



European Federation of
Audiology Societies

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EFAS WG AID: Working Group Audiology and Intellectual Disability

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EFAS WG AID: members

- ANDERSSON Eva, Audiologist, Sweden
- BRENNAN Siobhan, Audiologist, UK
- CRAVO Melissa, Audiologist, Portugal
- GEORGESCU Madalina, ENT & Audiologist, Romania
- NEUMANN Katrin, ENT, Germany
- **SCHAEFER Karolin, SLP, Germany**
- WILLEMS Melina, Audiologist, Belgium

- *CONINX Frans, Audiologist/Teacher of the Deaf, Germany*

EFAS WG AID: topics



- Introduction
- Accomplishments:
 - Questionnaire
 - Guidelines
- Future projects
- Conclusions and discussion

EFAS WG AID: topics



- **Introduction**
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EFAS WG AID: target group

- People with Intellectual Disability (ID)
- Definition ID (DSM-5 (R), 2013)
 - Deficits in intellectual functions
 - Deficits in adaptive functioning (conceptual, social and practical skills)
 - Onset during developmental period
- Children and **adults**
- Prevalence ID: 1-3% (WHO)
 - World population: up to 21 million people
 - Europe: up to 2 million people

EFAS WG AID: introduction



THE ENJOYMENT OF THE HIGHEST ATTAINABLE STANDARD OF HEALTH IS ONE OF THE FUNDAMENTAL RIGHTS OF EVERY HUMAN BEING WITHOUT DISTINCTION OF RACE, RELIGION, POLITICAL BELIEF, ECONOMIC OR SOCIAL CONDITION.

—Preamble to the Constitution of the World Health Organization

- ➡ On average, people with ID die 16y earlier than general population

EFAS WG AID: introduction

- Ear, hearing and vestibular problems in people with ID
 - Limited amount of data
 - Increased prevalence
 - Most unknown, undiagnosed, untreated
 - Limited/no access to health care
- Children and **adults**



European data

- ▶ European data on ear and hearing screening in people with ID:
 - ▶ Special Olympics Healthy Hearing data 2007-2017
 - ▶ 7 European countries
 - ▶ N = 15,363
- ▶ 40.3% excessive ear wax
- ▶ 30.1% middle ear problems
- ▶ 27% hearing loss / 12.9% SNHL
- ▶ Overall referral rate: 58.7% → would be up to 1 million European citizens with ID with possible ear/hearing problems

EFAS WG AID: topics



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EFAS WG AID: accomplishments

➔ 1. Questionnaire:

- ➔ To gather information on screening and assessment of ear, hearing and vestibular problems in people with ID in different European countries
- ➔ EFAS representatives: 23 responses out of 22 countries

Austria	Greece	Slovakia
Belgium	Lithuania	Slovenia
Bulgaria	Luxembourg	Spain
Croatia	Norway	Sweden
England	Poland	The Czech Republic
Finland	Portugal	Turkey
Germany	Serbia	

- ➔ Presented at 2017 EFAS conference (Interlaken/Switzerland) → online

EFAS WG AID: accomplishments

- 1. Questionnaire: conclusions
 - Many countries focus/offer neonatal/school-age hearing screening
 - High-risk protocol includes babies with ID
 - No reference to adult hearing screening programmes
 - No specific hearing screening programme for people with ID
 - Most (19/22) indicate the need for a specific programme

EFAS WG AID: accomplishments



➔ 2. Guidelines:

- ➔ WG decided to develop guidelines instead of protocols. Guidelines can be used on European level, and can be adapted to protocols on National level.
- ➔ Frequency of Hearing Screening
- ➔ Presented at 2017 EFAS conference (Interlaken/Switzerland) → fine tuned → online

EFAS WG AID: accomplishments

➔ 2. Guidelines:

AUDIOLOGICAL CARE	PERSON WITH ID IN GENERAL	PERSON WITH DOWN SYNDROME	PERSON WITH ID ELIGIBLE FOR HEARING DEVICE
EARWAX REMOVAL	Annual	2x/ year	2x/ year
HEARING SCREENING	Neonatal Hearing Screening	Neonatal Hearing screening	2-4x/year < age 6
	Annual screening < age 6	2x/ year < age 6	
	Every 3 years from age 6 to 18	Every 2 years from age 6 to 18	2x/year ages 6 < 10
	Every 5 years from age 18 to 50	Every 3 years from age 18 and 35	Annual hearing evaluation > age 10
	Every 3 years > age 50	Annual > age 35	
	Annually if 8h/ day noise exposure (>75dBA)		

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GUIDELINES

The following table is a summary of the preliminary guideline proposal for audiological hearing screening and management for people with intellectual disability (ID). These guidelines were based on the available literature and publications.

AUDIOLOGICAL CARE	PERSON WITH ID IN GENERAL	PERSON WITH DOWN SYNDROME	PERSON WITH ID ELIGIBLE FOR HEARING DEVICE
EARWAX REMOVAL	Annual	2x/ year	2x/ year
HEARING SCREENING	Neonatal Hearing Screening	Neonatal Hearing screening	2-4x/year < age 6
	Annual screening < age 6	2x/ year < age 6	
	Every 3 years from age 6 to 18	Every 2 years from age 6 to 18	
	Every 5 years from age 18 to 50	Every 3 years from age 18 and 35	Annual hearing evaluation > age 10
	Every 3 years > age 50	Annual > age 35	
	Annually if 8h/ day noise exposure (>75dBA)		

WORKGROUP MEMBERS

WILLEMS Melina - Audiologist/ SLP/Deaf Interpreter - **Belgium**
 ANDERSSON Eva – Audiologist - **Sweden**
 BRENNAN Siobhan – Audiologist – **England**
 CONINX Frans – Audiologist/ Teacher of the Deaf - **Germany**
 CRAVO Melissa - Audiologist - **Portugal**
 GEORGESCU Madalina – ENT/ Audiologist - **Romania**
 NEUMANN Katrin – ENT – **Germany**
 SCHAEFER Karolin – Speech and Language Therapist - **Germany**

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AUDIOLOGY & INTELLECTUAL DISABILITY WORKGROUP

DEFINITION OF INTELLECTUAL DISABILITY

Intellectual disability (intellectual developmental disorder) is a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains. The following three criteria must be met:

- Deficits in intellectual functions, such as reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience, confirmed by both clinical assessment and individualized, standardized intelligence testing.
- Deficits in adaptive functioning that result in failure to meet developmental and socio cultural standards for personal independence and social responsibility. Without on going support, the adaptive deficits limit functioning in one or more activities of daily life, such as communication, social participation, and independent living, across multiple environments, such as home, school, work, and community.
- Onset of intellectual and adaptive deficits during the developmental period.

GOALS & JUSTIFICATION

- Create awareness to the importance of hearing screening and management for people with intellectual disability (ID).
- Develop guidelines towards audiological care for people with ID.
- Ear and hearing problems in people with ID are more common than in the general population.
- Hearing problems remain undetected, un-served and/or under-treated.

WHAT HAS BEEN DONE?

- Literature review.
- Online questionnaire to identify current practices and approaches across Europe.
- Preliminary guidelines regarding hearing screening for people with ID in general and with Down Syndrome.

27-28th September 2018, Montpellier/France

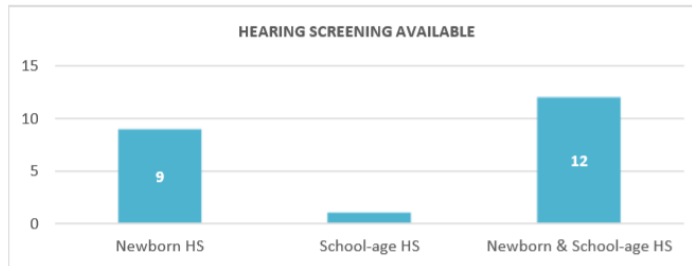
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QUESTIONNAIRE RESULTS

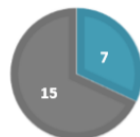
The questionnaire was sent via email to EFAS representatives. The summarized data presented below was collected between September 2016 and January 2017. There were a total of 23 answers received from 22 countries.

HEARING SCREENING (HS)



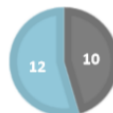
ARE THERE HS ADJUSTMENTS FOR PEOPLE WITH ID

■ Yes ■ No



IS THERE A FOLLOW-UP FOR PEOPLE WITH ID WHEN THEY HAVE PASSED HS?

■ Yes ■ No



IS THERE A SPECIFIC FOLLOW-UP FOR PEOPLE WITH ID WHEN THEY HAVE FAILED HS?

■ Yes ■ No



ARE THERE SEPERATE HS PROGRAMMES FOR PEOPLE WITH ID?

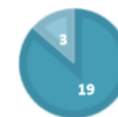
■ Yes ■ No



IMPLEMENTING HEARING SCREENING (HS) FOR PEOPLE WITH INTELLECTUAL DISABILITY (ID)

DO YOU THINK THAT SPECIFIC HS FOR INDIVIDUALS WITH ID ARE NECESSARY?

■ Yes ■ No



ARE THERE ANY AUDIOLOGICAL/ENT GUIDELINES/PUBLICATIONS IN YOUR COUNTRY

■ Yes ■ No



POTENTIAL BARRIERS TO IMPLEMENTING HS FOR PEOPLE WITH ID



PROFESSIONALS WHO ANSWERED THE QUESTIONNAIRE

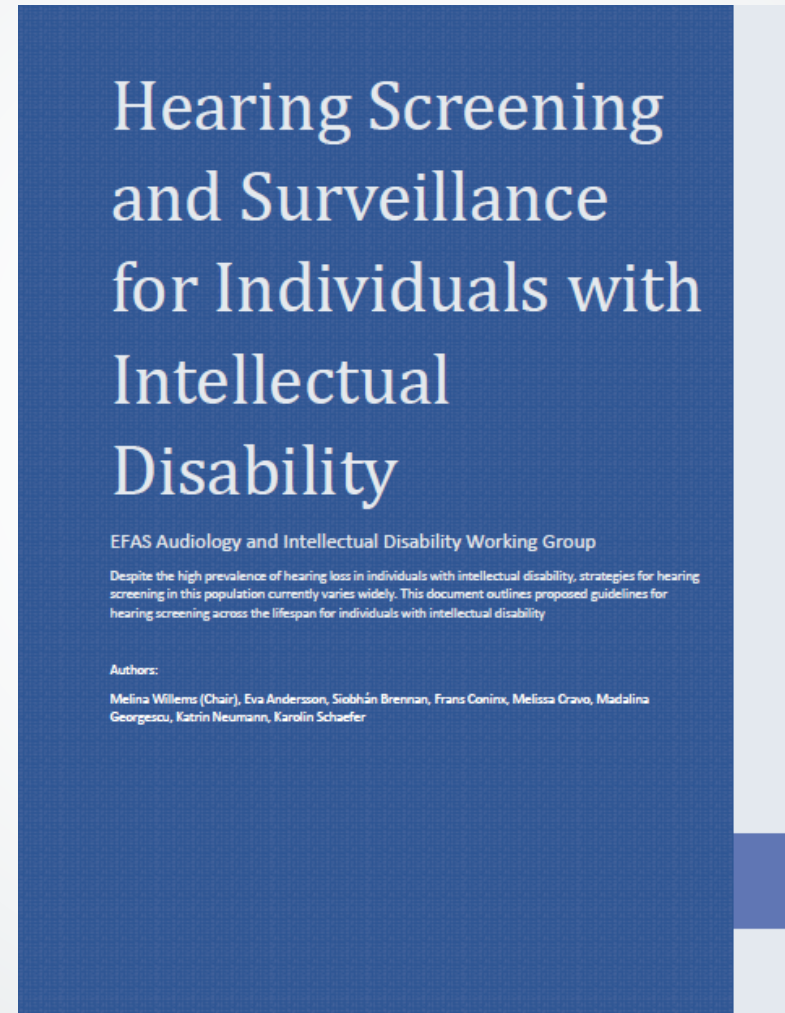


EFAS WG AID: accomplishments



➔ 2. Guidelines:

➔ Creation of document:



EFAS WG AID: accomplishments



- 2. Guidelines: Hearing Screening and Surveillance for Individuals with ID
 - Background
 - Defining ID
 - Defining hearing screening
 - Principles of hearing screening for individuals with ID
 - Current European hearing screening for individuals with ID
 - Reference list

Hearing Screening and Surveillance for Individuals with Intellectual Disability

EFAS Audiology and Intellectual Disability Working Group

Despite the high prevalence of hearing loss in individuals with intellectual disability, strategies for hearing screening in this population currently varies widely. This document outlines proposed guidelines for hearing screening across the lifespan for individuals with intellectual disability

Authors:

Melina Willems (Chair), Eva Andersson, Siobhán Brennan, Frans Coriis, Melissa Craven, Malalena Georgescu, Katrin Neumann, Karolin Schaefer

EFAS WG AID: accomplishments

➤ 2. Guidelines: Hearing Screening and Surveillance for Individuals with ID

➤ *Principles of hearing screening for individuals with ID*

- The hearing impairment to be screened for should be an important health problem
- There should be an accepted rehabilitation means for cases identified by screenings
- Facilities for assessment, diagnosis and rehabilitation should be available
- The hearing impairment should be recognizable at an early stage
- A suitable hearing screening test should be available
- The hearing screen should be acceptable to the individual and their family/carers
- There should be an agreed policy on whom to treat as patients with hearing impairments

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EFAS WG AID: future projects

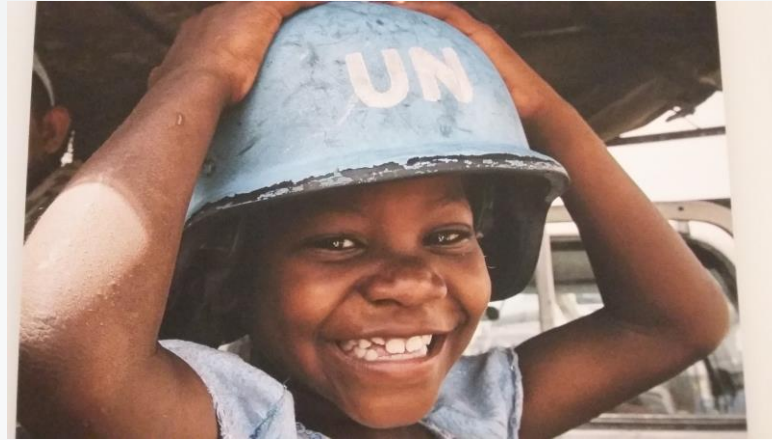
- Guidelines on Hearing Screening and Surveillance for Individuals with ID
→ online after final approval WG
- Guidelines on Hearing Assessment for Individuals with ID
- Preparation of 2019 EFAS conference workshop
- WG meeting January 2019

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EFAS WG AID: conclusion



- UN Sustainable Developmental Goal 3:
"Ensure healthy lives and promote well-being for
ALL at ALL ages"

EFAS WG AID: conclusion

- ➡ How to motivate European countries/professionals to take their responsibilities towards this population?
- ➡ How to increase access to health care for people with ID?
- ➡ How to initiate screening/increase the screening frequency, and include adults?
- ➡ Future projects for EFAS WG AID?
- ➡ Workshop topics for 2019 EFAS conference?

EFAS WG AID



THANK YOU FOR ATTENTION!

27-28th September 2018, Montpellier/France



EFAS WG AID: conclusion

- ➡ How to motivate European countries/professionals to take their responsibilities towards this population?
- ➡ How to increase access to health care for people with ID?
- ➡ How to initiate screening/increase the screening frequency, and include adults?
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- ➡ Workshop topics for 2019 EFAS conference?