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ABSTRACT

IDENTIFIERS

This report describes results of six focus groups of people with disabilities convened by the Maine Bureau of Health to determine the feelings, attitudes, and experiences of this population. Four groups were comprised of adults ranging in age from the early twenties to the late seventies; two groups were comprised of adolescents and young adults. The groups also included family members and staff of agencies serving people with disabilities. Among the disabilities represented were spinal cord injury, vision impairment, developmental disability, deafness, mental illness, learning disability, arthritis, diabetes, seizure disorder, traumatic brain injury, chronic fatigue syndrome, and kidney disease. Major findings included: health providers were seen as either great assets or great hindrances to living well with a disability; participants acknowledged the importance of their own attitudes to their quality of life. Recurrent themes included: the need to be listened to, the importance of family and friends, the need for economic security, major problems with the implementation of the Americans with Disabilities Act, the need for health insurance, and desires for the same things other people want. Of particular interest to those in the education field are the difficulties many children with disabilities face attending school. Appended are summaries of points made at each of the six groups. (DB)

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Report On Results Of Focus Groups Conducted With People With Disabilities

Bureau of Health Department of Human Services

January 1997

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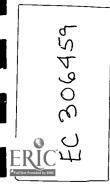
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Acknowledgment

The Bureau of Health wants to thank the focus group participants for sharing their knowledge and experiences.

A copy of the report is available from the Bureau of Health, 11 State House Station, Augusta, Maine 04333.

The report is available in alternative formats.



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I. Background

Disability is part of the human condition. It occurs across the life span and is the consequence of impairments that are congenital or may begin in early life (e.g. developmental disabilities), occur as a result of injury, or develop later in life (e.g. chronic conditions). Disability affects not only the individual's life but impacts the individual's family and community and society as a whole.

The Americans with Disabilities Act defines disability as a physical or mental impairment that substantially limits one or more of the major life activities of an individual. In its 1991 report, <u>Disability in America</u>: Toward a National Agenda for Prevention, the Institute of Medicine estimated that one in seven Americans has a disability. According to the Maine Opinion, a scientific survey conducted in Maine in 1994, 28% of the 300 households polled reported that at least one family member had a disability or permanent condition that limited one or more major life activities. Two trends account for an increasing prevalence of disability: medical advances resulting in an increasing life span for persons with disabilities and the aging of the population.

Preventing disease and promoting health of all people has typically received low priority in the allocation of health resources. Disease prevention and health promotion specifically targeted to the needs of persons with disabilities has received even less attention. Much needs to be done to shape health care policies and programs so that they promote well being and quality of life for people with disabilities. The Bureau of Health hopes this report will assist the health and social service community think about how to be appropriately responsive to the needs of people with disabilities.

II. Focus Groups

A. Methodology

The Bureau of Health chose focus groups as a method of data collection because they are planned discussions that provide



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insight into the feelings, attitudes, and experiences of the participants regarding a specific issue. The Bureau convened six focus groups with people with disabilities between May and August 1996 in the following sites: Sanford, Gardiner, Bangor, Presque Isle, Lewiston, and Dover-Foxcroft. Four of the groups were comprised of adults ranging in age from the early twenties to the late seventies; two of the groups were comprised of adolescents and young adults.

The focus groups included people with the following disabling

The focus groups included people with the following disabling conditions: spinal cord injury, vision impairment, developmental disability, deafness, muscular dystrophy, mental illness, learning disability, arthritis, diabetes, seizure disorder, multiple sclerosis, traumatic brain injury, chronic fatigue syndrome, and kidney disease. The groups also included family members of people with disabilities and staff of agencies serving people with disabilities.

The meetings were conducted by a facilitator. A young man with a disability co-facilitated the adolescent and young adult groups. Each group met once for one and a half to two hours. The groups ranged in size from six to eleven participants.

Standard questions were used. The questions were not tested prior to use. The following questions were used as a guideline for discussion with the adult groups:

- What does living well with a disability mean to you?
- What prevents you from living well with a disability?
- What contributes to living well with a disability?
- What secondary conditions have you seen or experienced?

The following questions were used as a guideline for discussion with the adolescent and young adult groups:

- How is your life different from that of your friends?
- What stands in the way of you reaching your dreams?



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- What /who supports you in living well with a disability?
- What do you need in order to live well with your disability?
- What do you wish that professionals knew and/or did?
- What have you learned or what would you like to tell people about living with a disability?

B. Focus Group Themes

The themes that ran throughout the responses to each question across all focus groups are summarized below. See Appendices 1-6 for responses by individual focus groups.

Adult Focus Groups

1. What does living well with a disability mean to you?

Living well means having access, i.e., access to communities, access to information, access to equipment and technology, and access to support services. For many of the participants living well began with their own acceptance of their disability followed by the acceptance of others in their families and communities. Having choices and control over their own lives and being listened to are necessary to living well. Adequate financial resources are essential not only to the person with a disability but also to his/her family. For many participants living well means being an active participant in their communities.

2. What prevents you from living well with a disability?

The lack of access to transportation, assistive technology, housing, employment, and information is critical in preventing people from living well with their disabilities. Inadequate financial resources and limited



earning power had dramatic consequences for people with disabilities and their families. Stigma about people with disabilities routinely interferes with living well especially when it means that people are only seen as their disabilities rather than as complete human beings. The medical community has proved inadequate for many of the participants; participants spoke of their discouragement with health care providers who didn't listen to them, who didn't know the latest medical information about their disability, who didn't recognize their non-disability health needs, and who didn't treat them with the same value as their non-disabled counterparts. The historical lack of responsiveness in the public education system was a barrier for many with lifelong disabilities.

3. What contributes to living well with a disability?

Living well with a disability is enhanced by medical communities which are responsive and educated, schools that aggressively include students with disabilities, supportive friends and family, recreational opportunities, and communities which include and encourage people with disabilities. Access to transportation, assistive technology, resources, employment, and housing are important to living well with a disability.

4. What secondary conditions have you seen or experienced?

The range of secondary conditions cited was extensive. They include many health related conditions such as pressure sores, fractures, diabetes, scoliosis, cardiac and pulmonary problems, contractures, chronic pain, exhaustion, and disreflexia. Secondary conditions which affect daily functioning include depression, sleep disturbances, dependency, loss of self-esteem, anger, disappointment, and issues around sexuality. Poverty



and economic insecurity are prevalent for many individuals and their families. Secondary conditions which affect the relationships of people with disabilities include the loss of trust in others and the "system", being victimized, isolation and loneliness, sexual and physical abuse, loss of privacy, and the disintegration of marriages and families.

Adolescent And Young Adult Focus Groups

1. How is your life different than that of your friends?

The young people in these focus groups felt that their families are more protective of them than other families are of their children who do not have disabilities. Their peers behave as though life will last forever and that they are invincible; these young people with disabilities know that they are mortal and that health and well-being are to be valued. Their friends are generally able to do more activities with less thought and effort as to how that will happen. Most report being stared at or being made fun of because of their disabilities.

2. What stands in the way of you reaching your dreams?

Low self-esteem and lack of confidence were mentioned by several participants as barriers to reaching their dreams. The mechanics of dealing with some disabilities, e.g., blood testing for diabetes, lack of transportation, inability to concentrate, and needing assistance to complete homework interferes with reaching their dreams easily. Issues of accessibility confront many of these young people almost daily.



3. What/who supports you in living well with a disability?

Family and friends are the major supports for the young people in these focus groups. Some educators, counselors, nurses, and doctors were mentioned as being supportive beyond what they would have expected.

4. What do you need in order to live well with your disability?

Living well while dependent upon the care of others resulted in many responses about the health care community, e.g., we need to have health care professionals who listen, who understand, who believe me, and who have accurate and current information. Many also stated that it would be helpful if they and their families had access to current information which would help them live well with their disabilities.

5. What do you wish that professionals knew and/or did?

In addition to the responses about health care professionals mentioned in question 4, some of the young people wished that their schools were more hospitable to people with disabilities. This would include having teachers who know about disabilities in general as well as the disabilities specific to the students they have in their classes. They also mentioned that regular education teachers should have more knowledge about how to teach students who have a hard time in school.



6. What have you learned or what would you like to tell people about living with a disability?

Several said that they felt as though they had to grow up quicker than their friends because of the stresses of dealing with their disabilities. Having been teased and rejected themselves, several participants said that they had developed empathy for others that they probably wouldn't have without their disabilities.

C. Summary And Findings

- The people in attendance at the focus groups willingly shared their ideas and opinions about what it is like to have a disability.
- Many participants commented on how helpful it was for them to just have the opportunity to be in the same room with other people with disabilities and to speak candidly about their experiences and hopes.
- Health providers were great assets or great hindrances to living well with a disability. For some participants, their health care providers were well-educated about their disabilities, knowledgeable, and consistently available to them. For others, they had to deal with providers who were insensitive, lacking in current knowledge, and unaware of secondary conditions associated with their primary disabilities.
- Participants acknowledged the importance of their own attitudes in being able to live well with their disabilities.
- The importance of family and friends on a day-to-day basis was a consistent theme throughout all of the groups.
- Economic security was a recurrent theme, e.g., injured workers being unable to provide educational opportunities



for their children, young people concerned about the continual drain they were causing on the finances of their families, the poverty that accompanies many disabilities.

- Participants frequently stated that it was probably more important to be listened to respectfully than it was to have someone try to jump in and try to fix their situation.
- The implementation of the Americans with Disabilities Act in Maine sorely misses the mark for many of the participants.
- The need for health insurance reform was a consistent theme in 5 of the 6 groups.
- People with disabilities want the same things that other people want, i.e., to work, to go to school, to have friends, to marry, to have children, to volunteer in their communities, and to be as healthy as they can be.
- The two groups of young people were open about their struggles and sometime successes in being accepted for who they are rather than being defined by their disabilities.
- The young people had an uncommon maturity in the perspectives which they expressed about their families, friends, and providers. All too frequently they are put in the position of being educators to adults who should be knowledgeable and supportive of them.



APPENDICES



APPENDIX 1

ADULT FOCUS GROUP SANFORD MAY 30, 1996

1. What does living well with a disability mean to you?

- having a job
- having an attitude which makes people around me comfortable and myself happy
- access to supports to live independently
- control over things that are happening to me
- daily life lived with a minimum of pain
- acceptance from community
- maintaining rights
- having friends
- having family that's involved with me
- being valued
- participating in my community
- having alternatives and choices
- having useful things to do to fill my days
- support, including support groups
- support for my family
- access to information and adaptive equipment
- acceptance of myself
- --- spiritual support

2. What prevents people from living well with disabilities?

- other people
- issues internal to the person who has a disability
 - self-confidence
 - physical pain
 - mistrust of doctors
 - depression
 - pessimistic vs. positive outlook
 - lack of spiritual center
 - fear of label/stigma
 - lack of education



- sense of being a burden
- dependence
- lack of advocacy skills
- doctors who don't refer
- nobody willing to listen
- lack of money
- lack of transportation
- lack of awareness in public systems, e.g., legal, education
- ignorance re: parking issues
- lack of community education re: disabilities
- isolation
- people who are afraid to talk to someone who has a disability
- economic status
- financial disincentives to work
- having to start all over again in the world of work
- how the bureaucracy decides who has the priority for getting the limited resources available
- stigma
- lack of flexibility in work place
- lack of central access point for information
- lack of health care providers who have current knowledge of conditions and treatment
- worker's compensation

(following specific to young people)

- limitations because of labels
- ignorance
- lack of transitional services
- self-contained classrooms
- lack of educators who are adequately trained
- lack of appropriate educator:student ratio
- lack of information on school committees

3. What contributes to living well with disabilities?

- support groups
- family, i.e., understanding, listening, performing tasks that I can't perform anymore
- mobility training
- people getting angry and getting organized



- friends who stay connected
- --- love
- books-on-tape
- information that is accessible
- assistive technology
- access (including money)
- therapists who are knowledgeable of the available technology
- generic community supports
- advocacy and self-advocacy
- volunteers
- transportation (when it's available)
- places that are truly accessible
- knowing your own symptoms and medications

4. What secondary conditions have you seen or experienced?

- mental/emotional stressors
- being in denial
- -- ulcers
- bowel disorders
- disreflexia
- blood pressure problems
- body awareness difficulties resulting in burns/injuries
- lack of stability resulting in falls/injuries
- side effects of medication
- pain
- fatigue
- under prescription of drugs
- over prescription of drugs
- lack of information which results in secondary conditions
- sexuality issues
- loss of birth child to the state due to lack of information/counseling/understanding
- poverty and economic threats including the trickle down effect on the rest of my family
- -- incarceration



APPENDIX 2

ADULT FOCUS GROUP GARDINER JUNE 11, 1996

1. What does living well with a disability mean to you?

- being able to take care of yourself
- freedom to come and go
- being able to direct your own care
- to work
- to marry
- to have children
- unpaid supports; friends
- deinstitutionalization
- not being segregated by disability
- having adequate economic resources
- access to resources and adaptive equipment necessary to live independently, e.g., chairs, vans, computers
- source for medical help and information
- doctors who prescribe accurately
- having doctors who are educated

2. What prevents you from living well with a disability?

- transportation
- discrimination
- medical community which:
 - doesn't listen
 - doesn't know
 - doesn't recognize health needs which are unrelated to the disability
 - doesn't deal with all equally without regard to money
 - doesn't embrace alternate health methods
 - has an attitude that people with disabilities have less value than other people
- being seen as a disability rather than as a person
- insurance coverage not adequate re: reimbursement
- better medical services for those who are institutionalized



- adequate medical evaluations which could prevent tardif dyskinesia
- poverty
- sexual bias, e.g., it's just menopause
- costs of equipment seem disproportionate to what is received, e.g., wheelchairs, clothing with Velcro closures
- lack of physical accessibility to public buildings and handicapped parking
- lack of education in general community
- lack of meaningful work for people with mental illness and other disabilities
- if disability isn't obvious or readily known, tough to get support
- delay in getting Social Security
- to be handcuffed and taken to Augusta Mental Health Institute

3. What contributes to living well with a disability?

- having spouse, parent, children who contribute to well-being and who listen
- having adaptive equipment identified by individual or family
- economic stability
- social clubs for people with mental illness
- good doctors
- responsive medical community
- personal care
- responsive community in general
- education of community
- good information
- feeling of personal self-worth based on valued roles in community
- accessibility to resources
- being known in neighborhood and community; broad network of supports
- being called and checked in with

4. What secondary conditions have you seen or experienced?

- tardif dyskinesia
- skin breakdown
- marriages disintegrate
- effects on siblings



- lack of societal acceptance
- cardiac and pulmonary problems in people with Down Syndrome
- anti-psychotic and anti-convulsive medication side effects
- families that burnout
- being treated as "less than"
- difficult to form relationships
- pain
- life threatening health conditions which aren't diagnosed and/or treated
- what is appropriate etiquette
- over medication
- loss of trust in medical community and/or people in power
- institutionalization
- abuse
- isolation for individuals and their families
- contractures
- having too much personal information spread around
- loss of privacy medically and in group living
- dependency



APPENDIX 3

ADULT FOCUS GROUP BANGOR JUNE 13, 1996

1. What does living well with a disability mean to you?

- accepting your own disability
- having access to community options
- having others accept my disability
- not being patronized
- being in charge of my own schedule
- having meaningful relationships
- feeling productive
- having money
- doing the best I can with what I'm able to do
- being as independent as possible
- having a social life, friends, peers
- being healthy physically, mentally, emotionally

2. What prevents you from living well with a disability?

- attitudes and behaviors of other people
- low self-esteem
- poverty; insufficient money
- lack of transportation
- safety issues
- lack of assistive technology
- lack of accessible apartments
- general lack of accessibility
- lack of accessible showers
- lack of employment that is full time, with benefits, flexible, creative, and with accommodating employers
- lack of knowledge about what educational opportunities are available
- managed care
- lack of flexible funding re: employment opportunities
- inadequate financial supports to prevent mental and emotional disabilities



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- inadequate funding for durable medical equipment and assistive devices
- earning limitations re: loss of benefits
- lack of qualified sign language interpreters
- doctors, lawyers, other professionals who don't buy into the American with Disabilities Act requirements
- lack of knowledge within public education system

3. What contributes to living well with a disability?

- volunteering
- people who are nice to you
- talking computers
- appropriate technology
- Personal Care Assistant programs
- network beyond those who are paid
- accessible apartments
- staff who is well-trained, well-educated, well-paid
- being able to contribute
- qualified staff
- opportunities for fitness
- recreational opportunities
- peer support
- place to live with the appropriate level of support
- choices about where to live
- mainstreaming of children in school
- not being hidden away
- being actively involved in own health care
- a way to get around
- having health care options
- doctor that will listen
- medical community that recognizes current research and has knowledge base re: disabilities
- family support
- physician training about disabilities
- speaking to others about own disability
- sports, e.g., rugby, bowling, Special Olympics, basketball
- recreation, e.g., camping, fishing, swimming, aerobics
- your own attitude



- good sexuality information
- changed attitudes of other people
- people learning the appropriate etiquette that applies to different disabilities

4. What secondary conditions have you seen or experienced?

- depression
- muscle spasms
- loss of endurance/stamina
- pressure sores
- fractures
- contractures
- sleep disturbances
- diabetes
- poor nutrition
- skin breakdown
- loneliness
- isolation
- medication related conditions
- chemical dependency
- breathing problems
- -- scoliosis
- foot drop
- being victimized
- being exploited
- poverty, esp. for family
- divorce
- substance abuse
- blood pressure
- domestic violence
- sexual abuse
- physical abuse



APPENDIX 4

ADULT FOCUS GROUP PRESQUE ISLE JUNE 17, 1996

1. What does living well with a disability mean to you?

- having a good frame of mind
- mental and physical independence
- accepting and dealing with own disability
- having physical access to own community
- being listened to
- being understood
- having an advocate or being an advocate
- supportive family, friends, and community
- being treated as a person not as just a disability

2. What prevents living well with a disability?

- people and organizations doing the minimum to meet accessibility standards leaving you feeling like you are only safe in your own home and should just stay there
- language and labels
- insecurity about services and programs existing over time and into the future
- lack of appropriate and early intervention
- cheaper to have people disabled than to treat or to encourage rehabilitation
- not having work/nothing useful to do
- insufficient resources, i.e., money, technology, services
- lack of flexibility in work place
- person with disability not knowing what is available
- people being cruel
- finding a college that will meet all of my children's needs
- perhaps men have a tougher time being viewed as dependent
- lack of education about own disability
- lack of education re: avoiding primary disabilities
- attitudes of others
- when in wheelchair others acting as if you are deaf or invisible



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- perception that if you have one disability then everything else about you must also be disabled
- paternalism
- rural lack of recreational opportunities effects everyone
- not knowing where to start to get information
- high schools which don't have college information for students with disabilities
- feeling exhausted from dealing with the disability and then have to start fighting the "system"

3. What contributes to living well with a disability?

- having transportation
- people who care
- respecting people for who they are
- standing up for yourself
- educating young people about disabilities
- affordable assistive technology
- prevention of primary disabilities educating young people
- helping people understand the probable consequences of their behaviors
- inclusion of people with disabilities in public school
- more educational opportunities for people with disabilities
- more people who are knowledgeable and practicing advocacy on behalf of others

4. What secondary conditions have you seen or experienced?

- depression
- substance abuse
- isolation
- stigma; "having a sign on my forehead"
- increased dependency
- changes with progressive disorders and aging
- loss of privacy
- unrealistic expectations on people who have "hidden" disabilities
- exhaustion
- loss of self-esteem
- not working
- guilt re: needing help



- difficulty in accepting help
- being told "you can't do that"
- feeling like a thing rather than a person
- physical objects being moved if you have a vision impairment
- --- anger/rage
- disappointment and the fear of disappointing others
- feeling hurt when let down by the "system"



APPENDIX 5

ADOLESCENT/YOUNG ADULT FOCUS GROUP LEWISTON AUGUST 6, 1996

1. How is your life different from that of your friends?

- I can't stay out at night because I'm exhausted the next day
- my parents are more protective than my friends parents are
- my parents worry about me leaving home
- I don't go out with people from school because I don't know many of them and I'm too tired anyway
- I really want to be "normal"; Crone's and arthritis aren't going to hold me back but, sometimes I push too hard
- others can do more than I can; they can do sports without having to load sugar
- other people just don't "get it"
- I can't ride in anybody else's vehicle
- having to take medicine every day, especially in front of other people
- having to use "equipment"
- the stuff that people can see
- being stared at
- it's different if little kids stare at me; adults are worse
- some people will ask what's the matter with me

2. What are your feelings about what you just talked about?

- frustration
- anger
- just want to be alone if I'm not feeling well

3. What stands in the way of you reaching your dreams?

- being pitied
- having to take longer to get where I want to go and do what I want to do, e.g., taking five years rather than four to get through college
- doctors who tell me I don't know how I feel
- needing to gain more self-confidence
- lack of transportation



- my lack of confidence and sometimes feeling helpless
- earning a chance to participate in international Odyssey of the Mind competition and then having hotels and airplanes that had no way to keep my insulin refrigerated
- having to eat on schedules different from everyone around me
- difficulty in finding information
- my own denial that my sugar level is low
- other people's negative attitudes
- inadequate insurance

4. We'd like to tell you some of the benefits of having a disability.

- I appreciate things more
- I am stronger
- I've learned a lot
- I take better care of myself than my peers do
- I am less judgmental of other people
- my priorities are different than those of my peers
- I know that life doesn't go on forever; I won't drink, do drugs, or drive fast
- it's easier to "just say no"
- I've faced my own mortality

5. What/who supports you in living well with a disability?

- friends
- parents
- --- family
- --- support group
- some teachers
- my doctor
- guidance counselor
- Bates College
- --- school nurse
- school secretary
- --- principal

6. What do you need in order to live well with your disability?

- doctors who are good and who are understanding
- doctors who listen



- doctors who are trained differently
- doctors who believe me
- a network of people to talk with in order to get current and accurate information
- insurance reform
- to get a job that has benefits
- groups like the Muscular Dystrophy Association which supplement insurance, especially for buying equipment
- to know what resources are available
- to not feel guilty about what my disability costs my parents



APPENDIX 6

ADOLESCENT/YOUNG ADULT FOCUS GROUP DOVER-FOXCROFT AUGUST 7, 1996

1. How is your life different than that of your friends?

- peers put me down
- teachers don't "get it"
- because of my hearing impairment, my teachers thought that I wasn't bright
- people feel uncomfortable when I take shots or do my blood tests
- people sometimes think that I and my diabetes are contagious
- people avoid me
- others look at me funny when I take my medications
- I'm made fun of because of being different
- my learning disability has given me a different outlook on life than a lot of kids my age
- have to ignore classmates rude comments about my not being able to read
- I feel lonely
- if you're different, other kids have to make fun; it's cruel but, it's just the way it is
- for those of us who have been in foster care, failed adoptions, and/or abusive homes, other kids haven't been exposed to what this is like and so they don't "get it"

2. How do you cope with life as you described it?

- by having a couple of close friends
- I give people the cold shoulder when they make fun of me
- I just don't like it
- people think that I'm burnt out; actually, I'm just dealing with my feelings

3. What stands in the way of you reaching your dreams?

- low self-esteem
- don't like being with crowds



- pills, tests, lack of healthy kidney, feeling sick, being rejected by Job Corps
- not being able to read at a high enough grade level
- would need help with homework in order to get through college
- lack of money stands in the way of my going to Beal College
- I get shy and scared when I apply for jobs or go into new situations
- the schedule of my diet and shots
- not really much

4. What/who supports you in living well with a disability?

- diabetes educator from Eastern Maine Medical Center talking with my fifth grade class
- my friends who know my schedule and what I need
- family
- one teacher
- friends
- driving permit
- greater independence
- my father
- doctors
- my mother
- friend and mother
- my boyfriend's family
- being on my own a lot
- teachers
- counselors
- doing sports
- transition group
- riding my bike wherever I want to go
- foster parents

5. What do you wish that professionals knew and/or did?

- school faculty should know about diabetes
- all should have a good knowledge base about disabilities
- talk with me about what I want
- listen



- educating regular education teachers about how to teach students who are having a hard time
- give students more time when they need it
- do a Disability Day just as we do an AIDS Day

6. What do you wish was different?

- wish that just for one day others could be in my shoes
- that kids were more understanding
- there would be no resource rooms
- have the people in Augusta have a learning disability for just 24 hours
- that we were listened to
- the teasing would stop
- that we wouldn't be treated like aliens

7. What have I learned as a result of having a disability?

- my teachers have explained to me what a learning disability is
- because I've been made fun of I need to stand up for others
- my disability is a challenge to get through
- we all have different problems
- not to dwell on my diabetes or let it get in my way
- I just don't care anymore what people say





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Kevin W. Concannon, Commissioner

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