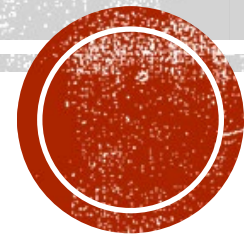


SPECIAL CASES GIVE A GIFT OF SPECIAL REWARDS

Leisha Eiten, AuD, CCC-A

Boys Town National Research Hospital

CAA, October 2024



HOW DID I GET HERE?

A DEDICATION TO MY
DAD



OUR AGENDA TODAY

General hearing loss prevalence in IDD populations

A discussion of practical clinic needs and patient preparation for clinical services

Discussion, suggestions for amplification options



- I am **very familiar** and comfortable working with adults with IDD
- I am **moderately familiar** and comfortable working with adults with IDD
- I am **not familiar** or comfortable working with adults with IDD, but I want to find out more!

A FAST QUIZ

Please be brave and raise your hand to indicate where you feel you land on familiarity and comfort:



INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

Barriers to high quality audiological testing

- Developmentally appropriate procedures to test hearing is crucial to care and outcomes
- Lack of knowledge or recognition of hearing problems
 - More than 30% of children with permanent hearing loss have additional disabilities

Barriers to high quality interventions

- Tolerance of devices
- Supportive caregivers
- Other SDOH that impact access to services



More than 30% of children with permanent hearing loss have additional disabilities



Children with IDD are 4 times more likely not to access gold-standard hearing assessment



Barriers to Audiological Evaluation for patients with IDD:

Behavioral hearing testing techniques

Objective testing with or without sedation

**MOST PREVALENCE DATA AVAILABLE IS
FROM PEDIATRICS**





SPECIAL OLYMPICS – HEALTHY HEARING PROGRAM

- Local / National / International Screenings performed since 2007
 - 39% of Special Olympics Athletes have blocked or partial blocked ear canals
 - 39% of athletes failed Puretone hearing examinations
 - 24% of athletes have permanent hearing loss
- Most athletes' hearing problems are previously undetected, un-served or under-treated.



HEARING LOSS AND IDD



Reported prevalence of hearing loss in patients with IDD, ranges from 24% to 93%, depending on Age



A variety of syndromes (metabolic and genetic) and birth injuries are included in the population with IDD



Inclusion of Down Syndrome into hearing loss statistics increases overall incidence rates

Patients under 30 with IDD have a 7.5% prevalence of hearing loss versus a 42.8% prevalence in patients with DS alone



Multi-Factoral

Sensory and Sensory Integration Issues

Hearing Loss / Tinnitus / Hyperacusis

Difficulty with walking and coordination

Rigidity in behaviors

Anxiety in new situations

AUTISM



DOWN SYNDROME

Hearing Loss

High Risk of
Otitis Media

Small / Low /
Malformed
Pinnae and Ear
Canals

Balance Issues

Speech &
Language Delay

Autism –
estimated 16%
prevalence in
People with DS

Skin Issues
(cerumen
issues)

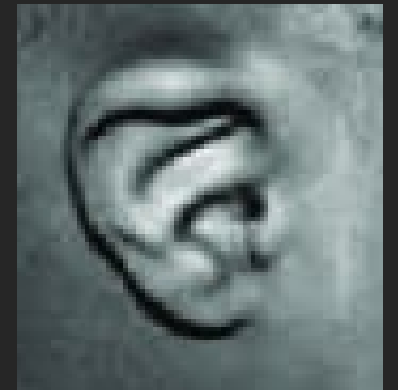
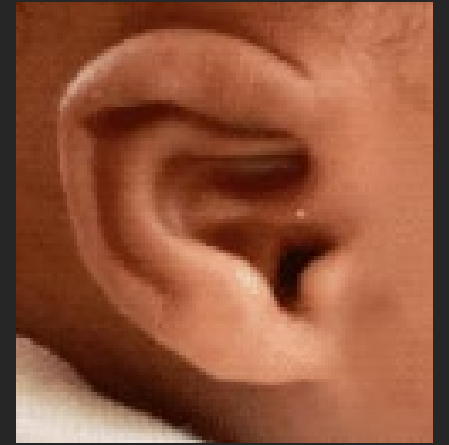
Epilepsy

Early Onset
Dementia



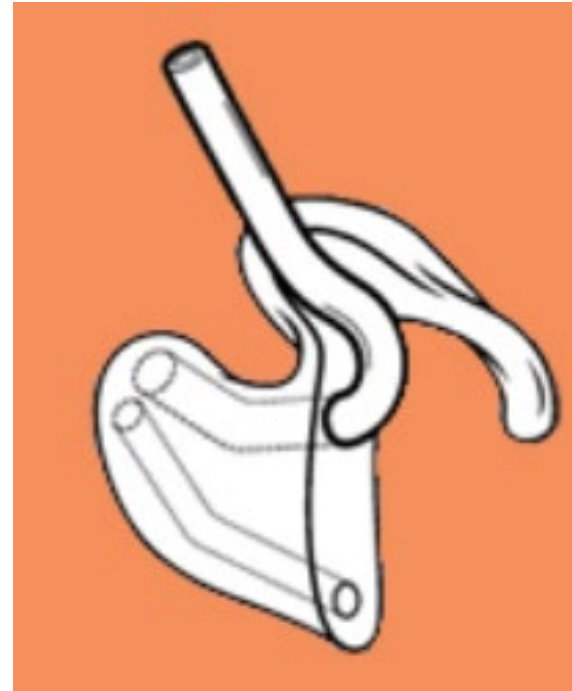
EXTERNAL EAR DIFFERENCES

- Stenotic canals
- Soft cartilage structure of pinna
- Prominent crus/separation between concha cavum and concha cymba
- Earmold / Custom Shell retention issues



CONSEQUENCES OF EAR DIFFERENCES

- Due to small ear canal size, individual **RECD** corrections are critical in accurate estimates of hearing and hearing aid targets
- Due to characteristics of dry skin and wax in people with DS, they are more prone to cerumen impactions
- Potential consequences of repeated ear infections / tubes and ear suctioning: Noise trauma from suction? High frequency hearing loss occurs early
- Consider earmold style for best retention





**LONG TERM GOALS
FOR ADULTS WITH
IDD**

Quality of life, independence,
safety

Communication

Social Functioning

Self-care

Slow progress is still progress

CHANGING WHERE AND HOW SERVICE IS PROVIDED



Community versus Institutional Placement

BT changed our care for patients in local institutional placement

How can you approach your care for patients with IDD in the community?



Promoting comfort and familiarity with hearing services

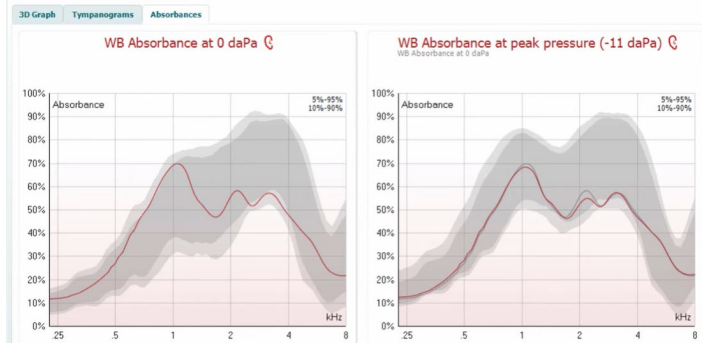
Home-based or Clinic-based care

Level of involvement of family and/or caregiver staff



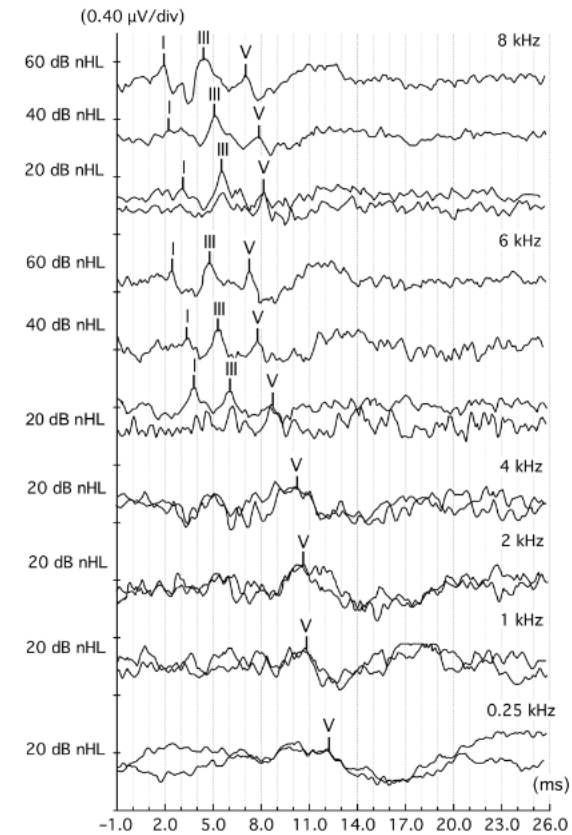
TEST PRIORITIES

- Objective:
 - Otoscopy
 - Tympanometry and/or Wide Band



- Behavioral
 - Observational / VRA / CPA
 - Responses to speech
 - Speech in Noise?

Figure 2. Sample auditory brainstem response waveforms for 0.25-, 1-, 2-, 4-, 6-, and 8-kHz tone burst stimuli for the left ear of a 5-week-old infant with normal hearing sensitivity. These data demonstrate feasibility of data collection within a clinical appointment and distinct waveforms for all test frequencies, including Waves I, III, and V for 6- and 8-kHz stimuli presented at 20, 40, and 60 dB nHL.



Porter, et al, 2022. Auditory Brainstem Responses at 6 and 8 kHz in Infants With Normal Hearing. AJA

- Evoked Potentials
 - DPOAE
 - Unsedated / Sedated ABR





Behavioral Observation Technique

Uses 2 individually determined response intervals



Blinds the “Observer” to which interval has the stimuli

Requires automation / computer controls of stimuli
Removes observer bias



Experienced “Assistant”

Knowledge about typical responses to expect
Define behavior being observed



Research utilization only at this time

2IFC TECHNIQUE DEVELOPMENT

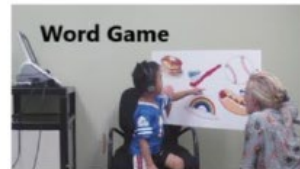
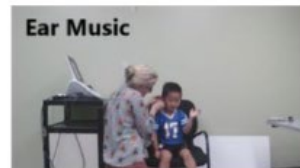


VISUAL SUPPORTS FOR TESTING PATIENTS WITH IDD

- Consider order of testing in light of individual reactions to touch, strangers, ear/head sensitivity
- Visual supports for children with ASD (McTee et al., 2019)
 - Using simplified scripts for CPA / Standard Audiometry
 - Photos to support scripts
- Consider filming video models in individual offices to review space and steps



MY AUDIOLOGY VISIT: MY SCHEDULE





**HEALTHY
HEARING STATION**

- “The visual schedule provides them with everything that we are going to be doing and reassures the patient that there will not be any surprises.”

Name:

Date:

	  Look in your ear	Look in my ears.
	 quiet  listen	Quiet, listen.
		Take a picture in my ear.
	 Hear it	Listen for the beep.
	 Hearing Aid	Hearing aid check.
	 Meeting	Meeting to report results.

- “I felt that the visual schedule was very helpful for almost every athlete I screened. I felt that it put them at ease if they were a little scared, made them less anxious about what was in the next room, and let them see what was expected of them without being told what to do.”

Martin, et al, 2016, Healthy Hearing at the Special Olympics: Visual Schedules Improve Patient-Provider Communication. Poster, Audiology Now!
DOI:10.13140/RG.2.1.3248.6806



OSF | AUDIOLOGY VIDEO MODELS AND VISUAL SCHEDULES

HTTPS://OSE.IO/B23UX

OSFHOME

Audiology Video Models and Visual Sch... Metadata Files

To access tools:

1. Be sure to use "Google Chrome" or "Firefox" as the web browser. Visual supports do not work with "Safari" or "Internet Explorer".
2. Click on the "Choose Your Too..."

[Read More](#)

Files

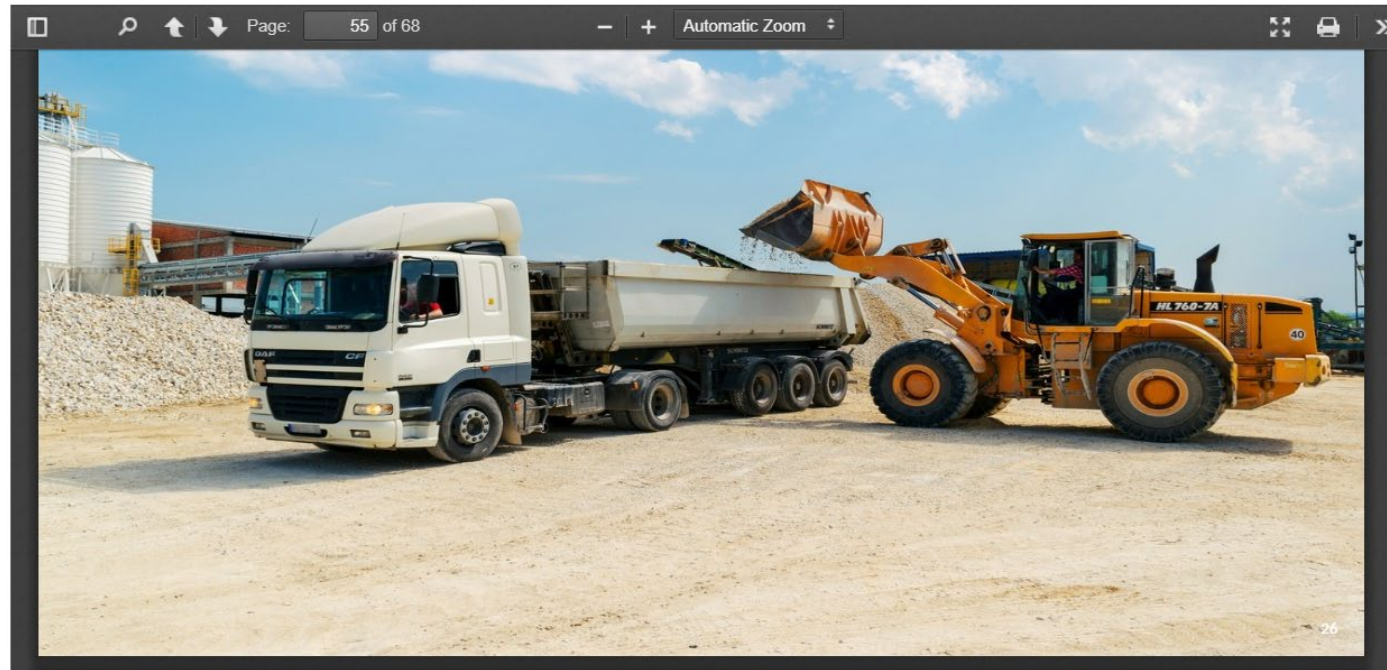
Download as zip Filter

Name	Modified
- Video Models	
- Captioned Videos	
Video Model 1 (Captioned).mp4	2019-06-30 10:40 AM
Video Model 2 (Captioned).mp4	2019-06-18 02:27 PM
Video Model 3 (Captioned).mp4	2019-06-13 05:51 PM
Video Model 4 (Captioned).mp4	2019-06-13 06:01 PM
Video Model 5 (Captioned).mp4	2019-06-13 07:38 PM
Video Model 6 (Captioned).mp4	2019-06-30 09:39 AM
Video Model 7 (Captioned).mp4	2019-06-15 12:20 PM



Library of Visual Reinforcers for Use in Behavioral Hearing Assessme...

Semis and Heavy Equipment.pptx




Library of Visual Reinforcers for Use in Behavioral Hearing Assessme...

Forest Animals.pptx




Navigation bar: Page: 39 of 68, Automatic Zoom, and other controls.

















18



Files

 Download as zip Filter

Name ^ v	Modified ^ v
 Frogs and Toads.pptx	2020-11-14 10:55 PM
 General Transportation.pptx	2020-11-18 11:18 PM
 Movement.pptx	2020-11-18 11:18 PM
 People Moving.pptx	2020-11-20 12:41 AM
 Race Cars.pptx	2020-11-08 10:47 AM
 Rainbows and Colorful Images.pptx	2020-11-08 10:32 AM
 Reflections.pptx	2020-11-20 12:45 AM
 Reptiles.pptx	2020-11-14 10:34 PM
 Sea Creatures.pptx	2020-11-13 11:26 PM
 Semis and Heavy Equipment.pptx	2020-11-08 10:47 AM
 Shopping.pptx	2020-11-20 05:10 PM
 Snakes.pptx	2020-11-14 10:34 PM
 Space Pictures.pptx	2020-11-08 10:32 AM
 Space videos.pptx	2020-11-18 11:14 PM

OSF | LIBRARY OF
VISUAL REINFORCERS
FOR USE IN
BEHAVIORAL
HEARING
ASSESSMENT
HTTPS://OSF.IO/BK6
RC



HEARING AID CONSIDERATIONS

1

Hearing aids may be an option, depending on individual's daily lifestyle needs and accommodations

2

Can a family member or caregiver help with changing batteries or charging the hearing aids?

3

Will the person tolerate the hearing aids on their ears, or will they try to take them off and lose them?

4

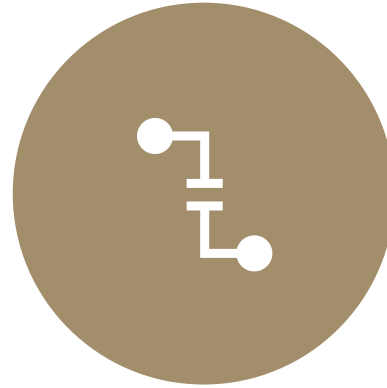
Loss and Damage protection or planning is important!



HEARING AID FITTING CONSIDERATIONS



**IMPORTANCE OF RECD FOR
ACCURATE THRESHOLD
ESTIMATES**

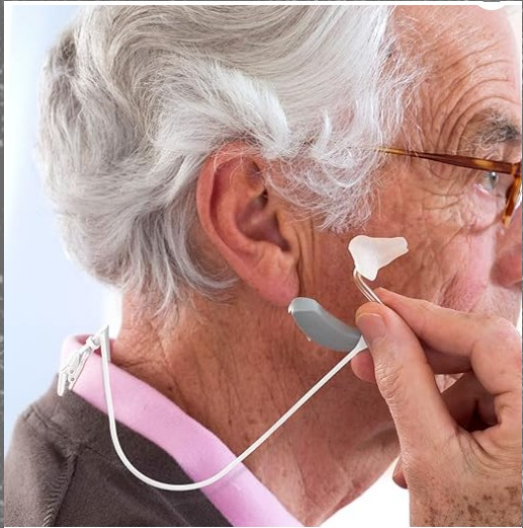


**MAY BE BASED ON ABR
(INCLUDE 6K & 8K HZ
RESPONSES)**



**OTHER ASSISTIVE DEVICES
MAY NEED TO BE
CONSIDERED**





LOSS PREVENTION



AUDIOLOGY'S RESPONSIBILITY

You may be a primary point of contact for adults with IDD

Work across disciplines & be part of the care team

- Primary nursing
- PCP / ENT / Neurology / Dermatology



DECISION MAKING APPROACHES

5 Conclusion and authorization

Note: the legal status of supportive decision makers varies among Canadian jurisdictions (see table 2 and supplemental materials for legislations^{iv}).

If you answered YES or N/A to all of the statements in step 4 :

The patient can exercise capability for making this decision.

Independent Decision

- the patient authorizes

Supported Decision

- The supportive decision maker authorizes with or without the patient. At present (i.e., February 2019) British Columbia is the only province in which a decision-making supporter can authorize a decision on behalf of the patient.^[iv]
- The patient authorizes. Only in Alberta, Manitoba, and the Yukon Territories the patient can authorize in a supported decision making arrangement.^[iv]

If you answered NO to any of the statements in step 4 :

The patient is unable to exercise capability for making this decision and is dependent on a substitute decision maker.

Substituted Decision

- Consent must be obtained from the highest ranking eligible person stipulated in the hierarchy of substitute decision makers set out in the provincial regulations.^[iv] If the substitute decision maker does not know the patient well facilitate discussion between the SDM, the patient and caregivers familiar with the patient.¹ In jurisdictions where supported decision making is not legally recognized, advise the substitute decision maker (if different than the person the patient requests for assistance) of the patient's supported decision to guide determining patient's best interest.

Patient's assent or dissent and his/her wishes:



PROMOTING CAPABILITIES TOOL



- Shared decision making, as much as possible
 - Determine patient's ability to consent
- Decision Support Professional present



DECISION MAKING APPROACHES FROM PRIMARY CARE RESOURCES

Level of intellectual disability ^[m] Psycho-educational assessments contain valuable information about what strategies will best help your patient with IDD to learn and process new information. Generally, patients with IDD benefit from plain language, additional time, repetition, and visuals.

- Mild Gear explanations to Grade 2 to Grade 6 level.
- Moderate Gear explanations to Grade 1 to Grade 4 level.
- Severe Gear explanations at preschool to Grade 1 level (ages 3-6 years). Include caregivers who know the patient well to assist.
- Profound Use simple language and one-step directions (age up to 3 years). Include caregivers who know the patient well to assist.
- Unknown

DISCUSS THE PROPOSED TREATMENT

Describe or show what you and your patient would have to do in the proposed treatment.

ASK THE PATIENT: *Can you tell me or show me what I am asking you to do?*

2. The patient is able to understand and does understand what the proposed treatment involves

Yes No Unsure



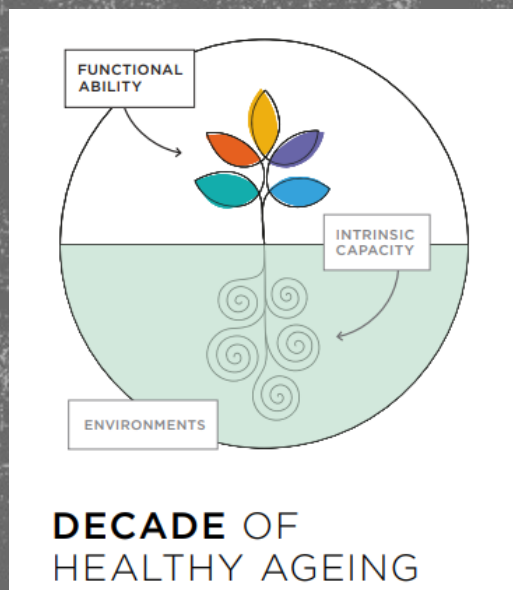
- **Change Appointment Times**
- **Incorporate a Decision-Making Tool**
- **Change Hearing Aid Decisions / Choices**
- **Adjust Clinic Set-Up: Virtual / Remote Clinics / Visual Schedules**

A FAST QUIZ

Select your top
Change



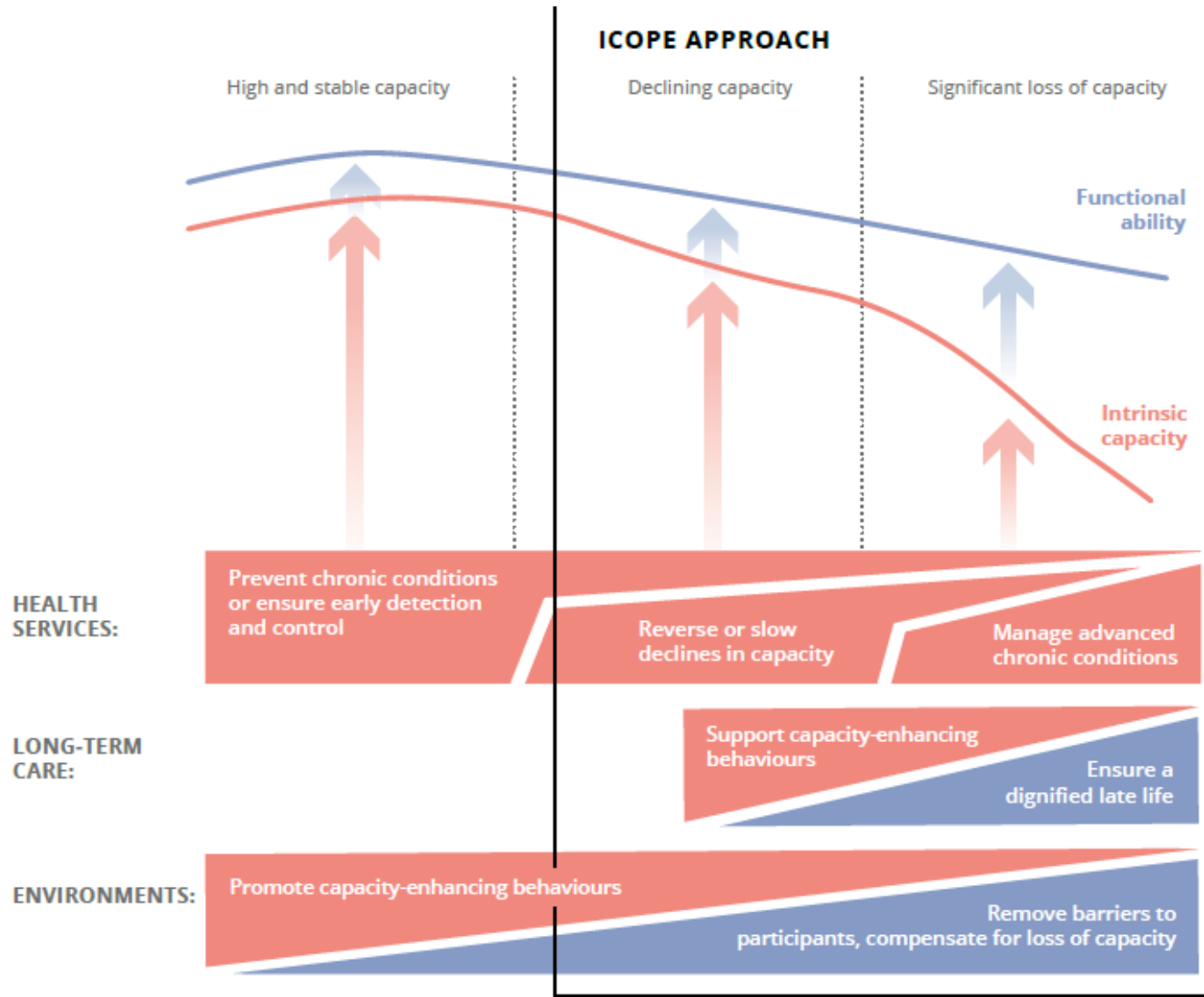
WORLD HEALTH ORG AND AGING



- Person-centered assessment and support for Functional Ability
- WHO's emphasis on Functional Ability is part of the Decade of Healthy Aging Program



WHO-ICOPE INTEGRATED CARE FOR OLDER PEOPLE



Source: World Health Organization, 2015 (1).



PRIMARY PERSON- CENTERED ASSESSMENT AND CARE PATHWAYS OF ICOPE

Cognitive Decline

Mobility

Malnutrition

Visual Impairment

Hearing Loss

Depressive Symptoms

Social Care & Support

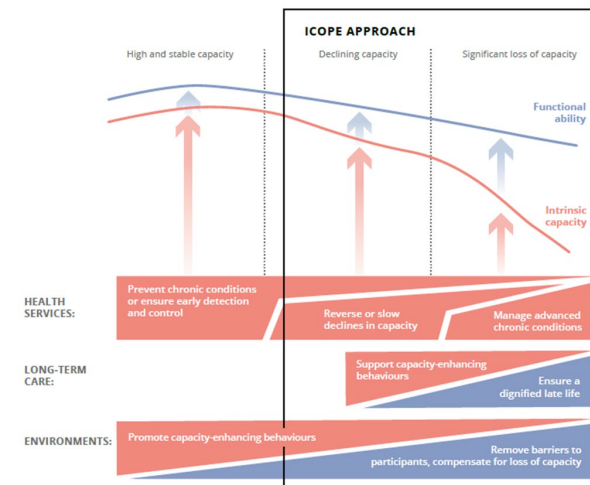
Supporting the Caregiver



HEARING HEALTHCARE FOR PATIENTS WITH DEMENTIA

- Promoting strong communication and referral patterns with Community Care Providers
- Promoting communication, social engagement, family interaction
- Devices that can be managed by person, as much as is possible
- Devices that can be managed by others
- Working with caregivers
- Planning for loss and damage

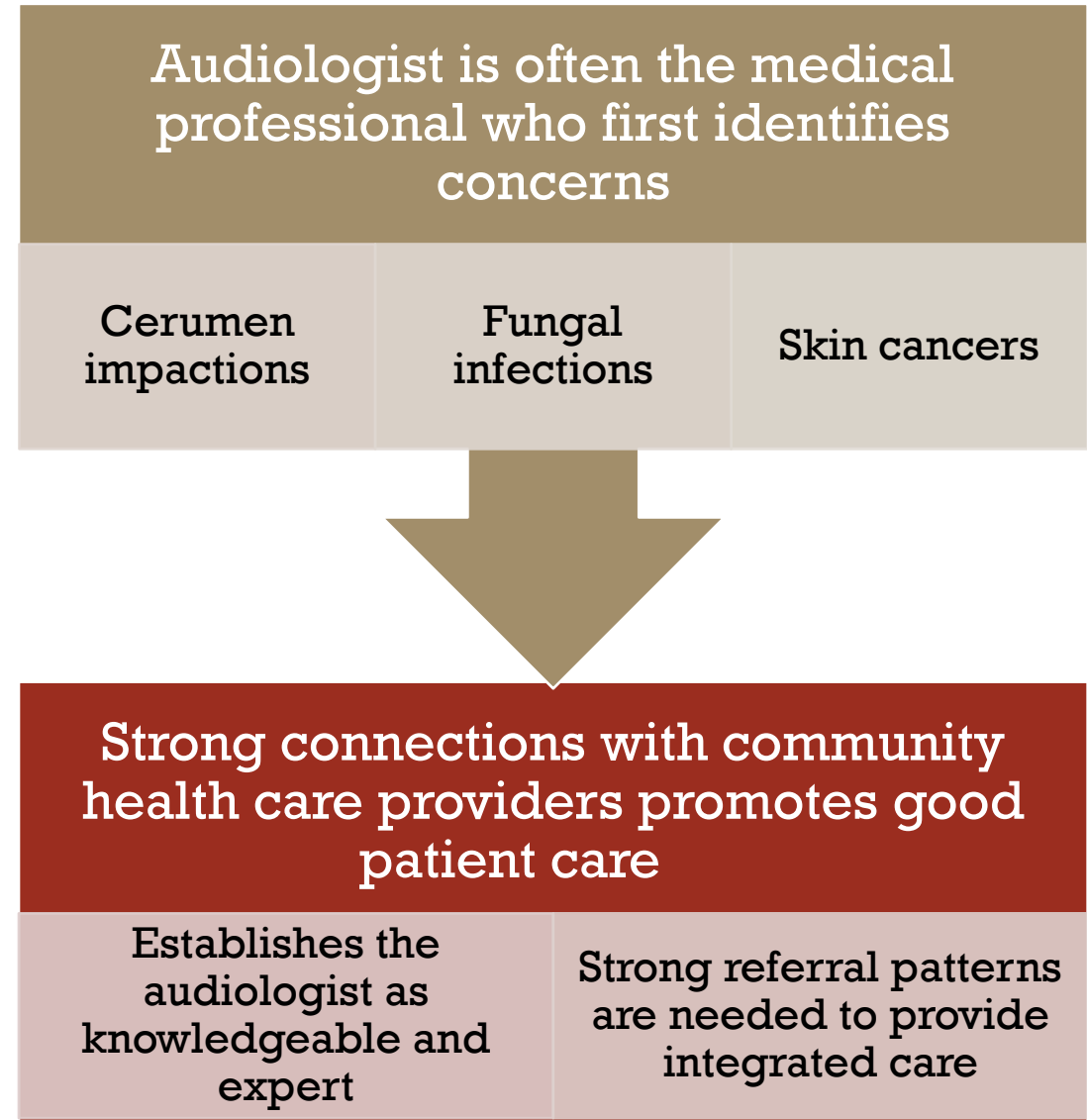
FIGURE 2. A PUBLIC-HEALTH FRAMEWORK FOR HEALTHY AGEING:
OPPORTUNITIES FOR PUBLIC HEALTH ACTION ACROSS THE LIFE COURSE



Source: World Health Organization, 2015 (7).



HEALTHCARE CONNECTIONS



AUDIOLOGICAL TESTING CONSIDERATIONS

- Visual Schedules during audiological evaluation may also be helpful in this population, with reminders
- Breaks in testing due to fatigue / napping may be needed
- Consider what audiological information is MOST important and prioritize test sessions
 - Several frequencies in each ear may be all that is obtained
 - Are bone conduction thresholds essential?
 - Speech testing completed binaurally versus monaurally
 - MLV versus recorded voice considerations
 - Consider short-term memory abilities



**CONSIDER LONG-TERM VALUE OF
RECD IN ON-GOING CARE**

**SLOW ACTING COMPRESSION TO
REDUCE DISTORTION OF SPEECH
INPUT**

**EXCELLENT DIGITAL NOISE
REDUCTION WITHOUT DISTORTION**

**ABILITY TO FIND LOST HEARING AIDS,
IF CONNECTED TO PERSONAL OR
FAMILY-MEMBER'S MOBILE PHONE**

HEARING AID CONSIDERATIONS



HEARING AID CONSIDERATIONS



Involvement of family, close care worker in hearing aid fitting and follow-up process



If appropriate, consider if OTC devices are appropriate



In advanced states of dementia, assistive devices (pocket talker) are a better option





Consider selecting two different color devices to differentiate between right and left hearing aids



Consider if ITE rather than RIC/BTE devices are easiest for person to manipulate



Rechargeable batteries

Vision / Dexterity
Common location of hearing aid storage



Use of loss-prevention clips may be needed

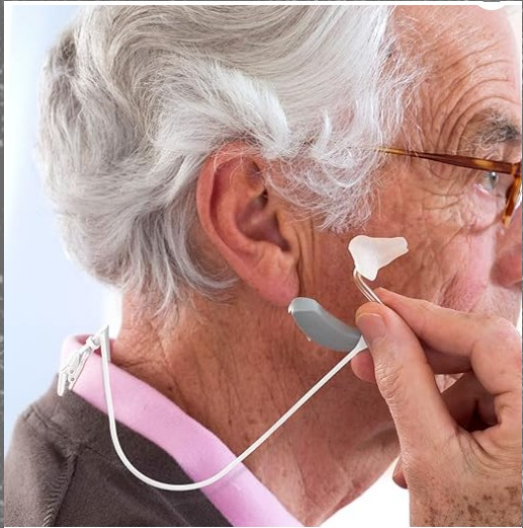
DEMENTIA-FRIENDLY HEARING AID FEATURES



- Provide hearing aid instructions to family members and caretakers
- Determine who is providing daily / regular support
- Consider putting small labels with person's name to find and identify devices when they get misplaced.
- Additional hearing aid insurance offered from companies like ESCO can be helpful in the event of a loss or misplacement.

DEMENTIA- FRIENDLY CONSIDERATIONS





LOSS PREVENTION



WHAT WILL I DO FROM HERE?

01

Evaluate unmet
Audiological
care needs in
my community

02

Make a
welcoming care
environment for
vulnerable
adults

03

Examine new
methods or
ideas for your
practice

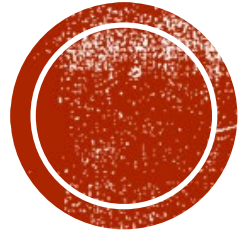


- Evaluate Unmet Care Needs in My Community
- Make a Welcoming Care Environment
- Examine new methods and ideas for your clinical practice

A FAST QUIZ

What will you do with this information?





QUESTIONS / COMMENTS





THANK YOU FOR JOINING ME!

- Leisha.eiten@boystown.org
- [DDPCP \(surreyplace.ca\)](http://DDPCP.surreyplace.ca)
- [AIDE Canada | Resources for Autism & Intellectual Disability](#)
- Data references available by email

