between organizations

# INTERPROFESSIONAL TEAMS: Interactions

## **HOW WOULD WE INTERACT WITH THESE OTHER MEMBERS OF THE TEAM?**

We interviewed and gathered information from the various organizations around the island.

## **WHAT DO WE WANT OUR PEERS TO KNOW ABOUT THESE POTENTIAL TEAM MEMBERS?**

It's important for health professionals to be aware of recreation services for their patients, particularly when there are additional barriers to accessing these resources.

Non-profits, advocates, and community organizations serving individuals for disabilities can have a huge impact on an individual's quality of life.



# PART 3

Health Advocacy

# ORGANIZATIONS THAT ADVOCATE FOR OUR POPULATION OF FOCUS

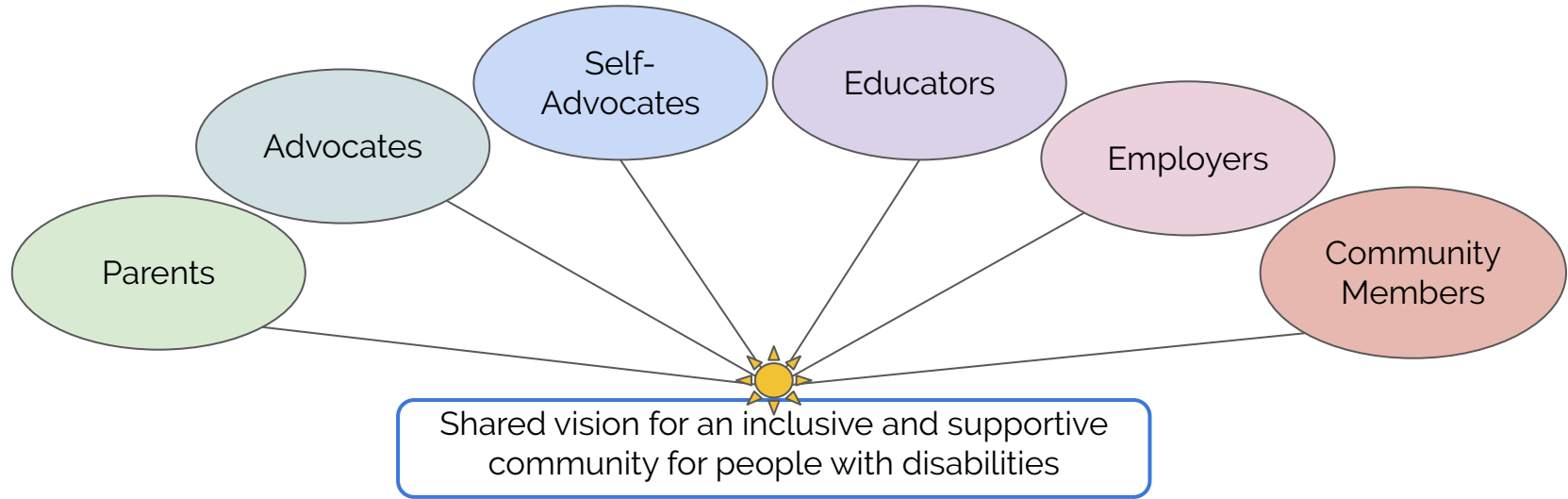
**LOCAL:** ISLAND DISABILITY COALITION (IDC)

**STATE:** INSTITUTE FOR COMMUNITY INCLUSION (ICI)

**NATIONAL:** AMERICAN ASSOCIATION OF PEOPLE WITH  
DISABILITIES



# LOCAL ORGANIZATION: 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.

# LOCAL ORGANIZATION: ISLAND DISABILITY COALITION (IDC)

## Major areas of advocacy:

- ❑ Employment opportunities
- ❑ Recreation and leisure
- ❑ School engagement

## To whom do they advocate?

- ❑ Local organizations and businesses
- ❑ Schools
- ❑ Local government

## Track Record:

- ❑ Formed only a couple years ago
- ❑ Trying to make a lasting impact instead of grant funded programs fizzling out

## Consequences of success/failure:

- ❑ Mental health/social lives of those with disabilities
- ❑ Physical well-being
- ❑ Making Martha's Vineyard a more inclusive community as a whole

## How providers can be advocates:

- ❑ Awareness of resources in the community
- ❑ Encouraging hiring
- ❑ Listening to parents who express a desire for a certain resources that might not exist and advocating for it

# STATE ORGANIZATION: INSTITUTE FOR COMMUNITY INCLUSION

## Major areas of advocacy:

- ❑ Employment, health care, education, transition, recreation, technology, organization building, policy

## To whom do they advocate?

- ❑ Local, state, national agencies, schools, institutions of higher education, national service programs, rehab providers, multicultural organizations, employers, and many others

## Track Record:

- ❑ Formed over 40 years ago
- ❑ Project List on website- employment outcome research - 20 year project

## Consequences of success/failure:

- ❑ Success: Greater inclusion of persons with disabilities in the State of Massachusetts
- ❑ Consequences: isolation of this population/little change in stigma

## How providers can be advocates:

- ❑ Awareness of resources in the community
- ❑ Involvement in local, state, and national policy for those with disabilities

# NATIONAL ORGANIZATION: AMERICAN ASSOCIATION OF PEOPLE WITH DISABILITIES

**Mission Statement:** To serve as a convener, connector, and catalyst for change, increasing the political and economic power of people with disabilities

**Areas of Advocacy:** Education, Employment, Health, Housing, Technology, Transportation, Incarceration, Sexual and Domestic Violence

**Successes:**

- ADA Amendments Act of 2008
- Presidential Order for 100K More Workers



# **PART 4**

**Service and experiential learning**



# 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, with one NP student and one medical student**

## **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



# 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

## 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

## 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



# WHAT DID WE LEARN?

## What did we learn from the experience?

- There needs to be **increased collaboration** between the schools, organizations, and businesses on the island
- Organizations and businesses require more **training around disabilities** to feel more comfortable
- The island struggles with finding **sustainable funding** for their school programs and organizations
- **Transportation** is an issue during the off season

## How might the time we spent in the community shape our approach to clinical practice?

- We will go forward with a **mindset that looks out for inaccessibility**
  - For example if a business does not have a ramp and there are are few steps required to be able to enter the business
- We have come out of this experience with more **understanding, compassion, and various definitions of what inclusion means to people** on the island of Martha's Vineyard



# **PART 5**

## **Acknowledgements**

# 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







**THANK YOU**



# REFERENCES

Center for Disease Control and Prevention (CDC), (2019). *Disability and Health: Disability Inclusion*. Retrieved October 28, 2019, from <https://www.cdc.gov/ncbddd/disabilityandhealth/disability-inclusion.html>

Hall, Sarah A. (2016), *Community Involvement of Young Adults with Intellectual Disabilities: Their Experiences and Perspectives on Inclusion*. Journal of Applied Research in Intellectual Disabilities/ Volume 30, Issue 5, DOI: <https://doi.org/10.1111/jar.12276>

Martha's Vineyard Commission (MVC). (2019). *Martha's Vineyard Statistical Profile, February 2019*. Retrieved from: [http://www.mvcommission.org/sites/default/files/docs/web01\\_MVSP%20FINAL%20PRINT%202019-03-21-3.pdf](http://www.mvcommission.org/sites/default/files/docs/web01_MVSP%20FINAL%20PRINT%202019-03-21-3.pdf)

Merrells, J., Buchanan, A., & Waters, R. (2018) *The experience of social inclusion for people with intellectual disability within community recreational programs: A systematic review*, Journal of Intellectual & Developmental Disability, 43:4, 381-391, DOI: 10.3109/13668250.2017.1283684

Institute for Human Centered Design (IHCD), (2019). *Principles*, Retrieved October 28, 2019, from <https://www.humancentereddesign.org/>.

Rimmer, J., & Rowland, J. (2008). *Physical activity for youth with disabilities: A critical need in an underserved population*, Developmental Neurorehabilitation, 11(2): 141-148.

Spencer-Cavaliere, N., & Watkinson, E. (2010). Inclusion Understood From the Perspectives of Children With Disability, *Adapted Physical Activity Quarterly*, 27(4), 275-293. Retrieved Oct 29, 2019, from <https://journals.humankinetics.com/view/journals/apaq/27/4/article-p275.xml>

U.S. Access Board, (1995), *Guidelines and Standards*, Retrieved October 30, 2019 from <https://www.access-board.gov/guidelines-and-standards/communications-and-it/26-255-guidelines/825-principles-of-universal-design>

U.S. Bureau of Labor Statistics, Unemployment Rate in Dukes County, MA [MADUKE7URN], retrieved from FRED, Federal Reserve Bank of St. Louis; <https://fred.stlouisfed.org/series/MADUKE7URN>, November 3, 2019.

Walsh-Allen, Mary (2010), *Integration or Segregation? The same or different recreation and leisure facilities for people with learning disability*, Critical Social Thinking: Policy and Practice, Vol.2, Retrieved October 28, 2019 from, <https://www.ucc.ie/en/media/academic/appliedsocialstudies/docs/MaryWalsh-Allen.pdf>

World Health Organization (WHO), (2007). *International Classification of Functioning, Disability, and Health, Children & Youth Version, ICF-Y*, (Accessed October 28, 2019).

World Health Organization (WHO), (2019). *Disabilities*. Retrieved October 28, 2019, from <https://www.who.int/topics/disabilities/en/>.

World Health Organization (WHO), (2001). *The ICF: An Overview*. Retrieved October 28, 2019, from [https://cdc.gov/nchs/data/icd/icfoverview\\_finalforwho10sept.pdf](https://cdc.gov/nchs/data/icd/icfoverview_finalforwho10sept.pdf).