

Disparities, Perceptions and Misconceptions: Putting PEOPLE Before their Diagnoses

PRESENTED BY:
Craig Escude, MD, FAAFP, FAADM
President, HRS



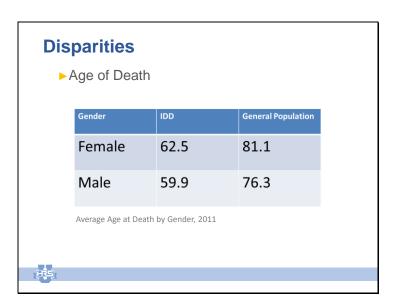
About the Presenter

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.







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

sability 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
- 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

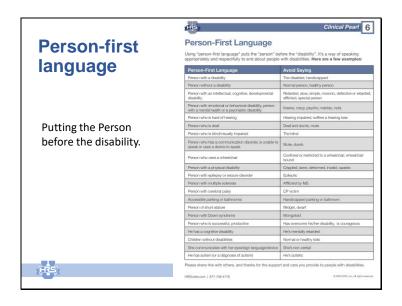
- ► Lead off with who the person is rather than their diagnoses
- ►Introduce them to others with respect and importance
- ► Describe their quality of life positively
- ► Ask about screening during healthcare visits
- ► Speak to the person and encourage others to do the same during healthcare visits



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."





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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

The heard to on many times colleagues infer that a person should be a DNR solely because they have a significant dissibility and they have a significant dissibility and they have a sole of the solely special or the sole of the sole of

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;



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

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







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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.



Clinical Pearl 14

Aging with Disabilities

These was a time when people with intellectual and developmental dissolities (IOO) did not get with Down syndrome who lend to show signs according to the state of the people with the time. It has definitely increased from what it was years ago. The care be attributed from what it was years ago. The care be attributed from the condition. The number of people with DO over the sage of 60 is expected to continue to grow.

With aging comes a whole sew subset of health concerns.

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With aging comes a whole new subset of health concerns, concerns that many people with IDD never lived long engought to experience. Several reproductives were often not considered in the past as the persons like expectancy was thought to be more similed by their disability than the condition for which they want to be screened.

► 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 exercis
- 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



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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

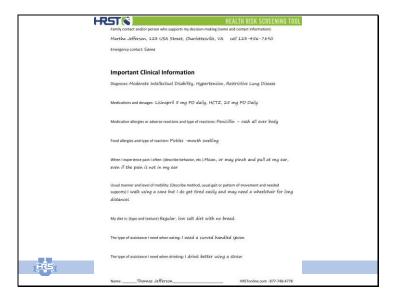


Health Passport

- ► 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













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!

