Improving crisis information for people with complex communication needs

– results from interviews and co-creation workshops with people with aphasia

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On-going research project:

From passive recipient to an active resource in the crisis management systems

Aim of the empirical study

to investigate what individual needs in the event of a crisis people with aphasia can identify, and to explore their experiences of crisis communication.

Background: lessons from Covid-19 information among people with communicative disabilities

- difficulties **finding**, **understanding**, and **following** directives independently
- dependent on others to provide and augment information
- lower compliance among those with weaker support systems
- other people acted as gatekeepers
- affected by interpreters' personal attitudes

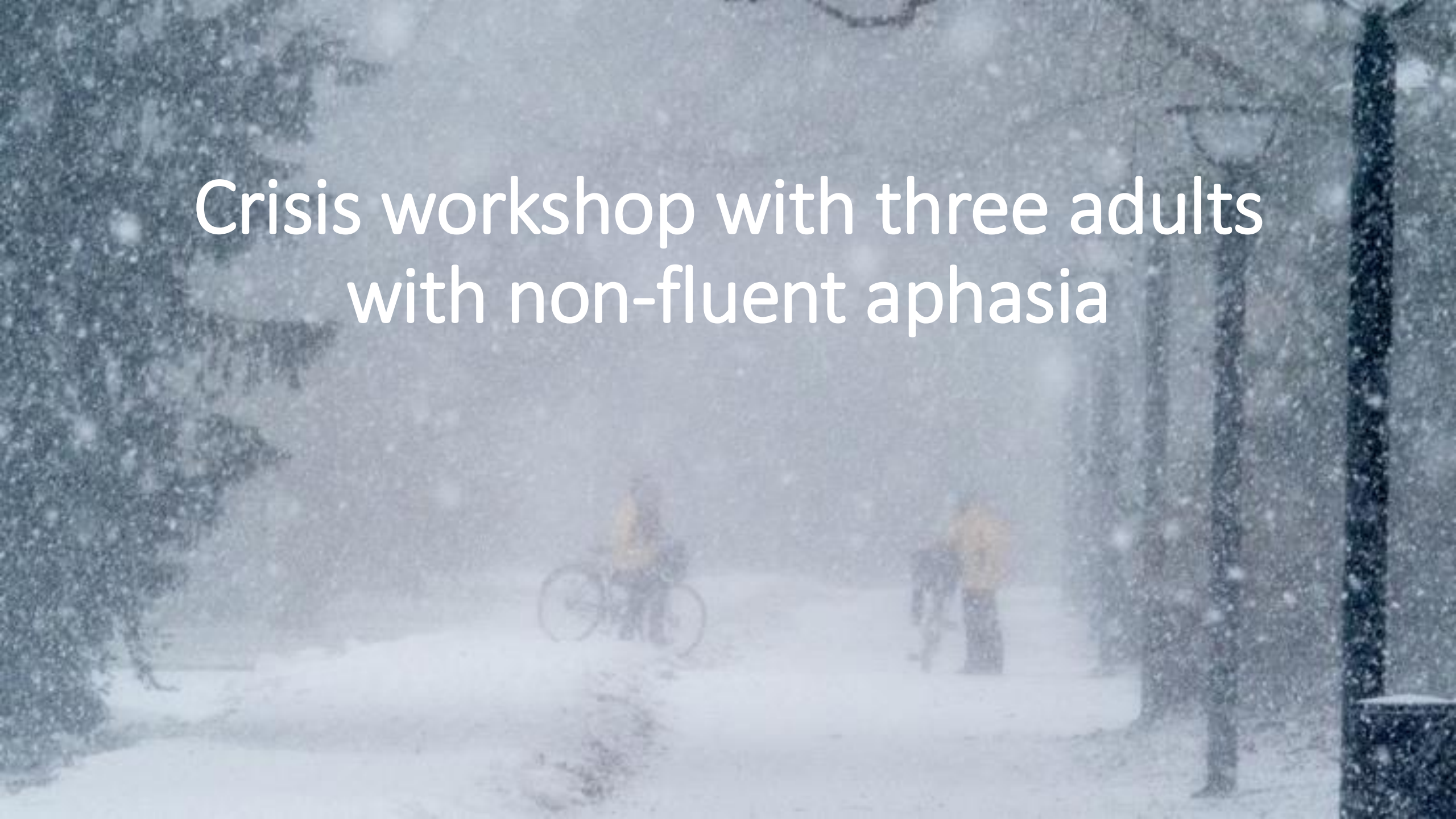# Aphasia: language disorder after brain injury
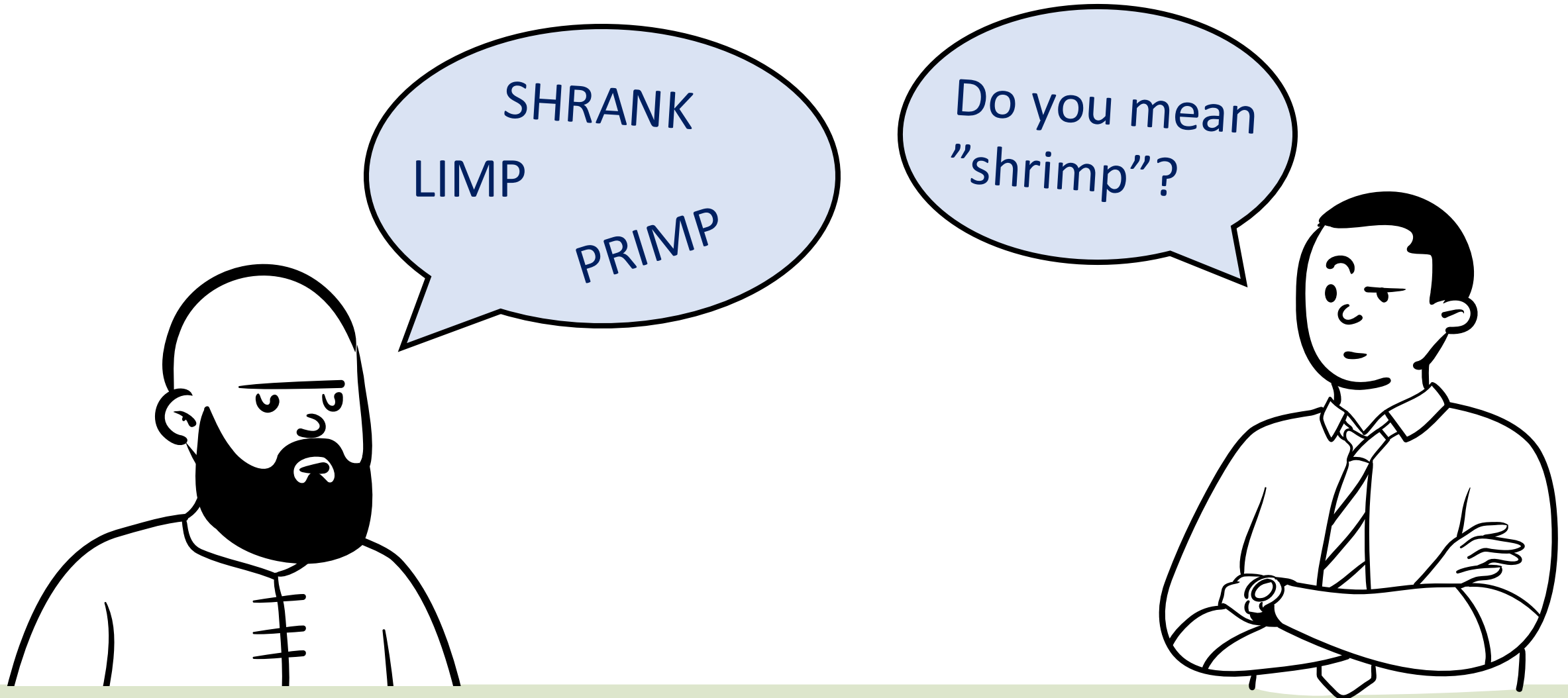
Example: non-fluent aphasia

- hard to get words out (eeeh…. uh!)

- exchange words

- understand better than they speak (but never understand perfectly)

- frustration, because they hear and understand their difficulties

…. ! …. ! … ? …. !!

Lane… no!
Lane… no!
JANE! Yes!

Crisis workshop with three adults with non-fluent aphasia

Participants

- from a local support group
- recruited by their speech and language pathologist (SLP)

- man, 60+ years, stroke
- woman, 60+ years, accident
- man, 40+ years, stroke

Methods for collecting data

Initial individual interview

- understanding each participant's language level

- the participant gains an understanding of crisis preparedness
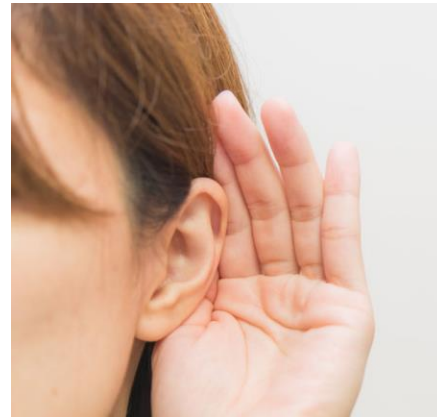
- quick simple answers – saves energy

Group workshop

- introducing hypothetical crisis scenario (pictures)

- Talking Mats, 10 questions

- looking at the Red Cross' Crisis box

Talking mat pictures
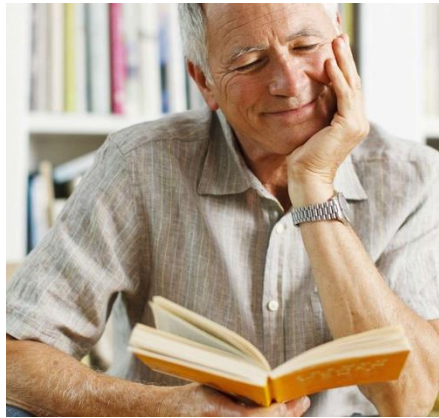
Understanding written information

Understanding spoken information

Find information

Remember and follow several instructions
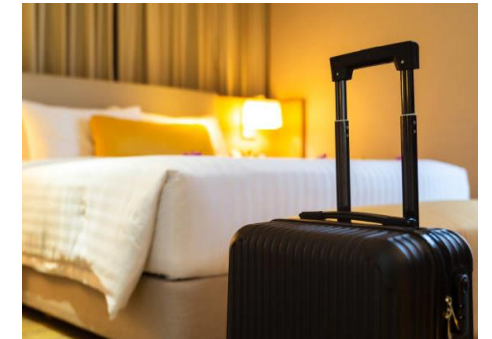

Walk and carry something heavy at the same time

Pack the right things to leave home

Talk to people you don't know

Tell someone your needs

Stay away for a few nights

RESULTS

Example: results from individual interviews

| In the event of a crisis, do you think anyone would contact you? Or would you contact someone to see that they are okay? | I would call my guardian if I need help.

I would not call someone else to see if they are okay.

Others with aphasia would perhaps not manage as well – some have big difficulties. | I become insecure if talking to someone I don't know – can sometimes mix things up.

I would call my ex partner for help with information.

I would call my sister to see if she is okay. | I would not call anyone. There is no one I wonder about.

Perhaps the support group might call me, but it's not necessary. They can call others who need it. |

Individual interviews: result summary

- understand information well – many others with aphasia probably don't

- skilled at using technology –many others with aphasia probably can't

- alone apart from the support group – need to find information themselves

- covid information was difficult to find, but easy when found.

- MSB brochure with national guidelines is simple and clear, but everyone can't follow everything.

VIKTIG INFORMATION TILL SVERIGES INVÅNARE

OM KRISEN ELLER KRIGET KOMMER

Results: Talking Mats

CRISIS BOX

To contrast: the SLP view

- upcoming interview with their language pathologist
- initial idea: the participants might have bigger difficulties than they express?

Concluding analysis

Participants are confident after having lived through covid

Participants need:

- time to process crisis information

- shorter crisis information

- help in finding relevant crisis information

Next step

- combine results with users of Blissymbolics.

- using Universal Design (UD) to develop suitable information tools

- test and evaluate the new tools together with people with different types of disabilities in cooperation with municipalities.

Thank you!

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