aaidd + HRS INC.
webinar

Disparities, Perceptions and Misconceptions: Putting PEOPLE Before their Diagnoses

PRESENTED BY:

Craig Escude, MD, FAAFP, FAADM
President, HRS INC.

Knowledge Empowers

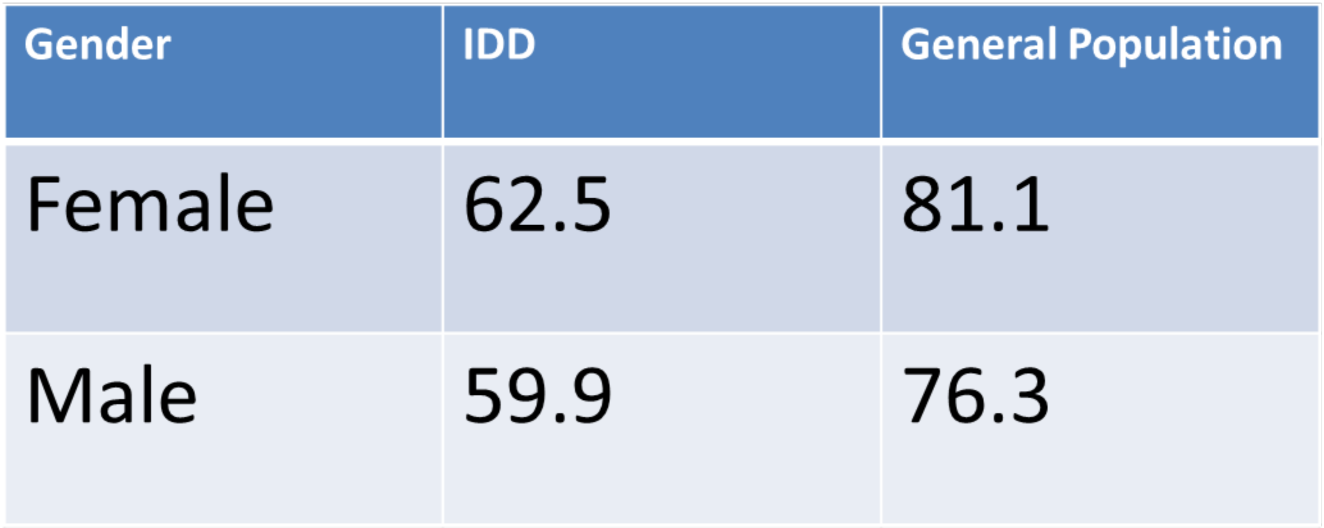
About the Presenter

Craig Escudé, MD

- Board-Certified Fellow of the American Academy of Family Physicians
- Fellow of the American Academy of Developmental Medicine
- Over 20 years of experience caring for people with mental illness and intellectual and developmental disabilities
- Medical Director of Hudspeth Regional Center in Whitfield, MS – Retired 2018
- Founder and Clinical Director of DETECT
- President of HRS, Inc.

Disparities

- Age of Death



Gender	IDD	General Population
Female	62.5	81.1
Male	59.9	76.3

Average Age at Death by Gender, 2011

Preventative care

Women with IDD are less likely than women without IDD to:

- Have had cervical and breast cancer screenings
- Have ever visited a gynecologist

Individuals with IDD are less likely than individuals without IDD to:

- Visit dentist regularly
- Get eye and hearing tests
- Receive timely vaccines

Disparities - CDC

- Live with complex health conditions
- Have limited access to quality healthcare and health promotion programs
- Miss cancer screenings
- Have poorly managed chronic conditions, such as epilepsy
- Be obese
- Have undetected poor vision
- Have mental health problems and use psychotropic medications

http://www.cdc.gov/ncbddd/disabilityandhealth/pdf/209537-a_idmeeting-short-version12-14-09.pdf

Health Disparities Among Adults with Developmental Disabilities - North Carolina

(Disability N=1,598 Non-Disability n=4,398)

- More likely to have a diagnosis of diabetes, high blood pressure, cardiovascular disease, and chronic pain.
- More likely not to have had their teeth cleaned in the past five years or never to have had their teeth cleaned.
- More likely to lack adequate emotional support
  - (24%of adults reportedly either had no one to talk with about personal things or often felt lonely)
- More likely to have had no exercise in the previous month
- Less likely to have a diagnosis of arthritis
- Significant disparities in breast and cervical cancer screening as well as oral health care

Health Disparities Among Adults with Developmental Disabilities, Adults with Other Disabilities, and Adults Not Reporting Disability in North Carolina; Havercamp, Scandlin, Roth, Public Health Reports / July August 2004/Volume 119

Perceptions and Misperceptions

- People with IDD have a disease
- People with IDD don’t need health screening because they don’t live as long
- People with IDD cannot lead a productive and fulfilling life
- Challenging behavior is mainly because they have a disability
- People with IDD can’t comprehend
- People with IDD cannot communicate

Not so long ago…

- Many were placed in institutions
- People with disabilities weren’t seen in the best light

More recently…

- People with disabilities have moved to communities
- Relying on community clinicians for healthcare
- Most have little training or experience in IDD healthcare

Result

Many people with IDD are looking to healthcare providers who have little understanding of their healthcare needs or even who they are as people, first.

Misperceptions can lead to…

- Reduced opportunities for inclusion
- Lower consideration of preventative care
- Lower consideration for life-saving measures
- Earlier referral to hospice care
- Earlier recommendation for “Do Not Resuscitate” status

COVID-19

- HHS received complaints from advocates in at least 4 states about exclusion from life-saving care such as ventilators
- HHS Office of Civil Rights responded March, 28,2020 reminding states that…

“persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person’s relative ‘worth’ based on the presence or absence of disabilities,”

American Academy of Developmental Medicine and Dentistry AADMD.org

- Policy statement -Ventilators and Covid-19 April, 2020

"We are resolved… that the presence of an intellectual or developmental disability must not be used as an exclusion criterion for ventilator support or the allocation of other scarce medical resources."

Combatting Negative Stereotypes

Steps for Combatting Misperceptions

- More research in the field
- Improve education
  - Healthcare providers
  - Supporters
  - General public
- Helping people with IDD to be seen as a PERSON, first

Changing perceptions – We have the power

- Lead off with who the person is rather than their diagnoses
- Introduce them to others with respect and importance
- Describe their quality of life positively
- Ask about screening during healthcare visits
- Speak to the person and encourage others to do the same during healthcare visits

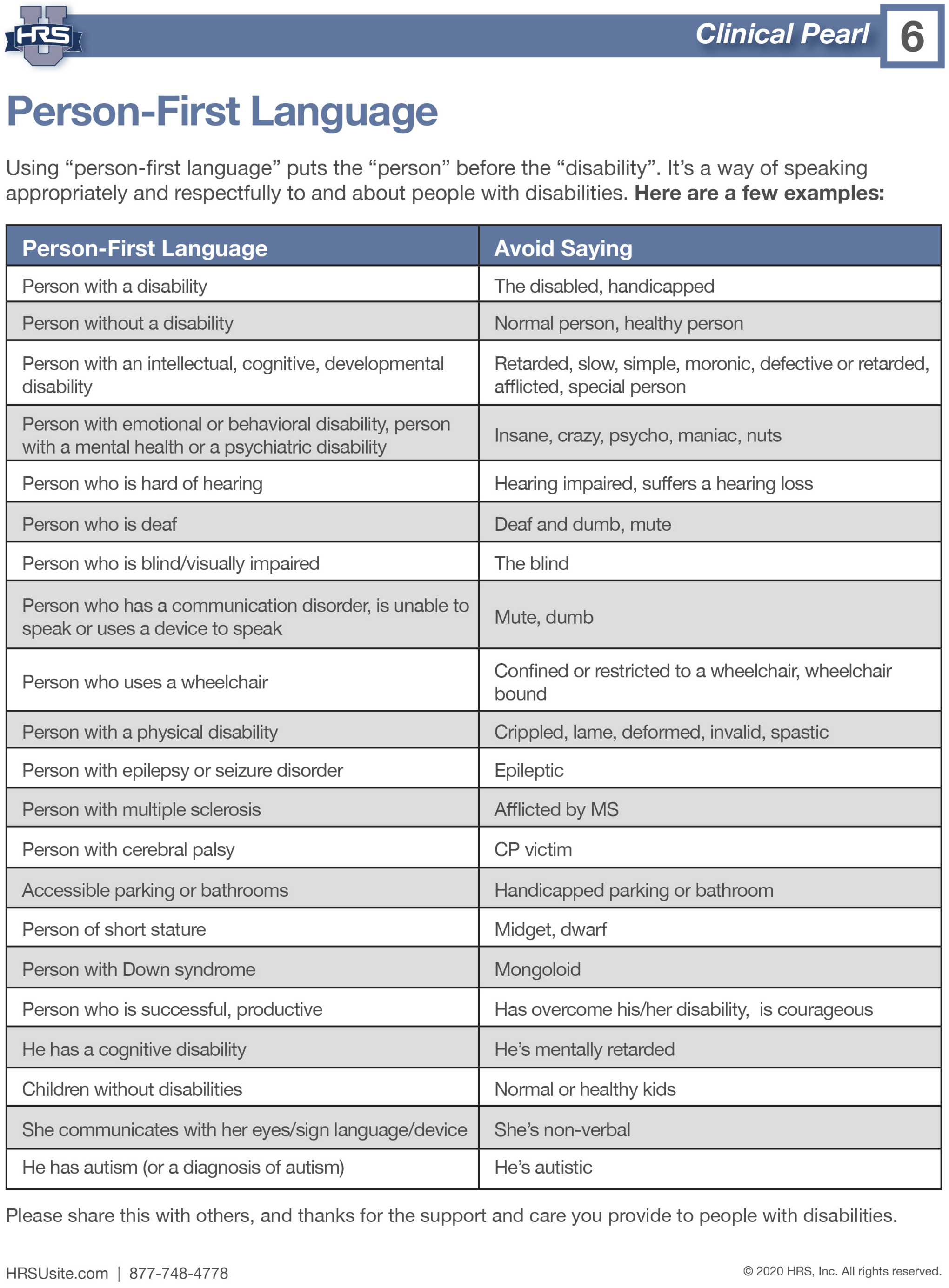
Introductions

- “This is Mike, he’s an avid watcher of sports. In fact, you should see him cheer when someone hits a home run! His favorite team is the Cubs, but lately his vision seems to be causing him some difficulty.”

- “This is Frannie. She made the scarf she has on today and is quite talented in painting as well. Lately, we noticed that she is having more trouble holding the paintbrush and seems to become agitated when she grabs it. This is how she often shows she’s in pain. We are here to see what can be done to get her back to painting again.”

Person-first language

Putting the Person before the disability.



Clinical Pearl 6

Person-First Language

Using "person-first language" puts the "person" before the "disability". It's a way of speaking appropriately and respectfully to and about people with disabilities. **Here are a few examples:**

Person-First Language	Avoid Saying
Person with a disability	The disabled, handicapped
Person without a disability	Normal person, healthy person
Person with an intellectual, cognitive, developmental disability	Retarded, slow, simple, moronic, defective or retarded, afflicted, special person
Person with emotional or behavioral disability, person with a mental health or a psychiatric disability	Insane, crazy, psycho, maniac, nuts
Person who is hard of hearing	Hearing impaired, suffers a hearing loss
Person who is deaf	Deaf and dumb, mute
Person who is blind/visually impaired	The blind
Person who has a communication disorder, is unable to speak or uses a device to speak	Mute, dumb
Person who uses a wheelchair	Confined or restricted to a wheelchair, wheelchair bound
Person with a physical disability	Crippled, lame, deformed, invalid, spastic
Person with epilepsy or seizure disorder	Epileptic
Person with multiple sclerosis	Afflicted by MS
Person with cerebral palsy	CP victim
Accessible parking or bathrooms	Handicapped parking or bathroom
Person of short stature	Midget, dwarf
Person with Down syndrome	Mongoloid
Person who is successful, productive	Has overcome his/her disability, is courageous
He has a cognitive disability	He's mentally retarded
Children without disabilities	Normal or healthy kids
She communicates with her eyes/sign language/device	She's non-verbal
He has autism (or a diagnosis of autism)	He's autistic

Please share this with others, and thanks for the support and care you provide to people with disabilities.

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Importance

- “This is John. He’s the opinion leader in our home.”
- “This is Judy. She prefers managing the meal preparation at home, but she’s here for her check-up.”
- “Tom took off from his job at Sam’s Club today for this appointment.”
- “Samantha told me she’s not fond of having to come to the doctor. I guess she’s just like most of us in that respect.”

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Quality of Life

- “This is John. His favorite activities are baseball and basketball. You should see him hit the ball!”
- “When Susan goes to church, she’s having a harder time going up the steps.”
- “Tim makes the best sandwiches. Next time we should bring you one.”
- “Sharon’s friends at work mentioned that she seems to be having a harder time seeing.”

Quality of Life

A different quality of life does not equal a lesser quality of life.

Quality of Life for People with Intellectual and Developmental Disabilities

I've heard too many times colleagues infer that a person should be a DNR solely because they have a significant disability and they have a poor quality of life. I have seen a person with a disability placed in hospice care because she would no longer eat during a hospitalization for pneumonia with no investigation as to the cause. Once her acute illness was resolved to the point where she could be discharged, her support team decided that home was a better place for her than hospice or the hospital. When she came home where she was among her friends and people who knew how to support her, her eating returned to normal.

The Nursing Outcomes Classification (NOC) defines quality of life as the extent of positive perception of current life circumstances. There are many definitions of quality of life, some much more complex than this. However, this simple one relates to the person's perception of the quality of his/her life. It puts the person first. Quality of life can also be thought of as the balance between pleasant and unpleasant factors and experiences as they apply to one's physical and mental state.

The American Association on Intellectual and Developmental Disabilities (AAIDD) and the Arc of the United States adopted a joint position statement on quality of life for people with IDD. In it, it states that: People with intellectual and/or developmental disabilities must have the opportunity to lead lives that offer them a meaningful quality of life.

A meaningful quality of life exists for them when they:

- Receive, at all stages of their lives, the support, encouragement, opportunity and resources to explore and define how they want to live and who is in their lives;
- Choose the services and supports they need and receive them anywhere in the country without waiting for an uncertain and extended length of time;
- Direct the services and supports they receive;
- Lead a life enriched by friends and family and have opportunities for intimate relationships based on informed consent and responsibilities;
- Experience life-long learning and develop decision-making skills;
- Work in a job that is meaningful to them;
- Enjoy the same rights and respect for their dignity and privacy as do people without disabilities;
- Are fully informed about options, understand the risks associated with the options and are allowed to take risks inherent in the options they choose; and
- Receive support to live in a healthy and safe environment.

We all have the ability to define what a good quality of life means, and the definition would likely be a little different for each of us. Caution is warranted in applying our definition of what is fulfilling, pleasing and satisfying to others around us.

Good physical health has a profound impact on the quality of a person's life. The time you spend getting to know your patients with IDD, investigating their sometimes complex health needs and creating a person-centered health and wellness plan for them plays a major role in one's ability to live a comfortable, healthy and fulfilling life, even if it's different than the way we might define it. Thanks for your support.

End of Life Decision-Making

A DNR order should never be made simply because a person has an intellectual or developmental disability.

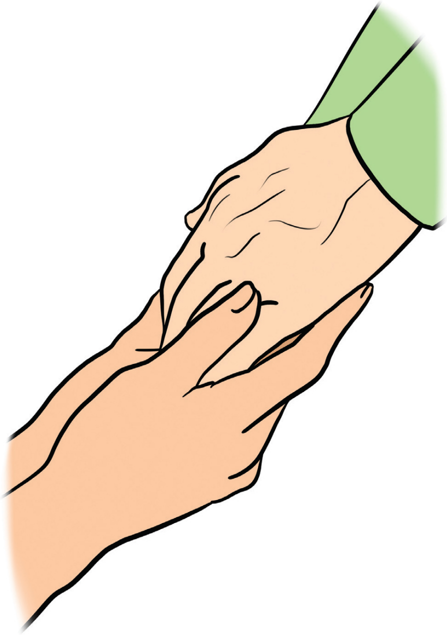
End-of-Life Decision-Making in People with IDD

Death. It is inevitable. Dying with dignity is usually preferred over dying in a cold, dark, lonely place or in a harsh manner. As clinicians, we are often faced with helping people make informed decisions about end-of-life care including the extent to which they want life-prolonging and resuscitative measures. As a physician in this field, I have been asked, “Why is he not a DNR?” by another physician based solely on the fact that the person had a disability. I have had to intervene when a patient who was in a hospital setting for pneumonia was placed on hospice because she wasn’t eating, rather than looking for reasons like constipation and environmental changes that were actually found to be the problem. These are things that I am sure would never have been considered if the person did not have a disability.

> There are certainly times where withholding care or resuscitation efforts are clinically warranted.

Deciding on end-of-life care and support in people who have difficulty with verbal communication and intellectual functioning is challenging, but not impossible. Many times, people with IDD have someone, or a group of people, such as their support team, who has the role of helping with decision making. This person could be a parent, sibling, legal guardian or friend.

It could be that you are the clinician providing care for them at that critical time, but there is another clinician who has a professional healthcare relationship with the person and can shed light on what the person’s wishes may have been at a less critical time. Hospital medical ethics committees might be a resource in cases where best interest standards are not clear. Reaching out to a local advocacy organization such as The Arc in your state may also be helpful.



There are certainly times when withholding care or resuscitation efforts are clinically warranted, but we should examine ourselves to make sure that the fact that someone may have a disability or an assumed lower quality of life is not the reason for the decision.

Thanks for your compassionate and caring support of people with IDD.

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Screening

- “Is it about time for her mammogram?”
- “When was the last time his cholesterol was checked?”
- “Do you have any diet recommendations to help him stay healthy as he gets older?”
- “What age should he have a PSA test for prostate cancer screening?”

Aging and Health Screening

Utilize the same preventative screening recommendations that are used for people without a disability.

Aging with Disabilities

There was a time when people with intellectual and developmental disabilities (IDD) did not get old; they died first. While the life expectancy for people with significant IDD is less than that of people without them, it has definitely increased from what it was years ago. This can be attributed to better healthcare and improvement in living conditions. The number of people with IDD over the age of 60 is expected to continue to grow.

With aging comes a whole new subset of health concerns.

With aging comes a whole new subset of health concerns, concerns that many people with IDD never lived long enough to experience. Screening procedures were often not considered in the past as the person's life expectancy was thought to be more limited by their disability than the condition for which they were to be screened. With longer lives comes the need for appropriate screening.

- Utilize the same screening recommendation for people with IDD as those without it
- Look for current screening recommendations for people with specific syndromes such as Down syndrome, fragile X and Prader-Willi
- Encourage health habits like diet and exercise
- Manage pain from things like arthritis that are seen more often as people age. People with physical disabilities may experience joint pain earlier than others
- Monitor for the long-term adverse effects of medications including things that increase the risk of conditions like obesity, osteoporosis, tardive dyskinesia and thyroid conditions
- Screen for dementia, especially in people with Down syndrome who tend to show signs earlier
- Help people remain as mobile as possible
- Consider hearing and vision-related changes associated with aging as these might show up as adverse behaviors because they can no longer hear or see well
- Facilitate community inclusion and participation as these issues are already challenging in people with IDD and often worsen as people age

Thanks for what you do in supporting healthy aging in people with IDD.

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Directing the Conversation

- “That’s a good question, let’s ask Jack.”
- “I don’t know doc, let’s see what Mary thinks about your recommendation.”
- “Why don’t we ask Denise if she thinks she would be able to sit still for that eye exam?”

Communicating Value and Human Traits

There is a Document that Can Help

Health Passport

- Summary of health information
  - Diagnoses
  - Medications
  - Past med/surg history
- Other helpful information
  - Pain expression
  - Diet modifications and needed assistance
  - Communication style
  - Likes and dislikes
  - Calming techniques
  - Best way to give medications
  - And more

My Health Passport

This document has important information so you can get to know me and better support me when I am receiving medical, dental, or other care. Please keep this information where others can easily reference it, and please READ THIS BEFORE trying to help me with care or treatment.

Demographic Information

Name: Thomas Jefferson

DOB: 4/13/1743

Address: 123 USA Street, Charlottesville, VA

Phone: 234-234-5577

Gender: Male

Race: Caucasian

Marital Status: Married

Insurance information: Medicaid number 123-456-7890

Other ID Numbers: Case number 11-23--44

Primary Care Physician:

Name: Doc Holiday, MD

Address and Phone Number: 999 9th Street, Charlottesville, VA, 222-333-4444

Psychiatrist:

Name: None

Address and Phone Number:

Dentist:

Name: Lester Tooth, DDS

Address and Phone Number: 888 8th Street, Charlottesville, VA, 111-222-3333

Preferred Hospital: George Washington Memorial

Family contact and/or person who supports my decision-making (name and contact information):

Martha Jefferson, 123 USA Street, Charlottesville, VA cell 123-456-7890

Emergency contact: Same

Important Clinical Information

Diagnoses: Moderate Intellectual Disability, Hypertension, Restrictive Lung Disease

Medications and dosages: Lisinopril 5 mg PO daily, HCTZ, 25 mg PO Daily

Medication allergies or adverse reactions and type of reactions: Penicillin – rash all over body

Food allergies and type of reaction: Pickles -mouth swelling

When I experience pain I often: (describe behavior, etc.) Moan, or may pinch and pull at my ear, even if the pain is not in my ear

Usual manner and level of mobility: (Describe method, usual gait or pattern of movement and needed supports) I walk using a cane but I do get tired easily and may need a wheelchair for long distances

My diet is: (type and texture) Regular, low salt diet with no bread.

The type of assistance I need when eating: I need a curved handled spoon

The type of assistance I need when drinking: I drink better using a straw

Name: _______Thomas Jefferson_______________________

Most recent weight (and date) 156 on March 30, 2020

Weight over past 6 months (list monthly weights and dates measured) Sept 20, 2019 -154, October 27, 2019 -157, November 29,2019 - 153, December 30, 2019- 158, January 28, 2020 - 154,February 27, 2020- 155

I take medications best in this form: (liquids, pills, mixed in pudding, etc.)I can swallow small pills with liquids but larger ones I prefer crushed up in applesauce

How I use the toilet: (Continence level, assistance, aids or products needed) I and go to the bathroom alone

My usual bowel movement pattern: 1 BM every 1-2 days

Important Information About Communication

I communicate best using: (words, gestures, sign language, behaviors etc.) Some words and points to things I want. A picture card is very helpful.

Hearing: (normal, somewhat impaired, fully impaired, etc.) Normal

Vision (normal, somewhat impaired, fully impaired, etc.) I wear glasses and can see well with them

Important Social information

My friends and people who know me describe me as: (fun, likeable, smart, good at puzzles etc.) I'm friendly and I make great sandwiches! I like hugging people and smile a lot.

I Like: Watching Wheel of Fortune and going outside on the front porch

When I like something I express it by: Smiling, saying "yes", getting excited.

I dislike :Thunderstorms, having anyone try to undress me

Name: _______Thomas Jefferson________________________

When I dislike something I express it by: *Running away, or hitting at others if I am really angry*

The best way to communicate with me is: *Sitting down, looking at my face and speaking in short sentences*

My usual sleep pattern is: *I go to bed around 10 pm, I usually get up once to go to the bathroom and get us at 7 am ready to eat breakfast!*

My favorite activities are: *Watching game shows and playing kickball*

I usually interact with friends this way: (friendly, smiles, anger, fear etc.)*Smile, and give a hug and a high five.*

I usually interact with strangers this way: (friendly, smiles, anger, fear etc.) *I like to hug everyone, even people I've never met.*

When I'm angry I sometimes: *Pull at my hair or ear, run away, strike at others*

When upset, the best way to help me calm down is: *Speak calmly, offer a magazine or to go on a walk.*

Things that I am sensitive to include: (specific sights, sounds, odors, textures/fabric, etc.) *Loud noises, Thunder, and I don't like blowing my nose in a paper towel, use something softer, please.*

Things that help me pass the time: *Television, looking at magazines and talking with my friends*

Overall Health Care Level ______
(Levels 1 and 2 low risk, levels 3 and 4 moderate risk levels 5 and 6 high risk)\

Date of most recent scoring:

Individual scores (Attach a print-out of the scoring summary)

Additional information:

Available Free at
HRSTonline.com

Name: _______Thomas Jefferson_________________________

Summary

- Health disparities exist, but improvements are being made
- There are misconceptions about quality of life and the valuation of people’s lives
- The federal government, advocates and organizations actively speak out and teach about equal consideration for life-saving measures
- There are things WE can do to help change misperceptions about people with disabilities

Call to Action

Continue… and increase your efforts

to help people with IDD

to be seen as

PEOPLE, first!

Thank you for joining us!

- Share the recording with others
- Visit HRSTonline.com to sign up for our newsletter and to download the Health Passport
- "Clinical Pearls in IDD Healthcare" available at HRSTonline.com
- Good Health and Wellness to all of you!