

*“I know it can change for people
with what I’ve had”:*

Environmental Factors and People with the Language Disorder of Aphasia

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**LIVING IN OUR ENVIRONMENT:
The Promise of ICF**

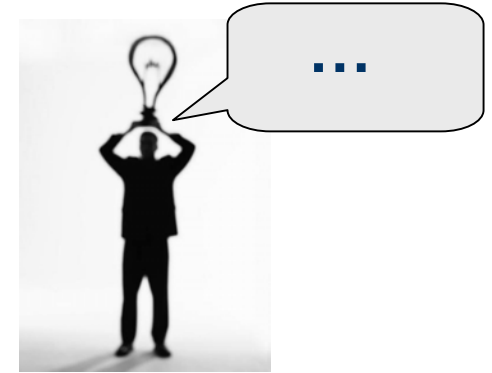
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Outline of Presentation

- **Introduction**
- **Overview of two research studies**
- **Compare research results to the *ICF***
- **Conclusion**

Aphasia

- ***“What’s in your brain doesn’t come out of your mouth”***
- **difficulty listening, speaking, reading, writing &/or using numbers caused by stroke or other damage to the language centres of the brain**



Aphasia

- Often significant **sudden life-altering longterm** impact
- **Communication = “currency”** through which life is lived!

*“I don’t...I not...I can’t – all no, not – what is it I can?
I miss the color of life!...I look, say, at the anger and
think through it...same with frustration...because the
frustration is always there. It’s part of everything,
every few minutes of the day.”* (Lyon & Shadden, 2001)

- With **communication difficulties – more difficult** to obtain needed emotional and psychological **support**

Aphasia

- **Estimated prevalence = 1 million in U.S.**
- **Much less U.S. newspaper coverage than diseases such as PD and MS yet similar/higher estimated prevalence**

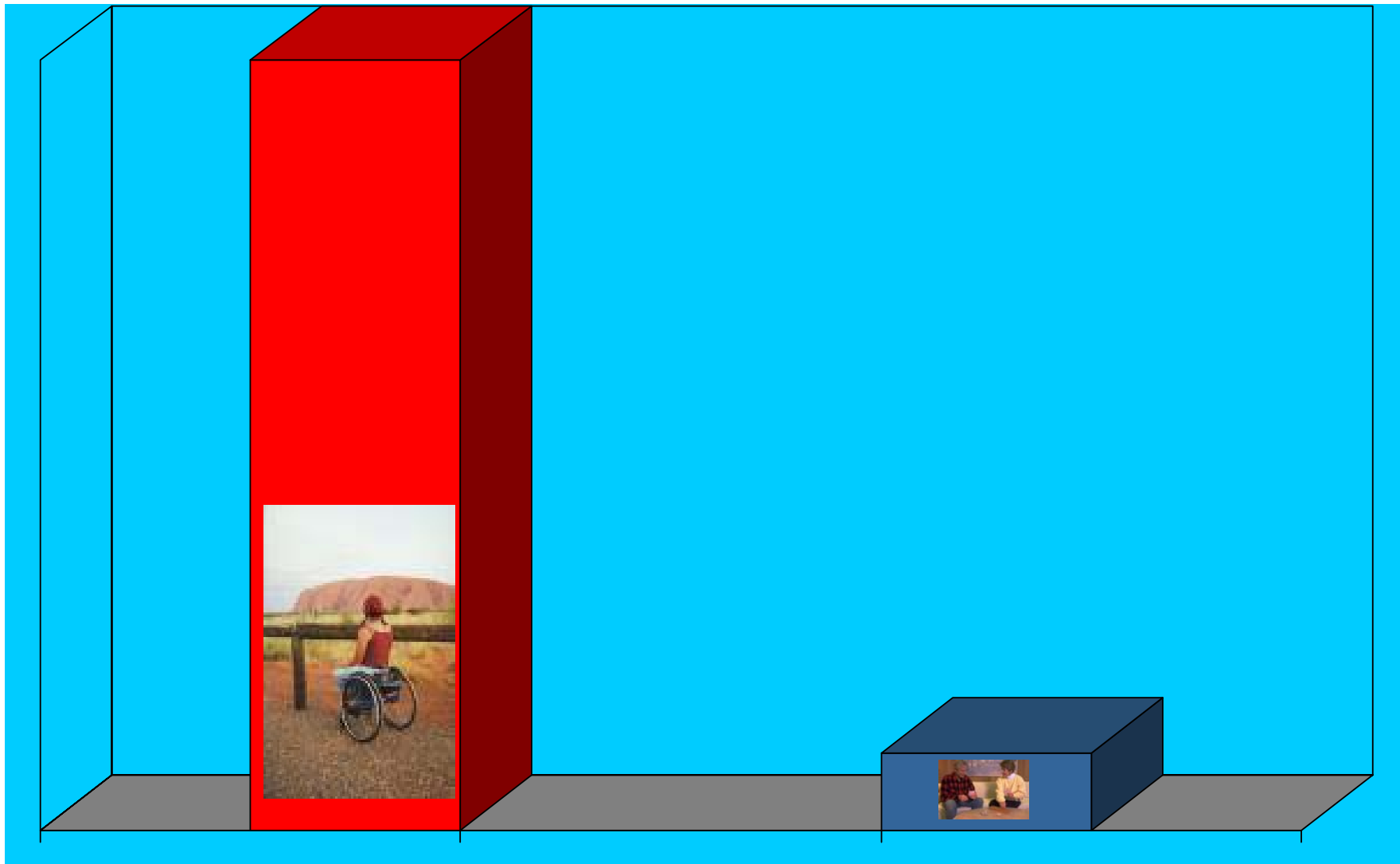
(Elman, Ogar, & Elman, 2000)

- *“Relatively few people know what aphasia is apart from speech . . . pathologists and . . . the persons with aphasia.”*

(Study participant)

*“While rights to **physical access** in the form of wheelchair ramps and accessible facilities are now **taken for granted** in many parts of the world, the right to **communicative access** is **often not considered in the same light.**”* (Kagan & LeBlanc, 2002)





**Research on
Environmental Factors**

- Physical Disorders

**Research on
Environmental Factors**

- Communication Disorders



Overview of Two Research Studies

Research Aim



- To explore the **environmental factors** that **hinder** or **support** the **community participation** of adults with **aphasia**

Method

Two **qualitative studies** to address this aim:

1. **Semi-structured in-depth interviews** with **25** adults with aphasia



Method

2. Participant observation of **10** adults with aphasia in **community** environments



Total time: **50 hours 44 minutes**

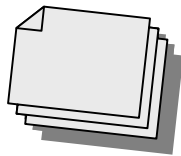
in 31 different types of places:

e.g., bus, doctor's office, stroke group, post office

Compilation of Some Results from the 2 Studies

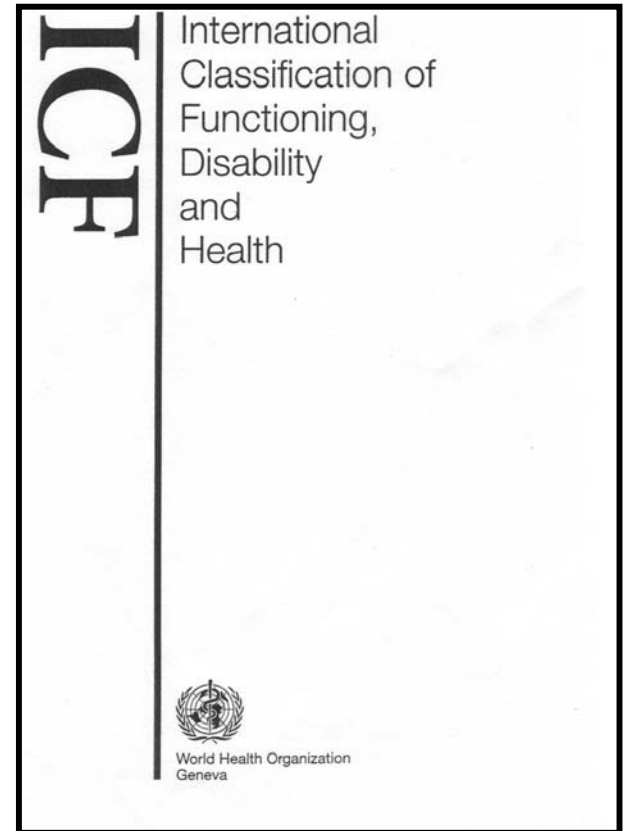
**181
Barriers**

**238
Facilitators**



**Interview transcripts &
Observation field notes**

How do the Research Results Relate to the *ICF* ?



A. All 5 ICF

EF Domains represented

EF DOMAINS

1. *Products & technology*
2. *Natural environment & human-made changes to environment*
3. *Support & relationships*
4. *Attitudes*
5. *Services, systems, & policies*

1. Products and Technology Domain

e1251 *Assistive products and technology for communication as a facilitator:*

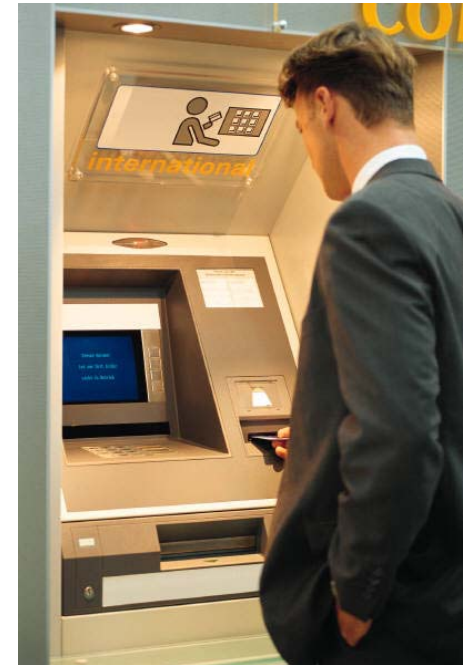


- **Written information** specifically modified for people with **reading difficulties** (e.g., by being “*plain speaking,*” “*sentences short,*” “*spaced [out]*”)

1. Products and Technology Domain

e198 Products and technology, other specified as a barrier:

- **Lack of standardized Automated Teller Banking Machines**



1. Products and Technology Domain

*e1502 Design, construction and building products and technology for **way finding**, path routing and designation of locations in buildings for public use as a **facilitator**:*

Colour coded signs
(e.g., for **different areas** of a **hospital**)

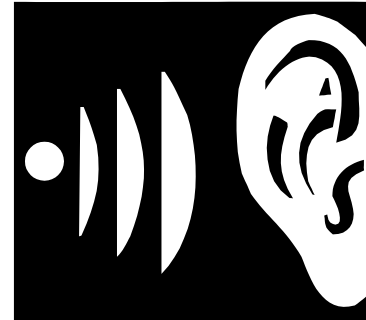


2. Natural Environment and Human-made Changes to Environment Domain

e2501 *Sound quality as a barrier:*



- **Background noise**



e2401 *Light quality as a barrier:*

- **Visual distractions**



3. Support and Relationships Domain

e399 *Support and relationships, unspecified as a barrier:*

- *“The person [service worker] was shocking . . . and didn’t . . . give me a chance [to speak].”*



3. Support and Relationships Domain

e355 Health professionals as a **barrier**:

Other person does **not verify** that the individual has **understood important information**:

- *The **doctor** tells the participant he wants him to have a **PSA blood test** and that he will give him some **prescriptions** After the appointment, the participant shows the researcher his lab test and prescription forms and asks **what the forms are for**.*

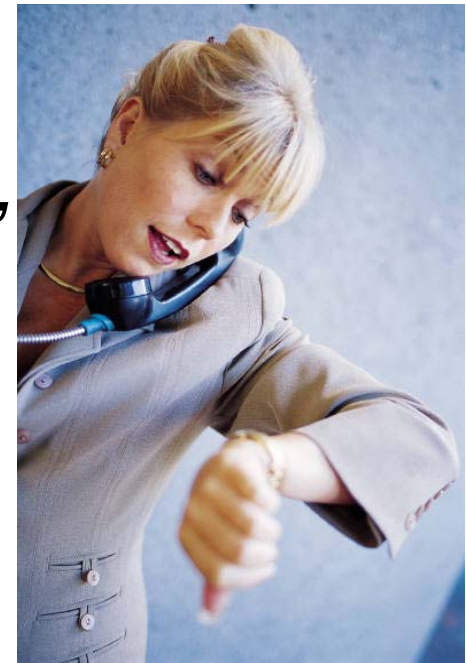


4. Attitudes Domain

e499 Attitudes, unspecified as a **barrier**:

- Participants reported other people think they are:

“stupid,” “a complete idiot”
“very mad,” “silly,”
“mentally deranged,”
“like a child,” “drunk”



- **“Impatience...number one [barrier]”**

4. Attitudes Domain

e450 *Individual attitudes of health professionals as a barrier:*

- ***“Don’t know many doctors that . . . appreciate . . . aphasia.”***



5. Services, Systems and Policies Domain

e5500 Legal services as a facilitator:

- **Advocate service –**
*“Should have a speech therapist...[present when you are meeting] with your **solicitor**. They will make sure that...I am... **laying out the conversation** how want it...like an **atcavat [advocate]**.”*



5. Services, Systems and Policies Domain

e5451 *Civil protection systems as a barrier:*

- *“Every one of them [employees at the police department] will tell you **bring it [complaint form] in black and white . . . and I can’t read and write.**”*



B. Insufficient *ICF* Emphasis on Key Areas for People with Aphasia

e.g. **Lack of time for communication as a barrier:**

“They [other people] don’t give me TIME”

only *ICF* categories involving time:
e245 Time-related changes – Natural, regular, or predictable temporal change



- Suggest **need 3rd & 4th level categories** such as other people’s actions related to **time** for communication

B. Insufficient *ICF* Emphasis on Key Areas for People with Aphasia

e.g. **Other people's knowledge of aphasia as a facilitator:**



*“Understanding...**Education about aphasia is the most important one [facilitator]**”*
possibly e460 *Societal attitudes*
– **conceals** the importance of this area

- Suggest **need 3rd level** categories such as **Societal/Other people's knowledge** of specific health conditions

C. Insufficient Detail in *ICF* Category Codes

e.g., EF involving **other people** –
key area for people with **aphasia**:
98 barriers & 111 facilitators

YET *ICF* Categories in Support &
Relationships & Services, Systems,
& Policies focus **only** on
role of other people:

e355 Health professionals

e5400 Transportation services (bus driver)



- Suggest **need 3rd & 4th level** categories such as: **Other people's actions**



Conclusion

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- **Future** versions of *ICF* need to consider including **more Environmental Factors** relevant for people with **communication disorders** such as **aphasia**



Conclusion

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