

**Island Disability Coalition
Martha's Vineyard
November-December, 2018**

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I. Introduction and Purpose

The intent of this report is to describe the expectations and vision for people with disabilities living on Martha's Vineyard, needs, services and supports currently used by people with disabilities and their families, challenges encountered and recommendations for addressing those challenges. Five surveys were developed – (1) adolescents and adults with a disability, (2) their families, (3) school personnel, (4) adult service providers and (5) general community members. These surveys were available in two languages and were disseminated by the Island Disability Coalition and other organizations on Martha's Vineyard.

There are multiple references in the disability literature that emphasize the need to **not** focus on disability, but on the breadth of life outcomes that comprise a comprehensive quality of life. There are several sources that outline these life domains. As a conceptual basis for the five surveys and for this report, we used the “key components of high quality community living” as described by the Research and Training Center on Community Living at the University of Minnesota (2014). These include

- (a) Where and with whom a person is educated;
- (b) Where and with whom a person lives;
- (c) Where a person works and how he or she earns money;
- (d) What a person does during the day;
- (e) The quality of the relationships developed with others during daily activities;
- (f) What and with whom a person does activities of personal interest;
- (g) An individual's health, both physical and emotional;
- (h) If, where, and with whom they worship;
- (i) Their interest and opportunities to engage in learning and personal growth; and
- (j) Their ability to make informed decisions about their lives.

This report will attempt to answer the following questions:

- (a) What are the expectations of people with disabilities and their families across the life domains cited above;
- (b) Is there a shared vision for people with disabilities across families, service providers and community members;
- (c) How important are each of the life domains as perceived by families, service providers and community members;
- (d) For each of the life domains, what are the factors that are most important in thinking about each domain;
- (e) For each life domain, what are the services and supports currently used by people with disabilities and their families;
- (f) For each life domain, what are the barriers and challenges....and what recommendations does the Island community have for addressing those challenges;
- (g) What are the qualities and strengths that make life good for people with disabilities on Martha's Vineyard, what are the challenges, and what would make life better.
- (h) What services and supports would the Island community like to exist in three to five years.

There have also been discussions with the Island Disability Coalition re: scope and capacity of the IDC. The functions and capacity of the IDC fall into four categories – (1) engaging service providers on the Island to enhance their services to address needs documented through the surveys; (2) providing people with disabilities and their families with accurate comprehensive information; (3) developing strategies that will assist people with disabilities and their families to effectively navigate systems; and (4) community organizing to maximize the use of community resources and supports by people with disabilities and their families. Recommendations will be organized around those four functions.

II. Survey Respondents

There were 241 respondents to the survey – 100 people completed the entire survey, 141 completed part of the survey. The most frequent respondents were community members (106 respondents) and family members (71 respondents). The following table describes the significant demographic characteristics of each group.

Demographic Notes:

- A third of the adolescents/adults who participated in the survey were adults who developed a disability later in life. Their perspective is different than the other adolescents and young adults.
- The majority of the disabilities listed by family members and service providers were individuals with learning or emotional/behavioral disabilities. Those who were described as having multiple disabilities, mostly had learning or emotional/behavioral disabilities.
- The majority of parents (72%) and all of the school personnel focused on school-aged individuals.
- We broke out siblings as a separate category; however, the sample of responses is very small.
- The majority of families responding have lived on the island for more than 10 years or their whole life.
- 75% of school personnel had been in the field for more than 10 years. The majority of adult service provider staff have been in the field for less than 5 years.
- Those responding to the survey were primarily white and primarily English speakers.

	Adolescents Adults	Parents	Siblings	School Personnel	Adult Service Personnel	Community Members
	Complete 9 Partial 18	Complete 22 Partial 42	Complete 2 Partial 5	Complete 9 Partial 16	Complete 6 Partial 6	Complete 52 Partial 54
				Admin 5 RegEd K-8 8 SpecEd K-8 7 SpecEd HS 2 Paraprof 5 Other 2	Employment 2 Mental Health 6 Other 4	
Age	Under 21 2 21-50 15 Over 50 8* <i>*These respondents reported developing disabilities later in life</i>	School 72% Adult 28% Under 14 21 14-20 21 21-34 14	School 43% Adult 57%	PreK – 8 92% HS 8%		
Primary Disability		LD 30.6% BD 19.4% ID 6.5% Physical 8.1% Sensory 1.6% Multiple 33.9%		LD 37.5% BD 8.3% ID 4.2% Physical 4.2% Sensory Multiple 45.8%	LD 18.2% BD 36.4% ID 27.3% Physical 18.2% Sensory 9.1% Multiple 72.7%	
Years in the field Disability				1-5 8.3% 5-10% 16.7% >10 75%	1-5 54.6% 5-10% 27.3% >10 18.2%	
Time on Martha’s Vineyard	75% have lived on the Island for more than 10 years or their whole life.					
Where do you live	Aquinnah 3.7% Chilmark 18.5% Edgartown 7.4% Oak Bluffs 25.9% Tisbury 22.2% W. Tisbury 3.7% Vineyard 18.5% Haven	Aquinnah 10.3% Chilmark 5.2% Edgartown 24.1% Oak Bluffs 25.9% Tisbury 3.4% W. Tisbury 13.8% Vineyard 17.2% Haven				
Race	96% identify as white	88% identify as white				
Language	English 100%	English 98%				
People in Household	1-2 48.1% 3 or more 51.9%	1-2 24% 3 or more 76%				
Household Income	<\$40,000 33% \$40-80,000 26% >\$80,000 19% No Answer 22%	<\$40,000 17% \$40-80,000 25% >\$80,000 44% No Answer 14%				

III. Shared Vision – Are the Expectations of People with Disabilities Aligned with the Expectations of Families, Service Providers and Community Members?

Expectations of People with Disabilities

Education - None of the respondents are in college or technical school, but 46% would like to go to college and 27% would like to go to technical school. Only one respondent is involved in any on line learning, a few reported topics they would like to learn about.

Housing – The responses to the housing questions about where do you live now and where would you like to live are almost identical. This most likely indicates a general lack of awareness of housing options. The need for accessible transportation was the most requested support.

Employment – 90% want to be employed – 40% want to work full time in a setting where most of the employees do not have a disability, 30% want to work part time in a setting where most of the employees do not have a disability, 20% want to work in a setting primarily for people with disabilities. 20% would like to start their own business. Responses to “what would you like to do” are unique to each individual.

Relationships, Daily Living, Recreation, Leisure – 60% of report having active social lives, 40% do not. Most were unaware of how to broaden their life activities or places in the community that could be the source of new relationships or new opportunities for broadening their life activities. 43% expect to be married, 33% expect to have children.

Personal Growth and Interests – Most of the respondents had interests, many did not know how to pursue them. 70% believe Martha’s Vineyard needs more places to go to have fun or explore personal interests. 56% are interested in going to educational events to learn more about their interests.

Decision-Making – 100% of those responding report making decisions about daily life events, only 60% report making decisions about big things (where to live, who live with, health decisions, financial decisions). 50% would like to make decisions about these major life choices.

Dreams – All the responses were personal. The most common responses focused on relationships and getting a job.

Challenges – Many cited their disability and/or emotional issues. Other challenges cited were difficulty making difficulty making friends, difficulty finding a job and “having enough stuff to do”.

One Thing that Would Have Made a Difference in Your Life – The most common response was “I don’t know”. Other responses included family references, more job opportunities, having a mentor.

General Impressions:

- Although the sample is small, the responses parallel responses in other national surveys.
- Respondents seem to be generally unaware of options and opportunities across most life domains.

- In most cases the respondents have expectations.....but don't really understand how to achieve those expectations.
- As is true with most people, the responses are personal and individual. This supports the need for a person-centered system for planning and navigation.
- There is a general lack of awareness and information about possibilities (organizations, clubs, learning opportunities, etc.) in the broader community.
- The priorities for the adolescents and adults who responded to the survey focused on jobs, relationships, increasing the number of activities in several domains (recreation and leisure, exploring interests, learning) and having information about people and supports that can assist them. One adult, in response to the question about whether there were people who could explore their interests, said "Probably, but I don't know who they are".

Expectations of Families, School Personnel, Adult Services Personnel, Community Members

For each of the life domains there is (a) a table which gives the percent of those completing the survey who answered yes and (b) a brief summary of the alignment of expectations among people with disabilities, family members, school personnel, adult services personnel and community members.

Education (Percent Answering Yes)

	Parents		Siblings		School Personnel		Adult Service Personnel		Community Members	
Will be educated in classrooms with typical peers	43	84.3%	2	66.7%	18	90.0%	7	70.0%	62	78.5%
Will be educated in special classrooms	26	51.0%	3	100.0%	16	80.0%	6	60.0%	28	35.4%
Will graduate from high school with a diploma	42	82.4%	4	100.0%	16	80.0%	9	90.0%	64	81.0%
Will go to college	22	43.1%	3	75.0%	8	40.0%	3	30.0%	37	46.8%
Will receive technical education in a trade or craft after high school	22	43.1%	3	100.0%	9	45.0%	6	60.0%	45	57.0%

There is strong expectation among all responding groups that (a) students with disabilities should be educated in classrooms with typical peers and (b) will graduate high school with a diploma. School personnel have more expectation that some students will be educated in special classrooms than do parents and community members. There is a lesser expectation that students will go to college or technical school. This aligns with the percent of individuals with disabilities who would like to go to college or technical school; however, at the current time none of the individuals with disabilities who responded to the survey are in college or technical school.

Employment (Percent Answering Yes)

	Parents		Siblings		School Personnel		Adult Service Personnel		Community Members	
Will have a job	44	86.3%	4	100.0%	19	95.0%	9	90.0%	66	83.5%
Will be employed in a setting where most of the employees are people without disabilities	34	66.7%	1	33.3%	16	80.0%	7	70.0%	56	70.9%
Will be employed in a setting where most of the employees are people with disabilities	7	13.7%	2	66.7%	8	40.0%	1	10.0%	12	15.2%
Will work less than 20 hours per week	13	25.5%	1	33.3%	8	40.0%	5	50.0%	21	26.6%
Will work more than 20 hours per week	31	60.8%	3	75.0%	13	65.0%	2	20.0%	34	43.0%

There is strong expectation across all groups that individuals will be employed. 90% of individuals with disabilities want to work. Although still strong, there is lesser expectation that individuals with disabilities will be employed in a setting where most of the employees are people without disabilities. 70% of individuals with disabilities want to work in a setting where most of the employees are people without disabilities. More than half of parents and school personnel expect that people will work more than 20 hours per week; adult service personnel and community members expect that people will work less than 20 hours per week. 40% of individuals with disabilities want to work more than 20 hours. For comparison, the December 2018 data from the Bureau of Labor Statistics reports that 30.4% of individuals with disabilities (age 16-64) were engaged in the workforce, compared to 74.1% of individuals without disabilities.

Housing (Percent Answering Yes)

	Parents		Siblings		School Personnel		Adult Service Personnel		Community Members	
Will live independently by themselves or with one or two others of their choice	34	66.7%	2	66.7%	16	80.0%	8	80.0%	55	69.6%
Will live with a family member	14	27.5%	2	66.7%	9	45.0%	9	90.0%	47	59.5%
Will live in a group setting with other adults who have a disability	11	21.6%	1	33.3%	9	45.0%	8	80.0%	44	56.4%

Will live in own home with supports (unpaid, service exchange for housing)	12	23.5%	2	66.7%	7	35.0%	7	70.0%	46	59.0%
Will live in own home with paid supports	13	25.5%	2	66.7%	7	35.0%	7	70.0%	48	61.5%

There are less common expectations about housing than most other life domains. All four groups have expectations that people will live independently or with one or two friends of their choice. It is very interesting to note that only 27% of parents expect that individuals with disabilities will live with family members – there are higher expectations among the other groups that individuals with disabilities will live with family members. *(By comparison, there are national studies that report that more than 80% of people with intellectual disabilities currently live with family members. The majority of those family members believe that living somewhere else would be better for their family member.)* Adult service providers and community members have higher expectations that individuals with disabilities will live in group settings or in their own home with supports.

Social Life, Relationships, Marriage, Children (Percent Answering Yes)

	Parents		Siblings		School Personnel		Adult Service Personnel		Community Members	
Will have an active social life with a network of friends	44	86.3%	3	100.0%	19	95.0%	10	100.0%	70	89.7%
Will have meaningful ways to have fun with others	46	90.2%	3	100.0%	19	95.0%	10	100.0%	71	91.0%
Will have hobbies or other ways of occupying time when alone	45	88.2%	3	100.0%	18	90.0%	10	100.0%	72	92.3%
Will have an active social life, primarily with other adults who have a disability	18	35.3%	3	100.0%	12	60.0%	9	90.0%	39	50.0%
Will be married or in a relationship	25	49.0%	3	100.0%	10	50.0%	5	50.0%	44	56.4%
Will have children	19	37.3%	3	100.0%	9	45.0%	4	40.0%	32	41.0%

All groups expect that individuals with disabilities will have an active social life, will have meaningful ways to have fun with others and will have ways of occupying time when alone. The percent of respondents who expect they will spend time primarily with other people with disabilities is much lower – except for adult service providers. There is a much lower expectation that individuals with disabilities will be married or have children. By comparison, 40% of people with disabilities report not having active social lives and most were uncertain about how to broaden their leisure and/or social lives. Most

people with disabilities had interests, many did not know how to pursue them. 70% believe Martha's Vineyard needs more places to go to have fun or explore personal interests. 56% are interested in going to educational events to learn more about their interests. 43% expect to be married, 33% expect to have children.

Decision-Making (Percent Answering Yes)

	Parents		Siblings		School Personnel		Adult Service Personnel		Community Members	
Will need a guardian	19	37.3%	2	66.7%	7	35.0%	5	50.0%	28	35.9%
Will make decisions about daily life events - what to wear, what to eat, when to go to bed, etc.	44	86.3%	2	66.7%	18	90.0%	9	90.0%	65	84.4%
Will make decisions about big things - where to live, who to live with, health decisions, financial decisions, etc.	24	47.1%	1	33.3%	12	60.0%	7	70.0%	40	51.9%
Will manage their own healthcare	20	39.2%	2	66.7%	10	50.0%	3	30.0%	27	35.1%
Will manage their own money	21	41.2%	1	33.3%	12	60.0%	3	30.0%	28	36.4%
Will get around independently by driving, using public transportation or something else	39	76.5%	2	66.7%	18	90.0%	7	70.0%	52	67.5%

All four groups expect that individuals with disabilities will make decisions about daily life events, but a much smaller percent expect that they will make decisions about bigger life decisions (where to live, health matters, fiscal matters, etc.). 100% of people with disabilities report making decisions about daily life events, only 60% report making decisions about big life decisions. 50% would like to make decisions about these major life choices. All four groups expect that people with disabilities will get around independently. 33% drive, 67% do not. 78% use public transportation. Transportation was frequently mentioned by individuals with disabilities as an important factor for most life domains.

Summary:

Based on the information summarized above, **the community of Martha's Vineyard expects that individuals with disabilities:**

- Will be educated primarily in classrooms with typical peers;
- Will graduate high school with a diploma;
- Will have access to a variety of affordable housing options and supports;
- Will be employed...primarily in settings in which the other employees do not have disabilities;
- Will have an active social life...primarily in inclusive community settings;
- Will have meaningful ways to have fun with others;
- Will have hobbies and other ways to occupy time when alone;
- Will have a network of friends and relationships;
- May or may not be married and may or may not have children;
- Will make decisions about daily life events;
- May or may not make bigger life decisions;
- Will get around independently either by driving or using public transportation.

These shared expectations can serve as the foundation or desired outcomes of a strategic plan. Strategies for achieving these outcomes, partnerships for implementing the strategies and progress indicators would provide the details of a plan.

IV. Shared Vision – Importance of Each Life Domain (1 least important, 5 most important):

	Parents		Siblings		School Personnel		Adult Service Personnel		Community Members	
Where and with whom they are educated	49	4.5	3	3.4	17	4.1	10	5.0	73	4.4
Where and with whom they live	49	4.8	3	4.3	17	4.1	10	5.0	73	4.6
Where they work and how they earn money	49	4.5	3	4.3	13	3.8	10	4.9	73	4.5
What they do during the day	49	4.6	3	4.3	17	4.1	10	4.9	73	4.7
The quality of the relationships they develop with others during daily activities	49	4.7	3	4.3	17	4.2	10	4.9	73	4.8
What and with whom they do activities of personal interest	49	4.6	3	4.7	17	3.8	10	4.8	73	4.6
How healthy they are, both physical and emotional	49	4.9	3	4.7	17	4.5	10	4.9	73	4.8
If, where, and with whom they worship	49	2.7	3	4.0	17	2.1	10	4.2	73	3.4
Their interest and opportunities to engage in learning and personal growth	49	4.6	3	4.7	17	3.9	10	5.0	73	4.5
Their ability to make informed decisions about their lives	49	4.5	3	4.7	17	4.1	10	5.0	73	4.6

All the life domains were rated highly...except for where and with whom they worship, which was rated very low.

Summary – Most Important Life Domains for Each Response Group

The most important issues for **individuals with disabilities** focused on

- (1) jobs,
- (2) relationships,
- (3) increasing the number of activities in several domains (recreation and leisure, exploring interests, learning) and
- (4) having information about people and supports that can assist them.

The most important domains for **parents** are

- (1) health,
- (2) relationships,
- (3) housing.

Siblings highest rated domains were

- (1) health,
- (2) activities of personal interest,
- (3) personal growth,
- (4) decision-making.

School personnel rated most highly

- (1) health and
- (2) relationships.

Adult service personnel rated most highly

- (1) housing,
- (2) personal growth and
- (3) decision-making.

Community members highest rated categories were

- (1) health,
- (2) relationships,
- (3) what people do during the day.

Shared Vision – Five Most Important Domains

The survey asked each respondent to choose the five most important life domains. The domains highlighted in the table were the five life domains most frequently chosen by each of the groups. Almost universally each of the groups focused on:

- Housing
- Employment
- Relationships
- Continued Learning and Personal Growth
- Health.

These areas align with the expectations and the importance rankings cited earlier.

	Parents		Siblings		School Personnel		Adult Service Personnel		Community Members	
Being educated with typical peers	26	53.1%	1	33.3%	52.9%	9	50.0%	5	37.0%	27
Housing	29	59.2%	2	66.7%	88.2%	15	100.0%	10	87.7%	64
Having a job and a career	35	71.4%	3	100.0%	76.5%	13	90.0%	9	67.1%	49
Having a variety of things to do	27	55.1%	3	100.0%	52.9%	9	40.0%	4	49.3%	36
Developing relationships	38	77.6%	2	66.7%	64.7%	11	80.0%	8	75.3%	55
Having opportunities for continued learning and to explore personal interests	35	71.4%	1	33.3%	58.8%	10	40.0%	4	58.9%	43
Being healthy	33	67.3%	2	66.7%	70.6%	12	80.0%	8	68.5%	50
Being a member of a faith community	2	4.1%			35.3%	6			2.7%	2
Having opportunities making informed decisions	20	40.8%	1	33.3%			20.0%	2	53.4%	39

V. Life Domains

For each life domain, this section will provide a summary of

- (a) The experiences of individuals with disabilities;
- (b) Services and supports currently used by families, recommendations of families;
- (c) Information needed by families, information sources used by families;
- (d) Challenges and suggestions identified by school personnel;
- (e) Challenges and suggestions identified by adult services personnel;
- (f) Challenges and suggestions identified by community members;
- (g) Summary, general impressions, recommendations.

Note – School personnel, adult service personnel and community members provided a deep array of ideas for addressing the challenges identified for each life domain. Although there were many overlapping comments and suggestions, we believe it was important to attempt to list all the ideas presented. We also decided that the best way to present those ideas was to use direct quotes from the surveys.

Education - Most Important Factors (Pick 3)

	Parents		Siblings		School Personnel		Adult Service Personnel		Community Members	
Going to school in the town where the student lives	18.2%	4			22.2%	2	40.0%	2	16.7%	4
Being in the same grade as other students of the same age	27.3%	6		1	44.4%	4	60.0%	3	20.8%	5
Receiving special services that are based on disability	81.8%	18		1	11.1%	1	60.0%	3	54.2%	13
Receiving information about grade level curriculum	13.6%	3		1	66.7%	6			4.2%	1
Receiving information about strategies and techniques that promote positive outcomes	45.5%	10			77.8%	7	20.0%	1	58.3%	14
Individual needs are taken into account	72.7%	16			22.2%	2	60.0%	3	62.5%	15
Receiving effective transition goals and services	36.4%	8			55.6%	5	60.0%	3	70.8%	17
Fully implement IEPs and other plans					55.6	5				
Other (please describe)	4.5%	1							12.5%	3

Other Factors Cited:

Educator Training on inclusion
 Well designed and fully implemented IEPs
 Person-Centered planning and thinking

The factors most frequently cited as important were:

- Meeting individual needs based on student's disability;
- Receiving information about strategies that promote positive outcomes;
- Receiving effective transition goals and services.

School personnel noted three other important factors – these focused on the daily implementation of instruction and curriculum:

- Fully implementing IEPs and other plans;
- Being in the same grade as other students of the same age;

- Information about grade level curriculum.

Although the different sets of factors are compatible, they do illustrate different perspectives about education and the need to have qualitative school-family communication so that families have a better understanding of the logistics of school and school personnel have a better understanding of family perspectives about disability and school.

Experiences of Adolescents/Adults

12 respondents to the adolescent/adult survey reported that 58% of their elementary school experience was mostly with typical peers, 75% of their middle school experience was mostly with typical peers, and 67% of their high school experience was mostly with typical peers. For this sample, approximately one third of their time was spent mostly with other students who had a disability.

58% rated their school experience as good or great. 33% rated their school experience as not very good or not very good at all. Comments re: the “best” part of school focused on friendships or specific curricular or extra-curricular experiences. The challenges listed were primarily difficulty with various academic domains. One respondent cited that “economic inequality was stigmatizing”.

Services and Supports Currently Used by Families, Recommendations of Families

Families describe using the specialized instruction and related services that are provided through special educational school programs. 76% describe these services as effective or very effective. 64% are satisfied or very satisfied with the services received. Comments focused on (a) creating more options for students with emotional/behavioral disabilities, (b) increased access to assistive technology and (c) difficulties with transitioning from elementary school to high school.

18% of parents rated the school experience as great, 32% as good, 36% as OK. Comments included (a) the need for more supports for students with emotional/behavioral disabilities – particularly at the high school, (b) better communication with “some” school personnel.

Recommendations for improving the school experience included a broad array of ideas. One of the major themes focused on communication with families and on accountability of school personnel to families. Another theme questioned the value of suspensions and the need both to understand the cause of behavior and for strategies to keep students with challenges more engaged in the process. Another major theme focused on professional development for school personnel across a number of disability topics. Other comments focused on supports for inclusion, assistive technology, more effective supports for transition and the need for after school programs.

Information Needed by Families, Information Sources Used by Families

Parents described a number of informational needs. These included more information about district goals and practices, transition, services and supports available for each student. 57% report receiving the information they need. Throughout the survey, families primarily received information from three major sources – (a) in person meetings (one-on-one or small group), (b) on line or (c) through public media.

Experiences and Recommendations of School Personnel

50% of school personnel report that students with disabilities spend more than 70% of their with typical students and receive the same curriculum more than 70% of the time. The other 50% report that students with IEP are educated with typical students 40-70% of the time. 90% believe these percentages are about right.

10% of teachers report having everything I need, 50% report having most of what they need and 40% report having some of what they need. In discussing what would increase their effectiveness, suggestions included (a) more time and space to develop differentiated instruction and needed accommodations, (b) training for paraprofessionals, (c) conference opportunities and (d) time to consult with behavioral therapists/adjustment counselors/social workers.

School strengths highlighted the experience and competence of staff and the Bridge Program. The challenges discussed included (a) responses to challenging behaviors, (b) misdiagnosis of the needs of some students, (c) inconsistent expectations (*this further supports the need for family-school communication*) and (d) the curriculum continuum. Several referenced the need for more vocational opportunities, both in school and in the community (*this is a consistent theme throughout all the groups responding the survey*).

70% of school personnel reported that students with disabilities participated in extra-curricular activities with typical. An array of activities (mostly school sponsored) were listed. Several commented on the need for more extracurricular activities, particularly in community settings.

School personnel emphasized the need for professional development and training for both school personnel and parents, particularly strategies for students with social/emotional needs and strategies that promote inclusion. There was also discussion of the growing population of high functioning students with Autism and the need for enhanced supports for students transitioning from school.

In response to the question “what would you like to be different in three-five years”, there was significant discussion about the negative impact of high stakes testing and the need to pass the MCAS to get a diploma (*Remember the expectation cited earlier that students graduate high school with a diploma*). Other discussion focused on (a) the need for administration to understand the supports needed to effectively instruct students with a wide range of disabilities, (b) the need for more inclusion and (c) the need for better post-graduation opportunities.

Additional Challenges or Suggestions Identified by Adult Services Personnel

Comments and suggestions from adult services personnel included:

- Students with disabilities should have somewhere to go after high school that can help them continue to learn and grow to live an independent lifestyle. Some students may be interested in going to college or learning a trade but other can seem to get lost in the community and isolate themselves.
- I think there should be more options for students with disabilities after high school. There should be a place where they can continue to learn some of the day to day things they will have to deal with as an adult. Ex. Money management, job skills, grocery shopping/nutrition/meal planning.
- More transitional programs for students once they finish with school.

- A more aggressive approach earlier in a person's life, with person's entire team including family, friends, educators and providers. More support earlier for person's future, support to identify goals that can be supported and in turn would have a more positive outcome later in their lives.

Additional Challenges or Suggestions Identified by Community Members

The challenges and strategies suggested by community members echoed the same themes as school personnel. Suggestions (these are actual quotes) included:

- Bigger thinking about what the school could/should initiate and deliver. more self-advocacy training for students with disabilities. an Island-located Independent Living Center to be the hub for education and the navigation and management of formal/informal supports.
- More accessible school buildings. Better training for all classroom teachers and support staff in how to support students with disabilities in the most inclusive ways possible. Focus on providing supports within the typical classroom rather than pulling them out for services.
- Everyone leaves the high school with someplace to go on the day the school bus stops coming
- Truly inclusive schools. Classrooms that support and recognize potential. Focus on transition, and how to begin preparing at an earlier age. the current mindset seems to increase challenges and barriers for students and families.
- More choice, classes and courses that assist them with transition from school to adulthood, more integration from early grades so students can form friendships and work and career opportunities.

Summary, General Impressions and Recommendations:

- One of the major themes is the need for increased **family–school conversations** re: curriculum, available options/services, parental requests, etc. A series of grade or age level discussions to explain school policy and goals, curriculum and available services and supports would be very useful.
- Several families described a need for information. The development of a **comprehensive guide** that lists all services and supports available for students and their families would help meet that need. Guide should describe specifically what each service does, eligibility criteria, how to access, cost (if any) and other pertinent information.
- There were a large number of comments about meeting **social/emotional needs** of students and about students with behavioral/emotional disabilities. Implementing something like Positive Behavioral Interventions and Supports (PBIS) would provide a structure for addressing those issues (*refer to www.pbis.org for information*).
- There were also a large number of comments about increasing **inclusion**. Families and school personnel often have different understandings of inclusion. There is evidence that facilitated student-centered planning meetings attended by regular educators, special educators and families have been effective in building a common understanding of inclusion and in developing an effective plan.
- **Transition** was another major topic. Recommendations included increasing pre-vocational instruction both in school and in the community, providing **internships** in a variety of island businesses and providing navigators to assist students/families during the transition process.
- The value of **mentors** was also discussed. An interesting suggestion was to do island-wide of adolescents/adults with disabilities with mentors with similar interests.

Employment – Most Important Factors (Pick 3)

	Parents		Siblings		School Personnel		Adult Service Personnel		Community Members	
	Siblings									
Opportunities to explore businesses on the island	44.8%	13		2	18.2%	2	57.1%	4	20.0%	8
Opportunities for work trials and internships	55.2%	16	100%	3	63.6%	7	71.4%	5	72.5%	29
Career training in school	24.1%	7		1	45.5%	5	28.6%	2	27.5%	11
Post-secondary education or training	41.4%	12		2	18.2%	2	28.6%	2	37.5%	15
Availability of job developers (a job developer is someone who assists with goal development, assessment, skill development, interview and applications)	31.0%	9			54.5%	6	14.3%	1	37.5%	15
Availability of on-site job coaches	37.9%	11			63.6%	7			7.5%	3
Accessible transportation	17.2%	5		1	18.2%	2	57.1%	4	35.0%	14
Incentives for employers	13.8%	4			9.1%	1	28.6%	2	35.0%	14
Use of technology and accommodations that support career development	31.0%	9					14.3%	1	25.0%	10
Other (please describe)	3.4%	1			9.1%	1			2.5%	1

Other Factors Cited:

Development of work-related skills during high school in a supported internship setting.
 Ways to ease the fears of the unknown as they relate to hiring a worker with disabilities. Provide clear descriptions of their capabilities and disability and how they are qualified to perform the task at hand.
 Assistance with paperwork needed to obtain and maintain employment services.

The need to create opportunities for work trials and internships was universally considered to be an important factor. The other factors most frequently cited as important were:

- Opportunities to explore businesses on the island;
- The availability of employment personnel such as job developers and job coaches;

- Post-secondary education or training (this aligns with the expectations and technical school cited earlier);
- Transportation.

Experiences of Adolescents/Adults

Although a few of the respondents had jobs while in school, very few reported having school-based internships. None of the respondents are in college or technical school, but 46% would like to go to college and 27% would like to go to technical school.

6 of the 10 respondents have jobs, most with the chocolate industry. 5 of the 6 are employed year round. 40% report having had prior jobs that they no longer have.

Services and Supports Currently Used by Families, Recommendations of Families

Only a few of the responding families report receiving any employment supports – *remember that the majority of responding families had younger children*. Parents recommend in-school training, job developers and job coaches, internships and mentorships. Most asked for information about options and employment supports. An important suggestion was the creation of summer employment as preparation for long term employment. There were several comments about there not being enough employers on the island willing to employ people with disabilities – this suggests the need for employer outreach and support.

Information Needed by Families, Information Sources Used by Families

82% are currently not receiving any information about careers or employment. Most families are unsure of exactly what information they need. As with most other domains, families primarily received information from three major sources – (a) in person meetings (one-on-one or small group), (b) on line or (c) through public media.

Additional Challenges or Suggestions Identified by School Personnel

School Personnel comments included the following:

- Job coaches and job developers should be available to families and students with disabilities as well as be working with the post-secondary program at the HS to prepare students for working after they age out of the HS. More trained staff providing job trials (4-6 weeks in length) and job analyses at those job trials.
- More on-island post high school education. The masters in teaching program is fantastic- I would love to see more of those types of programs as well as job training/apprenticeship for the trades.
- True internships and work trials with job analyses for individuals.
- Career discussions should start earlier than high school.
- Opportunities, early as possible, to practice job related skills that would translate into adult life. Job opportunities for young adults with disabilities in community settings with other typical adults.
- Education to potential employers/ businesses willing to employ individuals with disabilities.

- More people with disabilities in the public eye, working and being supported. Increase in funding both on the local, state and federal level.

Additional Challenges or Suggestions Identified by Adult Services Personnel

Comments and suggestions from adult services personnel included:

- The seasonal nature of the employment field on the island can be challenging for people whose disabilities make them more comfortable functioning within a routine. Inconsistent earnings can also impact their SSDI benefits.
- A job training center where individuals can be assessed in different areas to see what kind of employment they should be placed into or apply to. It can also act as a center to train and have individuals feel confident about learning a trade before going to apply for a job.
- The person that I work with will never be self-sufficient enough to not have a support person with him. And, there are others I am sure are the same. So, what could be helpful is to have a service where 2-3 adults share a support person in a working situation.
- Help island businesses create job opportunities for islanders with disabilities.
- Support for people who want to start their own businesses and/or become self-employed.

Additional Challenges or Suggestions Identified by Community Members

Community members were very descriptive of the challenges to employment and provided several suggestions for addressing those challenges. Although there were multiple overlapping comments, in an attempt to fairly describe the thoughts of community members and to include ALL ideas, the comments and suggestions below are direct quotes from community member surveys.

- Significant lack of year round employment for the general public.
- Many businesses aren't even accessible to people with disabilities.
- Some employers continue to hire off island people, and pay for their transportation back and forth, instead of investing in the island community.
- Lack of options, transportation - VTA routes create some long wait times between bus routes, businesses slow down, staff get laid off.
- Lack of recognition by employers of this untapped human resource; lack of aggressive job development and sufficient numbers of well-trained job coaches, quality transition during late adolescent and young adult stages.
- Lack of experiences to determine interests/skills, poor preparation for careers through schools, lack of serious commitment to transition planning through the schools.
- Solid transition services for HS students which include experiences and internships in a wide variety of local businesses, school liaison to employers, off season employer mentoring, parent training on creating visions of high expectations for a rich life.
- Programs with more flexible eligibility criteria, supports for paid and unpaid work, mentoring opportunities, community action on hiring people with disabilities.
- More programming and outreach, on the job supports and training. I also think it would be great to do more outreach to the business community to encourage them to create more opportunities.
- Industries like services and retail are year round, so those industries could allow for accommodations with greater ease.

- Possible incentives for employers but also training, education and recruitment of business managers/owners. Supplemental funding for pay.
- Job development work that cultivates opportunities for telecommuting for folks with disabilities.
- More wrap around resources for those who need even more help than most to navigate this challenging environment.
- Dialogue, connecting those who are already employing folks with disabilities with other employers, learn from what works, utilize existing supports and identify what is needed. greater employment supports and services for people with barriers to employment, paid and unpaid opportunities.
- Provide forums/training for employer support, provide opportunities for a wide variety of internship, volunteer or work experiences for HS students, increase of examples of vision for employment for all, have the expectation that individuals with disabilities will be living, working and recreating, etc. in the community, train parents to have high expectations for inclusive programs and school experiences and why this is important.
- More State funding (that pays for the true cost of services) and a true commitment to bringing services to the island, stop with the one day a month Case Manager being viewed as an adequate level of services. Better transitioning programming from the high school. More options from ACE MV. Transportation to off-island opportunities.
- A few quality providers who have job development and coaching as a specialty.
- More options – shredding, recycling.
- Additional work places, i.e. Chilmark Chocolates to train and employ those with disabilities. Follow the Chilmark Chocolate program and create more opportunities.

Summary, General Impressions and Recommendations:

- Families stressed the need for information. As suggested earlier a **comprehensive guide** for families would be very helpful.
- The importance of **transition** was stressed by all groups and the need for **navigators or mentors** to help individuals navigate transition and the adult world. Several people stressed the **role of school** in developing career education opportunities and providing job trials.
- The need for **internships** was stressed by all groups. Using labor market data to determine the types of businesses on the island as the basis for developing a series of summer jobs and internships for each person. Such “**discovery**” facilitates a real understanding of types of work available and increases the likelihood of choosing a career that matches individual aptitudes and interests.
- There was a call for a few quality **on-island service providers** (organizations or staff) with specialty **expertise in job development** and support.
- Community members and families also stressed the importance of **employer outreach** – providing information about the value of employing people with disabilities, providing supports (e.g., job coaches) and exploring the possibility of **incentives for employers**.
- Several suggestions were made about encouraging **public entities to create set-asides** to employ people with disabilities.

Housing - Most Important Factors (Pick 3)

	Parents		Siblings		School Personnel		Adult Service Personnel		Community Members	
Options for living alone or with a chosen friend	52.0%	13		2	46.7%	7	50.0%	5	47.5%	28
On-island	64.0%	16		1	13.3%	2	20.0%	2	47.5%	28
Options for living with other people with disabilities	28.0%	7		1	13.3%	2	10.0%	1	13.6%	8
Fiscal support from a public entity	40.0%	10			40.0%	6	30.0%	3	10.2%	6
Fiscal support for home modifications	12.0%	3			86.7%	13	40.0%	4	18.6%	11
Staff support from a provider organization	36.0%	9			53.3%	8	20.0%	2	37.3%	22
Location that is near transportation	28.0%	7		1	40.0%	6	20.0%	2	32.2%	19
Finding stable year-round housing					6.7%	1	90.0%	9	74.6%	44
Having housekeeping supports							10.0%	1	11.9%	7
Conflict resolution to help resolve issues with roommates							10.0%	1	3.4%	2
Options for co-housing (services in exchange for housing)	24.0%	6								
Other (please describe)	8.0%	2		1					3.4%	2

Other Factors Cited:

Opportunity to own their own home.

A healthy home that has whatever accommodations are necessary for their disability.

Housing near potential employment.

Change accessory apartment bylaw for caregiver apartment - for support and respite for family;

Creating opportunities that fit the diverse needs of this population.

The factors most frequently cited as important were:

- The need to develop affordable year-round housing options so that individuals with disabilities can live on Martha's Vineyard either independently or with a few selected friends;
- Fiscal support from a public entity for housing supports and/or home modifications;
- Other housing supports – i.e., support staff.

Experiences of Adolescents/Adults

Of the 10 respondents - 3 live alone, 2 live with friends or roommates, 4 live with family and 1 in a residence for people with disabilities. 70% are happy with their living situation, 20% are unhappy. 90% want to live on Martha's Vineyard, one wants to live off island because "there is more to do".

The responses to "what supports do you need" all focused on transportation.

Services and Supports Currently Used by Families, Recommendations of Families

Because of the youth of most of the children of most of the responding parents, few are currently using any housing supports. One family used the adult foster care stipend to pay for expenses, one uses Tempus Unlimited, one is in an off-island group home, two are on a waiting list. Two commented on the importance of the accessory apartment zoning bylaw for caregiver apartments as a model for respite housing or for a caregiver. Families are generally not satisfied with housing supports and rate their effectiveness poorly. Families express the "hope" that their family member will live independently. Several comment on the need to develop affordable housing options.

Family recommendations include (a) allowing the construction of accessory buildings on family property designated for mentally and physically challenged, (b) more places where the people with disabilities can live or have more staff support available for people who lives in their family home, (c) more apartments available like hillside or group homes for autistic adults. One parent recommended that people with different abilities should be part of conversation/planning. The housing model should be an inclusion model of mixed housing co-housing models, support systems that are part of the community, housing that's relationship based.

Virtually every family commented on the need for information and assistance planning for life requirements beyond graduation.

Information Needed by Families, Information Sources Used by Families

92% of families are currently not receiving any information about housing options or supports. Families want information about "everything". One family wanted information about how a person with a disability could own their own home. Another wanted to know that "the IHT and/or the Dukes County Housing Authority is undertaking endeavors to make this a reality". As with most other domains, families primarily received information from three major sources – (a) in person meetings (one-on-one or small group), (b) on line or (c) through public media.....and word of mouth.

Additional Challenges or Suggestions Identified by School Personnel

School Personnel comments included the following:

- Obviously we need more year round affordable housing, but we also need a consistent home for disabled people who need support in their adult lives to help them be as independent as possible.

- Students with Autism and other developmental disabilities need a place to live away from their families, while still getting the services they need. Students graduating high school have no place to reside and be an independent adult to the best of their potential. Students should be able to live in a group home with their peers and sufficiently trained staff to care for them.
- For students with multiple disabilities (our Navigator, Voyager program), there is no support system in place for job training, job exploration, and job coaching. Additionally, support for housing, etc.
- Group homes that are staffed, funded, and located near town centers.
- More co-housing options.
- Financial support from state/federal/towns. Housing built for qualified individuals.
- I think we need subsidized affordable housing in the form of apartments, to maximize the number of units in a given area. It is hard for kids to plan to live and work on this island after school when there are so few options for housing available.
- IDC could work on getting assistance from the state and other established programs in MA to help fund housing for people with disabilities.

Additional Challenges or Suggestions Identified by Adult Services Personnel

Comments and suggestions from adult services personnel included:

- Many people "fall through the cracks" of state offered services that would allow them access to some housing opportunities. Maybe building out own group homes and setting up our own guidelines as to who should be offered a housing opportunity biased off their disability, income, family situation etc. Listen to the family and therapists regarding their needs.
- Offering tax discounts to people who rent year round Get more funds for subsidized housing Work with state.
- Reliable homeless shelter for people on the Vineyard who are living on the streets or out of their vehicles. and local agencies on fundraising to purchase or build more group homes for islanders.
- Fiscal support for rent, home modifications, etc.
- I'm not sure exactly what services/supports could influence housing. I would think it will take many residents and community members all working together to make it happen.
- More group housing options that are less costly for families in order to allow individuals with persistent disabilities (or even shorter term issues) to remain in the community instead of having to leave the island
- Cluster housing.

Additional Challenges or Suggestions Identified by Community Members

Community members were very much in agreement with housing issues on the island and provided several suggestions for addressing those challenges. Although there were multiple overlapping comments, in an attempt to fairly describe the thoughts of community members and to include ALL ideas, the comments and suggestions below are direct quotes from community member surveys.

- Cost. Affordability. Same issues apply to everyone.
- No inventory of affordable year round housing.
- Identification of needs and capabilities of people with disabilities. Those same barriers that apply to affordable housing and the NIMBY attitude of so many of our residents.

- Zoning that keeps out multi-family units; lot sizes, density, cost.
- You can't do much about supply. And it's insensible to depend on charity. You can, however, allow for more legal tweaks--for example, if you rent below market perhaps you'll get better landlord protections and speedier evictions, thereby lowering the risk.
- Create sustainable affordable communal or non-communal housing options for all residents and be inclusive of the elderly and disabled.
- In home care and support.
- Initiatives that promote attainable, affordable housing need to be universal, but individuals and groups that support people with disabilities need to be aware of opportunities for funds and programs for those folks. more self-advocacy here, as well as ILC.
- Subsidies, homeownership education and networking for people to meet like-minded folks who are interested in possibly co owning a year round home.
- Higher taxes for second homes, with that money going straight towards community services.
- Mixed communities where young and old, disabled and able bodied will live in same community. Not the same house, but nearby.
- Create incentives and exemptions from regulations for assisted living/preferred living.
- Offering housing stipends through some sort of fiscal support, partnering with community members, offering some sort of incentive to landlords.
- Subsidies, leaving the island, tax incentives for renting out subsidiary apartments to year round occupants, seeking/creating more roommate situations where people have an extra room in the house.
- Make it more lucrative and enticing for contractors to learn the standards for ADA accessibility and take on those types of retrofit projects for homes that were not built to those standards.
- Redefining the Land Bank as Land Use and Housing Bank that would be administered by a private entity with oversight from all six towns with a shared vision for housing/land use across the island. The Land Bank tax itself is a barrier for working families to live here.
- Current residential programs need more appropriate funding from the state and federal government in order to provide options and supports. Staffing in those programs need to be paid a living wage.
- More VTA routes to remote areas of the island, more wheelchair vans with some assistance to riders.
- One man's opinion: We need a coordinated, shared vision for housing on this island that includes people with disabilities (what kind of disabilities?), elderly, frail elderly, seasonal workforce and young working families. In my opinion, one cannot talk about one of these demographics without including everyone or else you risk duplication of efforts and reduce efficiency. Unfortunately, there is very little political will to make this happen.

Summary, General Impressions and Recommendations:

- **Lack of information** about year round affordable housing is a major concern. As with other domains, the development of a **comprehensive guide** of options and supports would be helpful to families. The IDC could serve as a **central site for information**.
- Explore the possibility of housing **subsidies** (i.e., rent support) and subsidies for home modifications. Community members had several suggestions about regulations et al that would provide a variety of incentives to increase housing options.

- Pursue the use of bylaws to build **accessory apartments**, caregiver apartments.
- The IDC could facilitate an **island-wide discussion** about the development of affordable housing options.

Daily Activities, Leisure, Recreation - Most Important Factors (Pick 3)

	Parents		Siblings		School Personnel		Adult Service Personnel		Community Members	
Opportunities to join organizations open to everyone	47.1%	8		1	57.1%	4		2	60.0%	18
More leisure opportunities specifically designed for people with disabilities	47.1%	8		2	57.1%	4			33.3%	10
Removing barriers to public and private buildings	29.4%	5		1					53.3%	16
Accessible transportation	23.5%	4		1	28.6%	2		3	53.3%	16
Use of technology and accommodations that support daily living	35.3%	6		1	57.1%	4			16.7%	5
Instruction in life activities such as shopping, banking, etc.	29.4%	5		2	71.4%	5		2	26.7%	8
Reducing risk of social isolation and depression	76.5%	13		1				2	53.3%	16
Other (please identify)	11.8%	2			28.6%	2			3.3%	1

Other Factors Cited:

Depends on the nature of the disability.

Leisure Opportunities designed for all kids, not just kids with disabilities.

Inclusion opportunities with support for teenagers.

Support when joining organizations.

More trained staff to provide support to organizations.

Reducing the risk of isolation was a frequently cited outcome and purpose for this life domain. The factors most frequently cited as important were:

- Opportunity to join and participate in organizations that are open to everyone;
- Leisure opportunities specifically for people with disabilities;
- Instruction in life activities:
- Removing architectural barriers;
- Increased access to technology;
- Transportation.

It is worth noting that individuals with disabilities who responded to the survey wanted a greater number and variety of activities. Many were unaware of only a limited range of opportunities on Martha's Vineyard.

Experiences of Adolescents/Adults

60% of the respondents report having an active social life, 40% do not. Family and friends (with similar interests) are the most frequent social partners....co-workers are mentioned only once.

When asked what they need to do to make more friends, the most common answer was "I don't know". When asked if there were places where they could make more friends, 70% were unsure. Recommendations for types of places including coffee houses, drop-in center, places where "people had similar interests".

Many respondents reported using smartphones, tablets, laptops. Several said they would like to use the computer better.

33% drive, 67% do not. Only one person expressed interest in learning to drive. 78% use public transportation. Of those who not, one expressed interest in learning how to use public transportation.

Services and Supports Currently Used by Families, Recommendations of Families

71% of parents believe that Martha's Vineyard needs more places where their family member can meet other people. Parents list a variety of options. One parent summarized the issue – "**Flexible funding** to access programming. The real issue was when my son was younger and there was **NO available supported after school programming** for him -- this led to social isolation and depression. He has made enough gains now that he can access programming with typical peers in most cases. He does much better in **supported situations with adults available for support.**"

53% of parents are satisfied or very satisfied with leisure and recreation services on the island. Recommendations included structured social groups in school, more school sponsored after school activities, support for membership to community clubs and organizations, more sports, accessible spaces, inclusion training for leisure and recreation organizations, supports that help individuals participate, more activities during the off season.

Information Needed by Families, Information Sources Used by Families

Only 31% of families currently receive information about daily life, leisure or recreation activities. The most common source of information are on line and public media. Families want information about leisure and recreation options. Several recommended a centralized source for information, like the "over 55 section in the MV Times".

Additional Challenges or Suggestions Identified by School Personnel

School Personnel comments included the following:

- More after school activities/sports that allow students with disabilities to participate with typical, age appropriate peers. (The unified basketball team at the high school was GREAT).
- Increased opportunities for all children that are inherently missing in isolated communities such as ours.
- More peers to facilitate leisure activities.
- Expand opportunities for students pre-K-22 as well as adults. Clubs, classes, etc.. A variety of activities/sports that allow students with disabilities to participate with typical age appropriate peers and the staff that are trained to support these types of students in these activities.
- More partnerships with community businesses and organizations.

Experiences of Adult Service Personnel

Adult Service Personnel were asked a series of questions about professional development, service delivery models and other topics. This information is applicable to several life domains, but is being summarized here. (*Note – the number of responses to these questions were small*)

The personnel responding to the survey report providing supports in all the life domains referenced throughout this summary. They support an average of 4-5 people on a daily basis and about 20 people on an annual basis. 1/3 report that the people they support spend less than 5 hours per week in integrated community settings for all people, 1/3 spend 5-10 hours and 1/3 spend more than 10 hours. Half report that the people support spend less than 5 hours per week in settings primarily for people with disabilities, half spend more than 10 hours per week in such settings. Individuals with disabilities report that 50% participate in activities primarily in groups of other people with disabilities. When asked what would increase opportunities for integration, the most common responses were more staff, more community opportunities, transportation, willingness of provider agency to expand what they do.

Staff report that the strengths of their organizations were the variety of services they provide and their ability to link to other services. The challenges they report include “not reaching out to community enough”, difficulties in training staff for all the range of people they support, and fiscal issues. Also noted was that “Island Employment is a closed referral process, so we have to work with individuals that are referred from MRC. This may limit some opportunities for others.”

33% report that they have all the training, resources and support they need; 50% report that they have some of what they need. The average hours of professional development and training every year (the range was 0-45). Although the list of trainings were extensive, most were reported by only 1 or 2 people.

Additional Challenges or Suggestions Identified by Adult Services Personnel

Comments and suggestions from adult services personnel included:

- More transportation options. Not just for the disabled, but for anyone without a car. The VTA is tough, especially in the winter.
- More opportunities for inclusive events/gatherings in the community.
- More free/no cost/scholarship opportunities for activities like art classes or other active, community engaged things that encourage engagement with others.

- Overall case management is not something that is currently provided for individuals with disabilities.

Additional Challenges or Suggestions Identified by Community Members

As stated in the discussion of other life domains, there were multiple overlapping comments from community members. In an attempt to fairly describe the thoughts of community members and to include ALL ideas, the comments and suggestions below are direct quotes from community member surveys.

- I would love to see accessibility become the norm - that people with disabilities don't have to think about whether somewhere they want to go, or something they want to do can or can't support them.
- I would hope that in three to five years, individuals with disabilities and their families would not have to question if their child is welcome or able to participate in whatever activity they want to. I would hope that at that point there isn't even a question or conversation about whether they can participate, it is just a fluid thing that happens.
- Fewer physical barriers to daily life. More accessible sidewalks.
- Unless you have a roof over your head, nothing else matters. all the services in the world will not be of use to you unless you have a safe, affordable place to live. Housing opportunities are the beginning of everything. Once you have a stable living situation, everything else can fall into place.
- More options - more inclusive advertising and community outreach.
- A plan that lays out the actual needs and a prioritization of what is most important in the short term vs the long term.
- What I would want for that group would be what I would want for anyone living in our community: The freedom and access to a pursue a meaningful and healthy life.
- The bowling alley certainly increased the daily life opportunities for many rather than traveling to Falmouth for bowling. Accessibility to golf, swimming lessons, affordable membership for exercise at the YMCA, sailing, Special Olympics on the Vineyard.
- More transportation like The Lift for handicapped individuals who are not disabled enough to qualify for The Lift. There is a large group in the middle. Not disabled enough to qualify for the Lift, yet not able bodied enough to use regular bus service -- so they sit home and watch TV instead of going to the Y to work out and socialize in the Y cafe, so they can get some work, etc.
- Case management to navigate the service system; continued advocacy on inclusion and access to programs across the island; training and consultation for line staff in programs across the island to provide tools for increasing confidence to include all in programming. Provision of examples of success stories to demonstrate possibilities.
- Participation in all aspects of life. There seem to be very few people with disabilities at town meeting, at the movies, at concerts, and most of the beaches are difficult to access.

Summary, General Impressions and Recommendations:

There were several ideas pertinent to daily life, recreation and leisure suggested by survey respondents.

- Developing a **club house** (e.g., a drop in center);
- Providing **mini grants** to recreation/leisure organizations to increase accessibility;

- **Accessibility** of public (and private) spaces was a theme raised by all groups.
- Providing **fiscal support for membership fees**, admission fees, etc. to leisure and recreation organizations;
- Providing **support to community organizations** re: how to support/include people;
- Creating a **comprehensive list** of leisure and recreation options and a **centralized source for information**.

Relationships - Most Important Factors (Pick 3)

	Parents		Siblings (No Responses)		School Personnel		Adult Service Personnel		Community Members	
Skill development opportunities in how to build and maintain relationships	60.9%	14			75.0%	6	83.3%	5	65.9%	29
Healthy relationship education	34.8%	8			75.0%	6	83.3%	5	61.4%	27
Instruction in how to build and maintain relationships	47.8%	11								
Sex Education	4.3%	1								
Access to clubs and organizations open to everyone	43.5%	10			100.0%	8	50.0%	3	79.5%	35
Access to clubs and organizations primarily for people with disabilities	17.4%	4					16.7%	1	18.2%	8
Use of technology and accommodations that support the development of relationships	21.7%	5			12.5%	1	33.3%	2	36.4%	16
Opportunities during school day (lunch, recess, etc.)					37.5%	3				
Conflict Resolution							33.3%	2	25.0%	11
Feeling welcomed	52.2%	12								
Other (please describe)	17.4%	4							13.6%	6

Other Factors Cited:

Transportation - Ability to get around.

Unconditional love, acceptance, presumed competence.

Activity that comes to the person.

Money and resources to join and participate in social activities, support to do so.

Dances, bowling nights, book clubs etc. that are consciously and supportively encouraging friendships across disability boundaries.

Support for people with disabilities who may be at highest risk for violence in their personal lives.

Train or educate the temporarily able-bodied about developing and maintaining relationships with people with disabilities.

Good evaluation and clustering of folks who can readily interact and advance their social skills with individuals who can appropriately respond.

Relationships were one of the highly rated priorities across all groups (as cited in earlier sections). Universally, the factors identified as most important were:

- Opportunities for education and/or instruction re: how to develop and maintain healthy relationships;
- Access to activities, clubs, organizations open to everyone.

Again, it is worth noting that individuals with disabilities who responded to the survey wanted a greater number and variety of activities and that many were aware of only a limited range of opportunities on Martha's Vineyard.

Experiences of Adolescents/Adults

60% of the respondents report having an active social life, 40% do not. Family and friends (with similar interests) are the most frequent social partners....co-workers are mentioned only once.

When asked what they need to do to make more friends, the most common answer was "I don't know". When asked if there were places where they could make more friends, 70% were unsure. Recommendations for types of places including coffee houses, drop-in center, places where "people had similar interests". Interesting to note that the responses were generic.....no one referenced specific organizations or clubs.

30% of the respondents are married, 40% have children (*Note – remember that a third of the sample were older adults who developed a disability later in life*).

Transportation was intermittently referenced as a need in several of the life domains.

Services and Supports Currently Used by Families, Recommendations of Families

Families report that their family members receive relationship support from a variety of school and community counselors, family friends, club houses for people with mental illness, family services through MVCS, and various "everyday" activities. 64% rate the services they receive as somewhat effective or very effective. 50% are very satisfied or somewhat satisfied with these supports.

Recommendations include increasing community awareness and understanding of the nature and needs of people with disabilities, more organized social events for people with disabilities, helping individuals find a group of peers, more activities like unified sports, strategies for preventing bullying.

Information Needed by Families, Information Sources Used by Families

36% of families currently receive information related to relationships and social engagement. Families have very little information about how to help their family member develop and maintain relationships. As with most other domains, families primarily received information from three major sources – (a) in person meetings (one-on-one or small group), (b) on line or (c) through public media.

Additional Challenges or Suggestions Identified by School Personnel

School Personnel comments included the following:

- Ongoing support and teaching in the area of social interaction skills.
- More education regarding relationships and what it means to be in a healthy relationship. Perhaps mentors available to discuss relationship issues with.
- More social groups aimed at middle school/high school kids- similar to some of the programs offered at the Y.
- Increased opportunities such as clubs, sports, activities that are needed to augment the lack of things to do for all young people in general.
- Increased opportunities to interact with non-disabled persons/peers.
- Earlier intervention with intense support so that children, teachers, and families can all use similar language and routines to help teach emotionally/behaviorally challenged children and families critical social and coping skills.

Additional Challenges or Suggestions Identified by Adult Services Personnel

Comments and suggestions from adult services personnel included:

- Services such as case management for person's to assist/support a person in all areas of their needs. Some do not fall into a category that would qualify them with programs such as DDS or DMH.
- Less emphasis on group home activities and the notion that individuals with disabilities all need to be together "all the time".
- Public support groups and/or workshops that are run by someone who is familiar with working with individuals with disabilities.
- A place, a clubhouse where people can congregate.
- I would like to see more organizations be sensitive to the needs of those with disabilities. Even ICC's building is not sensitive to this e.g., long ramp with incline to building, handicapped parking availability and doorways.

Additional Challenges or Suggestions Identified by Community Members

As stated in the discussion of other life domains, there were multiple overlapping comments from community members. In an attempt to fairly describe the thoughts of community members and to include ALL ideas, the comments and suggestions below are direct quotes from community member surveys.

- Free transportation to community events.
- Development of community awareness around natural supports.
- More awareness of healthy relationship education for people with disabilities so they have more knowledge on building healthy relationships and warning signs for abuse and who to talk to if they are in an abusive relationship.
- Specifically focused clubs- gardening, knitting, reading, walking, etc.
- Social opportunities to bond over common interests, increase recreation and leisure to create opportunities to connect. the opportunities need to be marketed to ALL so folks know that they will be included.
- More attention in public education curriculum to skill development; continued and enhanced effort to make clubs and organizations more accommodating and inclusive.

- Starting at an early age, provide opportunities and support for students and parents to see what is possible and to learn from peers about how to be a good friend and why it is important. Connections with peers in HS so that peers can see gifts, talents and common interests in hopes of creating future opportunities for recreation, work, etc. Encourage/train students to connect with peers in authentic ways (not pity).
- Far more presence of people with disabilities in all community sectors, clubs, organizations not necessarily as a group but more individually.
- Show more people with disabilities in pop-culture arenas - commercials, movies - you never see people with disabilities on the Cricket Wireless commercial.
- Solid examples from teachers, school staff and community members on the belief that everyone is welcome and viewed as a contributing community member- who doesn't want to contribute??
- More opportunities to engage in team building events with people without disabilities.
- More of a chance to be heard and included in all the things that everyone else on the island is doing -- working, going to movies, bowling, eating pizza, book clubs, swimming, working out, hearing a concert, going to town meeting, etc.
- Micro transit opportunities in remote parts of the island where fixed route service shows low demand. MicroTransit will pick up folks with disabilities at their door (but will not always take them all the way to final destination). MicroTransit providers can typically traverse some roads that VTA buses cannot.

Summary, General Impressions and Recommendations:

There is evidence in disability research that most people with disabilities are lonely and have significantly fewer relationships than people without disabilities.

- Social support and **instruction** (both in school and through adult groups) in **communication and social skills** has proven to facilitate social engagement;
- Relationships are often rooted in **common interests and common places** – developing a comprehensive list where interests can be explored with others;
- Including people in **team-building and decision-making** activities;
- Mentors can be helpful. **Island-wide matching of people with disabilities with mentors** (as suggested by several people) can be an effective;
- Again, a **centralized source for information** about social activities, clubs, etc.

Continued Learning and Exploration of Personal Interests - Most Important Factors (Pick 3)

	Parents		Siblings (No Responses)		School Personnel		Adult Service Personnel		Community Members	
College					37.5%	3		1	9.1%	3
Continued education on a variety of topics	86.4%	19			87.5%	7		3	81.8%	27
Increased access to online learning opportunities	45.5%	10			12.5%	1			21.2%	7
Fiscal support for online learning	36.4%	8						1	33.3%	11
Use of technology and accommodations that support continued learning	40.9%	9			37.5%	3			60.6%	20
Island-wide matching of people with disabilities with mentors with similar interests	77.3%	17			87.5%	7		3	81.8%	27
Other (please describe)	13.6%	3			37.5%	3			12.1%	4

Other Factors Cited:

Support for those in jail.

Presumed competence

Skills training and job shadowing opportunities with private employers.

Degree or vocational programs that lead to jobs.

Depends on the nature of the disability.

Planning and support for access for what is best for the individual person.

Fiscal support for all types of post high school learning (college, trades, etc.).

The factors identified as important for continued learning and personal growth are very similar to the factors identified for daily living, recreation, leisure and developing and maintaining relationships. Most noteworthy was the cited importance of an island-wide system for matching people with disabilities with mentors with similar interests. Matching people with mentors was a theme across several life domains (education, employment, faith communities). Other factors cited as important were:

- Opportunities for continuing education on a variety of topics using a variety of media and modalities;
- Access to on-line learning opportunities;
- Technology.

Experiences of Adolescents/Adults

None of the respondents are in college or technical school, but 46% would like to go to college and 27% would like to go to technical school. Only one respondent is involved in any on line learning. A few

reported topics they would like to learn about. 56% would be willing to go to an educational event to learn more about something that interests them.

Most of the respondents had interests, many did not know how to pursue them. 70% believe Martha's Vineyard needs more places to go to have fun or explore personal interests. 56% are interested in going to educational events to learn more about their interests.

Services and Supports Currently Used by Families, Recommendations of Families

Other than services provided through the schools, most families are not accessing any supports geared towards continued learning and personal growth. Families recommended club house type activities, more topical education on island and off island appropriate to age, on line or in person college courses, peer mentors, community mentors with similar interests, opportunities to try new activities, increased access and instruction re: how to use technology. One parent summarized "an awareness of what all services on and off the island have to offer - perhaps a health, wellness, and education, and recreation/interests "fair" with tables/displays/brochures/short videos, essentially advertising a vast variety of what is 'out there' for the public to access".

Information Needed by Families, Information Sources Used by Families

Only 32% of families are currently receiving information about opportunities for continuing education and personal growth. As with most other domains, families primarily received information from three major sources – (a) in person meetings (one-on-one or small group), (b) on line or (c) through public media.

Additional Challenges or Suggestions Identified by School Personnel

School Personnel comments included the following:

- Continuing education programs for students after graduating high school that continue to teach them what they need to be functioning and independent adults on MV.
- More classes on-island and online, more funding to support those classes, and more personnel to act as coordinators in and out of school, helping people with disabilities navigate these opportunities.
- More mentorships, social groups, and outreach aimed at identifying interests and learning styles and finding opportunities for people with disabilities.
- Increased opportunities such as clubs, sports, activities that are needed to augment the lack of things to do for all young people in general.
- Places to hang out.... coffee shops, maker spaces. More opportunities to interact with non-disabled peers.
- Making sure families and students are aware of these opportunities.

Additional Challenges or Suggestions Identified by Adult Services Personnel

Comments and suggestions from adult services personnel included:

- More options for education on MV (College courses or continued learning classes).

Additional Challenges or Suggestions Identified by Community Members

As stated in the discussion of other life domains, there were multiple overlapping comments from community members. In an attempt to fairly describe the thoughts of community members and to include ALL ideas, the comments and suggestions below are direct quotes from community member surveys.

- Social isolation is something I see in a lot of our library patrons, especially the elders and those with disabilities. There is often a good range of classes, events and other programs on our island, even through the winter, but if one isn't aware of them, if they aren't accessible (for example, sign language interpreter for a book talk) and there is not free transport to them, those who need them most are left out.
- Promote craftsmanship and have a venue for selling handmade items. Creating Vineyard themed items to sell. Have a consignment shop.
- I like the matching idea for those with disabilities to be mentored by those with similar interests!
- Continuing education opportunities and access to the local labor market are critical concerns for the entire opportunity. We have a rapidly aging community and 66% of our workforce is 55 years or older. Who is coming up to take over for them (and who can afford to)? People with disabilities need access to education, skills training and job shadowing opportunities with trusted businesses.
- Adult ed. courses on island could offer ways for people to continue to learn, connect with others with similar interests, etc. On-line learning is great but can be isolating.
- I think a mentorship program would be great - it could serve as a second step in the STEP program and the internship could transition to a job opportunity after high school and beyond while keeping the mentorship component.
- More opportunities for people with disabilities to engage with community members in learning environments. Recruitment of instructors for adult ed. opportunities who are willing to support all learners and tailor the course to allow all to be successful.
- Increased use of technology. Bringing everyone into the digital age through tech use instruction opportunities and providing appropriate hardware (computers).
- Some kind of communication tool (like what used to happen on a bulletin board at a coffee shop) for better and more consistent outreach by existing classes and formal and informal groups so that they could be inclusive . . . and support for people who need support to get to these events or to take part in them.

Summary, General Impressions and Recommendations:

Continued learning and opportunities for personal growth is another life domain that has not been a focus.

- Develop a relationship with a community college to offer **online learning opportunities**;
- Engage on island “experts” to offer **local “interest based” learning opportunities**;
- **Island wide person-person matching based on common interests.**

Healthy Living - Most Important Factors (Pick 3)

	Parents		Siblings		School Personnel		Adult Service Personnel		Community Members	
Instruction in building healthy living habits	42.9%	6		1	75.0%	6	71.4%	5	33.3%	13
Tools and resources that support healthy living	64.3%	9			62.5%	5	28.6%	2	56.4%	22
Matching people with disabilities with groups, clubs, or other organizations that promote exercise and healthy living	57.1%	8			62.5%	5	85.7%	6	46.2%	18
Use of technology and applications that support healthy living									23.1%	9
Access to affordable year-round resources that support healthy living	64.3%	9		1	12.5%	1	42.9%	3	71.8%	28
Helping people to avoid social isolation and depression	57.1%	8		1	87.5%	7	71.4%	5	66.7%	26
Other (please identify)	14.3%	2							2.6%	1

Other Factors Cited:

Case Workers.
 Specific resources for obese youth.
 Free health care.

The instructions for this section focused on factors other than actual health care services. The factors cited as important were:

- Instruction re: developing healthy living habits;
- Year round tools and resources that support healthy living;
- Membership in organizations that promote exercise and healthy living;
- Helping people to avoid social isolation.

Services and Supports Currently Used by Families, Recommendations of Families

79% of families report that their family member always having access to quality health care, 21% do not. 50% of the services they receive are off island. The people who do not have health care report that the services their family member needs are not available on island or that they are on a wait list. 78% are satisfied with the services they receive. One parent stated that good pediatric care is available on island, but specialty care is only available off island. “That is time consuming, expensive, and requires a parent who can leave island regularly to take child to care – parents are not able to work full time.”

57% report that their family member always has quality dental care, 22% sometimes have dental care, 22% have no dental care. Families report that they cannot afford dental care, Mass Health and/or other insurers do not cover the services needed, appointments are hard to get, the care they need is not available on island, and that many dentists do not understand the needs of their family member. 36% report that the dental care they receive is very effective and 36% report it is somewhat effective.

71% report that their family member always or sometimes has access to quality mental health care, 29% do not. The reasons for not having mental health care are similar to the reasons for not having health or dental care. 29% describe the services as very effective, 43% describe services as somewhat effective.

57% of families report that their family members do not need substance abuse specialists. 14% always have access to substance abuse specialists, 21% sometime have access, 7% do not. Families report that more counselling options are needed.

One parent stated that pediatricians need to clearly explain to the parents of their patients w special needs how the parents can get care for their kids. Too often the pediatricians refer only to the school for an educational assessment, and parents don't understand that isn't sufficient -- all pediatricians need to educate parents, and assist them getting developmental evaluations by specialists who can give medical diagnoses and support. This will get the kids better care.

Another parent described the difficulties this way – “I wish there was someone who could help us coordinate our family members care... to figure out how to find the right help and supports. At this point, I have just stopped trying in many ways. It’s exhausting and frustrating.”

Information Needed by Families, Information Sources Used by Families

43% are currently receive health care information. As with most other domains, families primarily received information from three major sources – (a) in person meetings (one-on-one or small group), (b) on line or (c) through public media.....and word of mouth.

Additional Challenges or Suggestions Identified by School Personnel

School Personnel comments included the following:

- More practitioners that are easily accessible: dental, mental and physical health, and addiction.
- More clinicians at Island Wide collaborative. Counseling to students and families that happen when clients are stable, that is when even more profound work can be made. Full wrap around services.

- Doctors that are educated about our population
- The ability to access and have more providers accept Mass Health. Currently, there are insurances that do not cover people with Down Syndrome, eat- these are considers pre-existing conditions. That is nonsense - I had read not too long ago that more and more providers were not going to accept Mass Health- This is discriminatory and pushing off the island people who are economically struggling, people with disability, etc.

Additional Challenges or Suggestions Identified by Adult Services Personnel

Comments and suggestions from adult services personnel included:

- Matching people with disabilities with groups, clubs or other organizations that promote exercise and healthy living.
- Instruction in healthy living habits.
- Group classes offered for free on different cooking activities, walking clubs, etc.

Additional Challenges or Suggestions Identified by Community Members

As stated in the discussion of other life domains, there were multiple overlapping comments from community members. In an attempt to fairly describe the thoughts of community members and to include ALL ideas, the comments and suggestions below are direct quotes from community member surveys.

- More opportunities for people with disabilities to apply for, be hired for, and retain year round work. I would imagine that the high wait lists at existing health care, dental and mental health care sites are an additional barrier for people with disabilities. Perhaps more work with existing locations around how best to meet the needs of all islanders, or preferred spots?
- Much like housing, the paucity of primary, mental health and dental care are not disability-specific. The service-provision neighborhood needs to step up to benefit the entire community.
- A road map to care with wellness for people with disabilities.
- More ease of access/awareness of existing services and education being done with service providers.
- Providers trained (truly trained - not a one off course taken three years ago) in meeting the needs of people with disabilities.
- Build capacity of mental health providers to enable them to better support individuals with disabilities. Health care is an issue for many islanders due to the lack of providers on the island. Physicians need to be continually reminded about resources for families that include family members with disabilities, particularly when children are newborns. The lack of information, resources and connections for these families is significant.
- I don't know if MassHealth membership and disability needs completely overlap. If not, at least, that. Check overall MassHealth eligibility and island definitions to be sure that the high costs here don't keep Islanders from those supports and services.
- More participation of people with disabilities in inclusive exercise/fitness opportunities.

Summary, General Impressions and Recommendations:

The healthcare questions clearly delineate a sharp difference between those who have access to services and those who do not. There is also a strong description of the specialty services that are not available on the island. Thus, the need for **additional services** across the healthcare, dental, mental health and substance abuse domains is evident. Influencing this may not be within the reach of the IDC.

- Many families need **fiscal support** to increase access to healthcare.
- As with virtually every other domain, individuals with disabilities and families describe a huge need for **information**. IDC could develop a **comprehensive list** of service providers, resources, etc.
- There were ideas for promoting **healthy lifestyle**. These include (a) **health mentors**, (b) funding **membership fees** to organizations that promote fitness and (c) providing **support to fitness organizations** re: accommodations.

Faith Communities - Most Important Factors (Pick 3)

	Parents		Siblings (No Responses)		School Personnel		Adult Service Personnel (No Responses)		Community Members	
Outreach and support to faith communities to help each community support their members who have disabilities	100%	1							1	50%
Family connection to a faith community	100.0%	1								
Access to information about the different faith communities on Martha's Vineyard	100.0%	1							50.0%	1
Linking individuals to mentors from faith communities									100.0%	2
Transportation provided by community members									100.0%	2
Feeling welcomed										

There were very few comments about faith communities. For the few who did comment on this life domain, the focus was on outreach to faith communities, information and family connections. There was an important comment about faith communities as a source for mentors.

Experiences of Adolescents/Adults

44% belong to a faith community, 56% do not. Those who do not belong were not interested in learning or joining a faith community.

Summary

There were few comments or recommendations about faith communities. Nationally, faith communities have proven to be effective in helping people with disabilities achieve comprehensive quality lives. Refer to www.faithanddisability.org.

Decision-Making - Most Important Factors (Pick 3)

	Parents		Siblings		School Personnel		Adult Service Personnel		Community Members	
Information about alternatives to guardianship	20.0%	2					100.0%	2	33.3%	9
Information about supported decision making.	30.0%	3		1	75.0%	3			40.7%	11
Specific instruction and support in self-determination and decision-making	80.0%	8		1	100.0%	4	50.0%	1	74.1%	20
Specific instruction and support in making decisions about healthcare	50.0%	5		1	25.0%	1	100.0%	2	59.3%	16
Specific instruction and support in making decisions about fiscal matters	60.0%	6			50.0%	2	50.0%	1	51.9%	14
Specific instruction and support in conflict resolution	50.0%	5					25.0%	1	25.9%	7
Other (please describe)	10.0%	1					25.0%	1	7.4%	2

Other Factors Cited:

Self-advocacy training and on-going activities to develop skills, share strategies are key

The factors most frequently cited were:

- Specific instruction and support re: self-determination and decision-making;
- Information about alternatives to guardianship and supported decision-making;
- Instruction and support in specific types of decisions – i.e., health and fiscal decisions.

Experiences of Adolescents/Adults

100% of the respondents report making decisions about daily life events, only 60% report making decisions about big things (where to live, who live with, health decisions, financial decisions). When asked why they do not make these decisions, most were unsure. One simply said someone makes them for me.

50% would like to make decisions about these major life choices.

Services and Supports Currently Used by Families, Recommendations of Families

80% of families report that their family members make decisions about daily live events, 30% make decisions about major life activities, 10% make decisions about health issues. Most families report receiving little support re: decision-making. Some supports are provided in school....these focus on navigating school, not life after school.

Information Needed by Families, Information Sources Used by Families

Only 20% of families currently receive information about decision-making. Families report needing information about transition, post school opportunities, peer mentors, strategies for increasing independence.

Additional Challenges or Suggestions Identified by School Personnel

School Personnel comments included the following:

- Case managers for people to connect with on a regular basis to connect them resources & support.
- Support staff beyond school.

Additional Challenges or Suggestions Identified by Adult Services Personnel

Comments and suggestions from adult services personnel included:

- General case management services for individuals with disabilities. As a job coach, I see many individuals fall through the cracks with little/no support in navigating life's challenges.
- Support from appropriate team members that can guide the individual through life.
- Financial literacy instruction in school.

Additional Challenges or Suggestions Identified by Community Members

As stated in the discussion of other life domains, there were multiple overlapping comments from community members. In an attempt to fairly describe the thoughts of community members and to include ALL ideas, the comments and suggestions below are direct quotes from community member surveys.

- No-one currently sponsors an on-going self-advocacy series or group on the Vineyard.
- Standard set of skills to be taught in high school.
- Proper clubhouse supports can help the disabled make decisions to turn their lives around and improve not disprove.
- There are a lot of helpful programs out there, but it can be overwhelming for people to navigate especially in a stressful situation.
- Increased opportunities for education around all of the above areas, as well as increased opportunity for one on one support. (Or increased awareness/outreach to highlight currently available opportunities.)
- Good advice about health care decisions. Good example of bad outcome when folks were not well advised: 2 women I know are maimed for life because they were advised to let general surgeons work on their hand, in one case. shoulder in another. These are complex surgeries that

need highly trained specialists. They and their families opted for the easiest lets-just-stay-on-the-island route instead of seeking specialist care.

- A warm line for help specifically with decision making rather than mental or physical crisis.

Summary, General Impressions and Recommendations:

There is little attention paid to decision-making. Research has documented that individuals with disabilities who do not learn to problem solve and make decisions become increasingly dependent and have more limited lives than individuals who have acquired those competencies.

- Implementing **self-determination instruction** in school (and in post-school settings) correlates highly with positive adult outcomes (see www.ngsd.org for strategies and more information).
- Providing individuals and families with **information about alternatives to guardianships, supported decision-making**, etc. will help families understand the importance of teaching these issues.
- Creating a way of **providing advice when it is needed** – e.g., a call in help line, navigators, advice about health care, etc.

VI. Life on Martha's Vineyard

What are the strengths that makes life good for people with disabilities on Martha's Vineyard?

Responses to this question included:

- Strong sense of community
- Strong social networks
- Caring, supportive community
- Small and safe community
- “For the most part” people are welcoming
- Intimacy – people know each other and check up on each other
- Good schools; Specialized programs (Bridge and Navigator programs)
- Good public transportation

What would make life better for people with disabilities on Martha's Vineyard?

Responses to this question included:

- More options for work, housing and recreation
- More integration into all island activities
- More island-wide education about how to make integration happen
- Educating everyone about the strengths, capacities and needs of people with disabilities
- People with disabilities having a louder voice and more participation in making a civic difference
- Bridging the gap between adolescence and adulthood
- Schools partnering with other community services
- Working together across the lifespan
- Better public transportation, especially in the slow season
- More resources for individuals with disabilities and their families
- More after school programs for young children with disabilities – this will help their families work
- More after school programs for young teens focused on developing friendships and relationships
- More fun clubs and outings opportunities
- More alternatives for individuals who do not want to go to college
- More businesses willing to employ people with disabilities
- Quality adult providers who are actually able to deliver the services people need
- Accessible spaces and ADA compliant public buildings

What are the challenges that make life difficult for people with disabilities on Martha's Vineyard?

Responses to this question included:

- Island is a natural barrier – isolates some people
- Not enough affordable housing
- High cost of living
- Many buildings are older, less accessible

- Community is sincere, but needs more education about inclusion and accessibility
- Limited services outside of school
- Limited choices
- Limited activities, especially in the winter
- Insufficient financial support for all that is needed
- Not enough peers of the same age
- Not enough staff trained in how to make inclusion/integration happen
- Limited access to specialized medical care

What would you like to be different on Martha's Vineyard in three to five years?

Responses to this question included:

- More inclusive options for work and socialization
- More public education about how to make community more inclusive
- Change in language – use of people first language
- Mentors, people to help individuals with disabilities to become part of the community
- MVRHS offering coaching in skills for independent living
- More affordable housing
- More employment opportunities
- Increased opportunities for continuing education – on line and in person
- Providers that actually deliver the services people need
- Willingness for all of us to pay a little more for the good of people with disabilities

What services or supports that do not currently exist would you like to see in three to five years?

Responses to this question included:

- Mentorships
- Self-Advocacy Training
- Case management across the lifespan to help individuals and families to navigate
- On island Education Advocate – someone to go to for advice on all aspects
- More counseling services
- Affordable private clinics to supplement school services
- Better mental health education about social/emotional issues
- More resources to train non-profits in strategies that promote accessibility and inclusion
- Annual fair celebrating differences

VI. Concluding Thoughts and Recommendations

One of the more significant issues in systems that support people with disabilities is the **need for a comprehensive life view**. Systems often focus on one function – education or employment or health or something else. The intent of this survey was to prompt individuals, families, school personnel, adult services personnel and community members to think about **all life outcomes, not just one**. Individual lives are not just about one thing. There were several thousand comments made in response to the survey questions. The breadth and depth of these comments was amazing. Collectively, they provide a comprehensive picture of life on Martha’s Vineyard for people with disabilities and their families, the challenges they encounter and a multitude of suggestions for addressing those barriers and “making life better”. In a large community there are always many different opinions, many different preferences about form, many different learning styles – the intent of this survey was to provide multiple ways for those responding to express their view.

Disability is a very broad concept. One of the truths is that **disability is very individual and very personal**. Every person and every family has a different experience. Research has documented that **expectations often define what supports we provide**. Employment is perhaps the best example – research suggests that, if we believe people (or an individual person) should work, we are five times more likely to give that person access to internships, employment opportunities and employment supports than if we believe people should not or cannot work. The same is true with inclusion (and most other life domains). There are schools in which even students with the most significant disabilities are fully included....because there is a school wide and community wide expectation that they will be. Expectations for individuals with disabilities have traditionally been low. The first few sections of this report illustrates what individuals with disabilities expect to achieve in live...what families expect them to achieve...compared to what service providers and community members expect them to achieve. Although not universal, **there is a fair alignment of expectations across most life domains** across all the groups responding to this survey. These are detailed in the early sections of the report. **The concern is the people for whom a community does not have those expectations** – those are the people who are most likely to not have access to opportunities and supports.

Accommodations and supports always need to be responsive to the individual person’s nature, capacities and needs, but we need to have high expectations as the foundation for those accommodations.

One of the consistent themes from the comments was **the need for someone who can help individuals and families navigate the system**. Responses used phrase like case management, someone I can go to advice about everything, mentors and others. Individuals and families often simply do not know all the options, are unsure of how to access supports, and are unsure what choices to make. There are multiple national studies that document this need for navigation. Addressing this need for navigation could be one of the functions assumed by the Island Disability Coalition.

As discussed by several survey responses, this **need for navigation is most critical during the transition from school to adult life**. Responses indicate that there are high expectations for the role of school – in addition to educational responsibilities, school is expected to provide internships that ready students for employment, provide instruction in social skills and developing relationships, create in-school and afterschool programs for recreation and leisure, help students develop skills for independent

living, etc. However, several responses suggest “there needs to be services and supports beyond school”; “there needs to be closer alignment of school and community services”; “there needs to be private services that supplement school programs”; “we need to work together across the lifespan”. Thus, a possible role for the IDC could be to facilitate cross-community planning around each life domain.

Several responses in the survey addressed the need for “**person-centered planning**”. Navigation and person-centered planning go hand-in-hand. Comprehensive life plans should address **all** aspects of an individual’s life. There are multiple formats in the national literature for person-centered planning. For example, Charting the Life Course (www.lifecoursetools.com) provides a format for defining lifespan expectations across several life areas, defining the experiences that will help an individual achieve those expectations, and thinking about services and supports in a more comprehensive manner. One or more of the existing person-centered planning formats could be source tools for navigators.

Another striking theme from the survey responses was the **need for information**. Individuals with disabilities seemed largely unaware of options other than what they already do. In every life domain only a small portion of parents reported receiving information about options and supports. The most frequently accessed information sources accessed by families were

- Group meetings – IDC could facilitate group meetings about topics of interests;
- Computer – IDC could create a central website as an information source;
- Public Media – IDC could facilitate a predictable section in local media, could create focus stories drawing attention to resources and opportunities;
- Person-to-Person matching – IDC could help create family listserves, listserves based on interests, etc.

One of the more creative ideas from the survey responses was the suggestion to create an **island-wide matching of individuals with disabilities and community mentors**. These matches could be focused on employment, common interests, social activities or more. The importance of mentorships was extensively discussed in survey responses. There were also multiple references to **community outreach and education** to help the broader Martha’s Vineyard community (employers, organizations for leisure and recreation, public entities, others) understand the value and importance of community integration and practical strategies for including individuals with disabilities in island life.

Another theme in the responses was the need for “**more**” – more affordable housing, more internships, more job opportunities, more leisure opportunities, more accessibility in public and private buildings. Per discussion with IDC, service creation is not currently within their capacity. The role of IDC could be to facilitate island-wide discussion and planning about the needs and expectations illustrated by the survey responses.

What’s next for the Island Disability Coalition? In the introduction four possible functions were identified - (1) **engaging service providers** on the Island to enhance their services to address needs documented through the surveys; (2) providing people with disabilities and their families with **accurate comprehensive information**; (3) developing strategies that will assist people with disabilities and their families to **effectively navigate systems**; and (4) **community organizing to maximize the use of community resources** and supports by people with disabilities and their families.

IDC is currently developing a **strategic plan**. Based on the information garnered from these surveys and the suggestions and recommendations from all groups that responded to the survey (detailed in each of the life domain sections), IDC could select the areas in which they can have impact. The strategies for impact would be the four listed above – engaging service providers, providing information, creating a network of navigators, and organizing and expanding community opportunities and resources.

Finally, this “needs assessment” should simply be the beginning of the process. The intent was simply to describe the expectations, barriers and suggestions of all the stakeholder groups. We would recommend that the IDC host a series of island-wide community conversations. Using the format in *Launching Inclusive Efforts Through Community Conversations* (a resource I shared), we would recommend focusing on four topics –

- Housing
- Employment
- Health
- Life on Martha’s Vineyard – Expanding Inclusive Opportunities for leisure, continuing education, socialization, community participation.

These community conversations can be the basis for developing detailed island-wide outcomes and strategies.

Thank you!