Myndigheten för samhällsskydd och beredskap

Using Bliss symbolics to advance emergency information – results from a co-creation workshop with user experts

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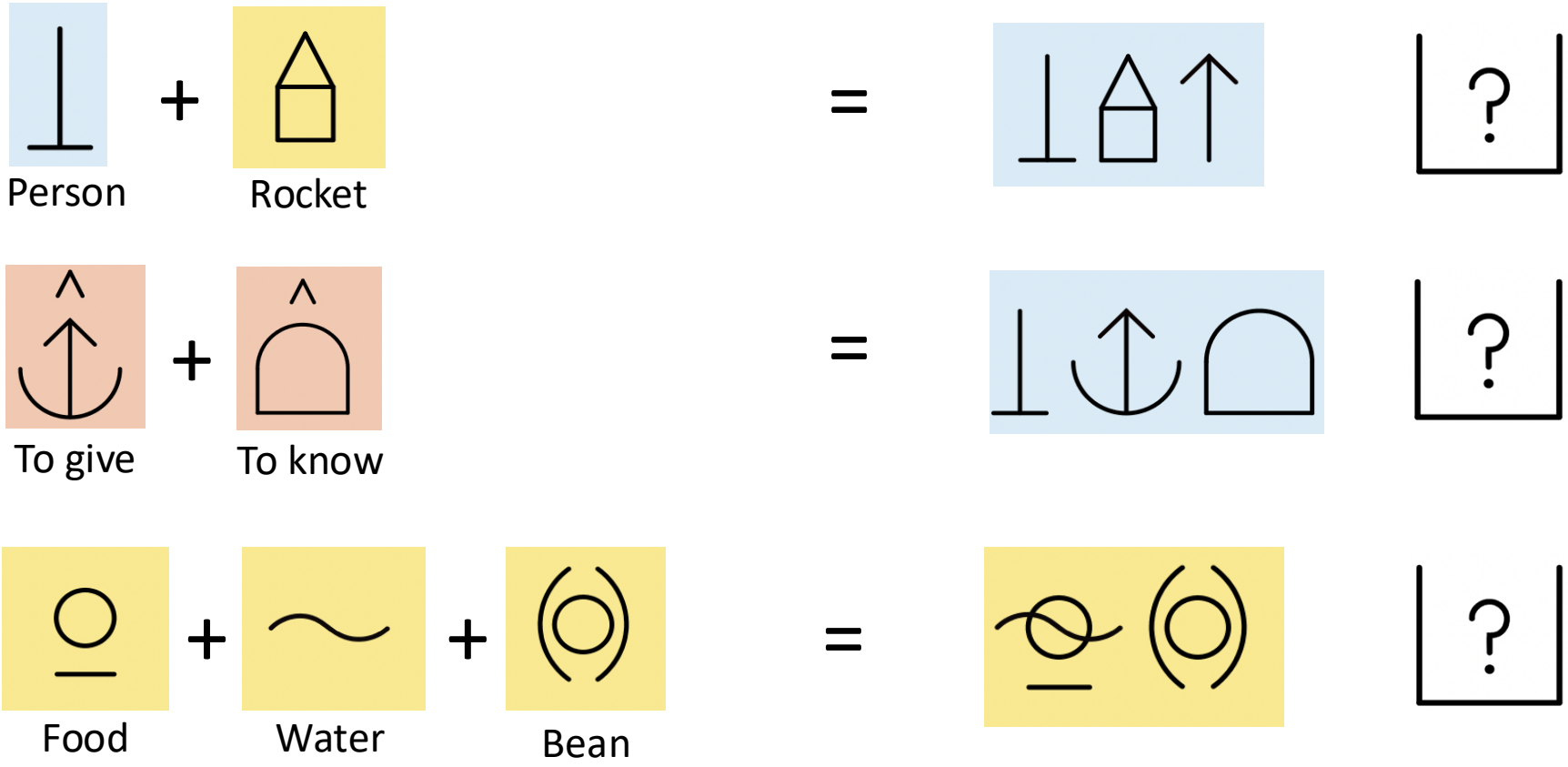
Bliss symbolics – an international symbol-based language



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

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Covid 19 information among people with 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

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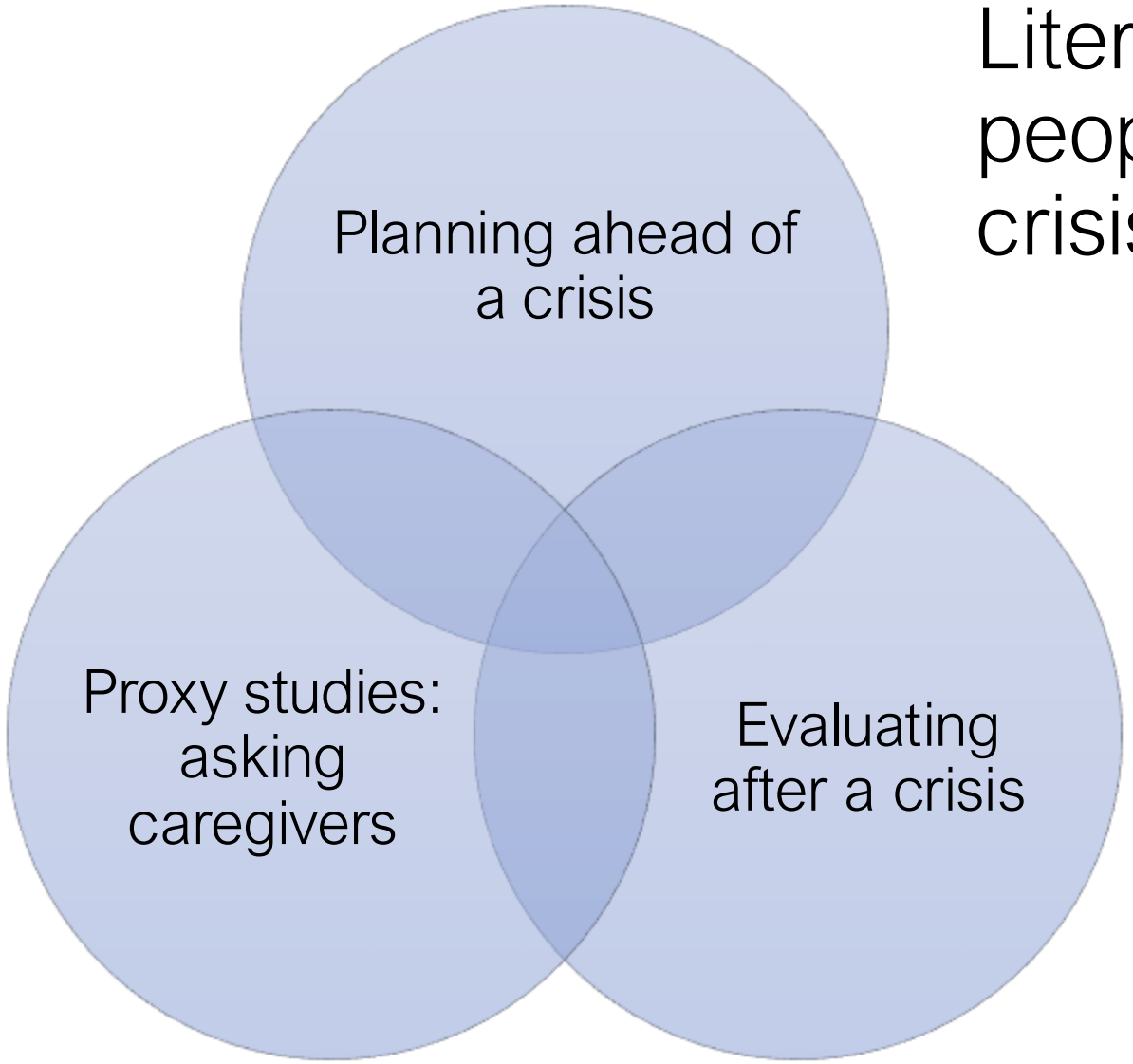

Literature on the occurrence of people with disabilities' within crisis communication work

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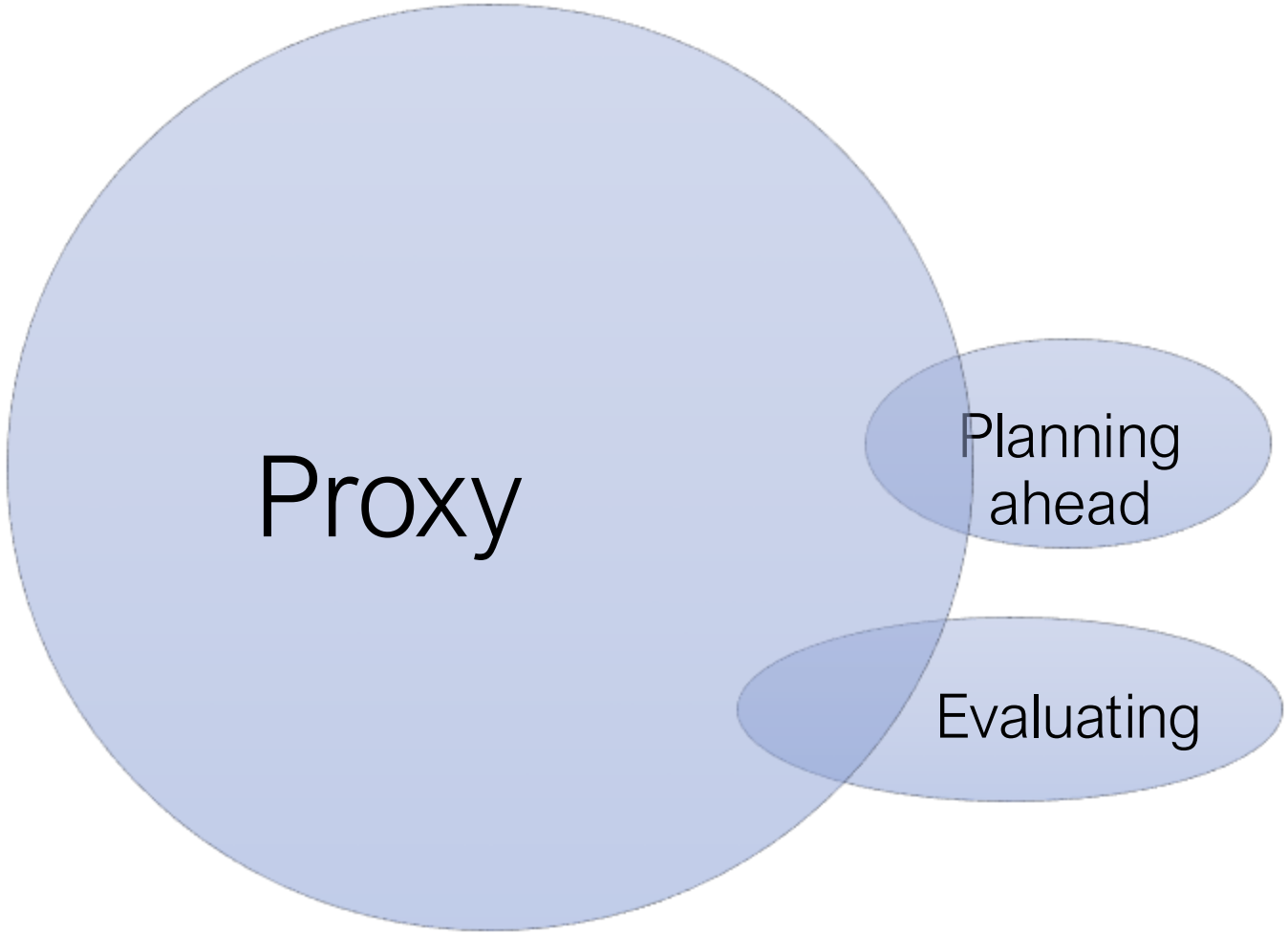
…but unevenly distributed.



Why?

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Bliss Symbolics: limitations in Swedish

- The Swedish translation from Bliss International is smaller, primarily a vocabulary put together by the Ministry of Special Education for school subjects.

- Many topics are missing, for example words relating to crisis and emergencies (other than health-related).

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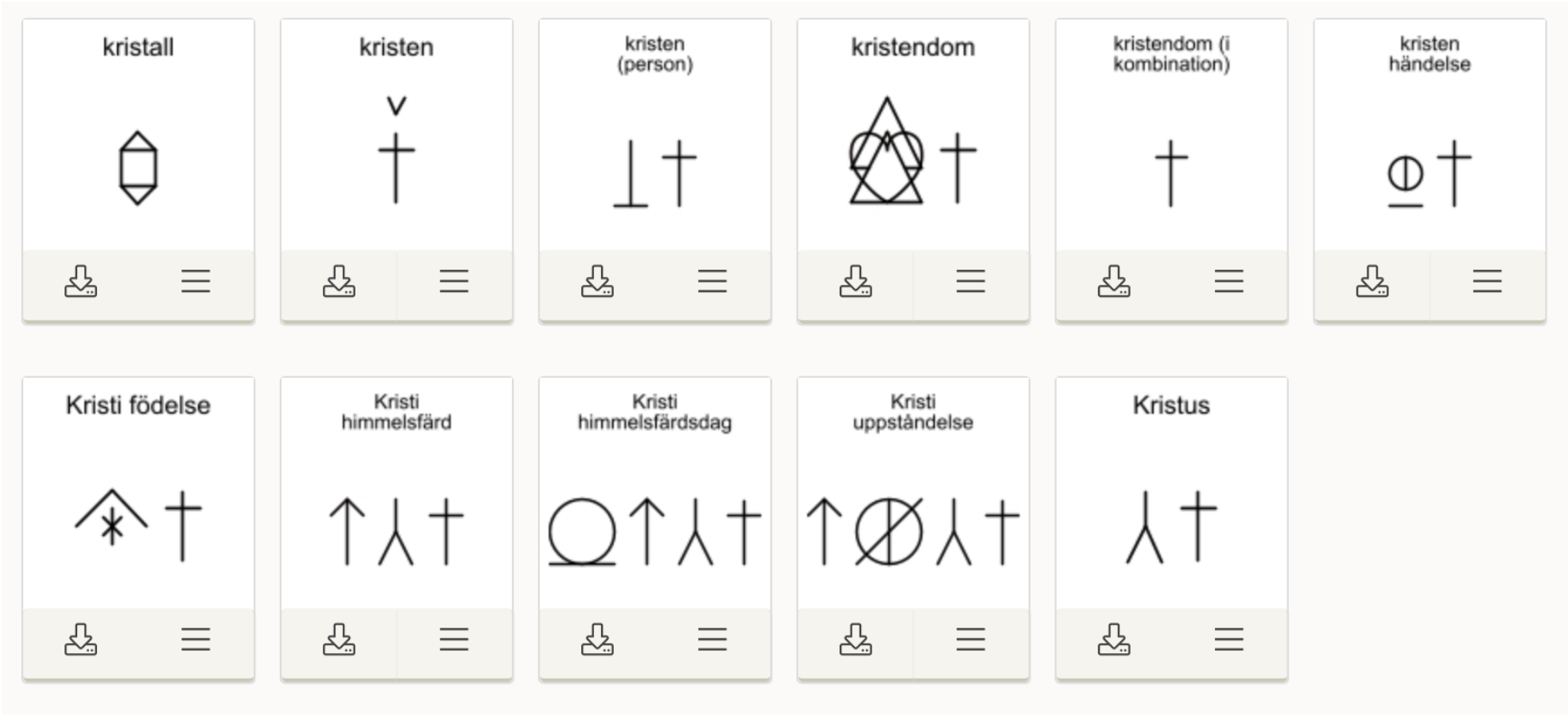
Vocabulary limitations: looking for crisis [kris]



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Pre-workshop with Bliss symbolics experts

- Five expert users
- **Method:**
  - interactive workshop
  - **talking mats** – a visual scale to answer and grade questions
  - Discussions with assistants, followed by group discussions.

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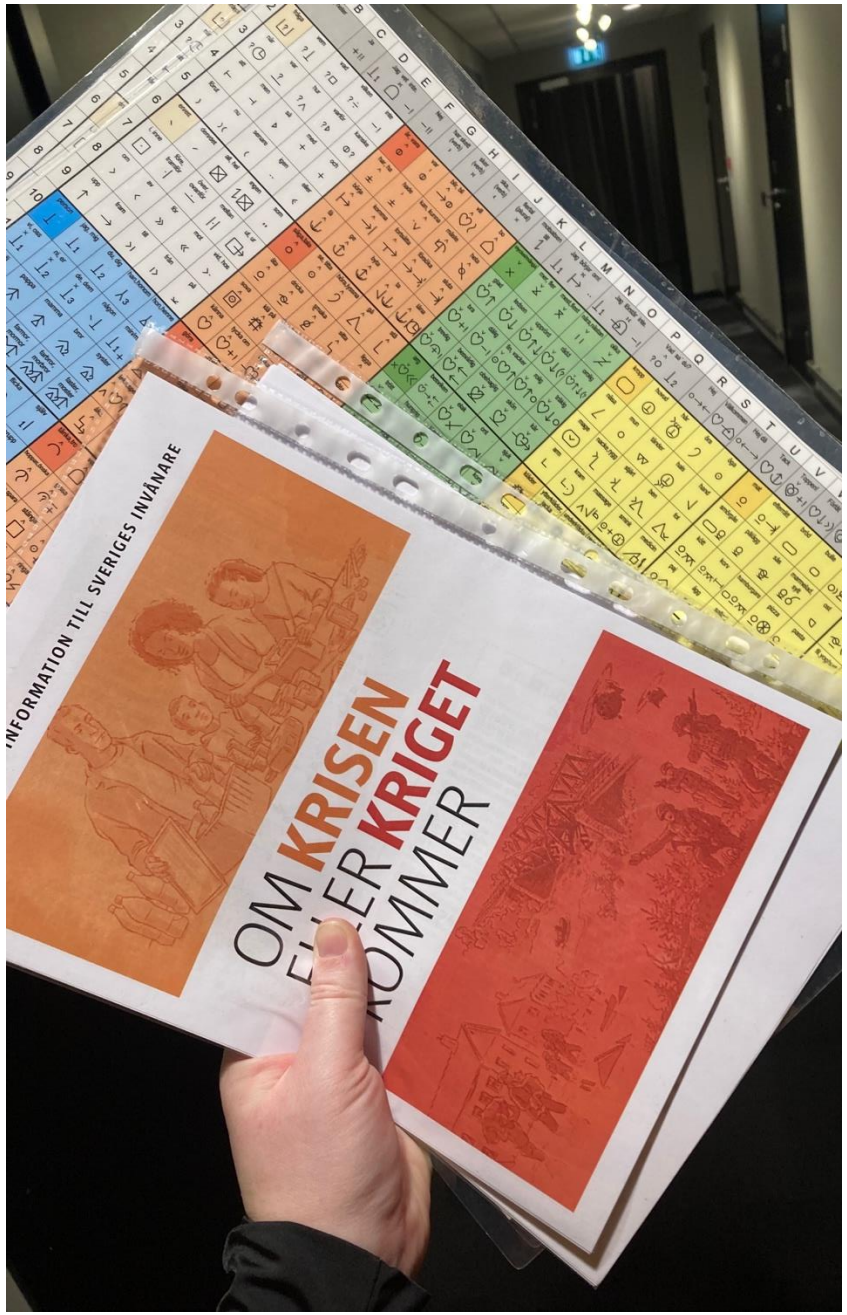
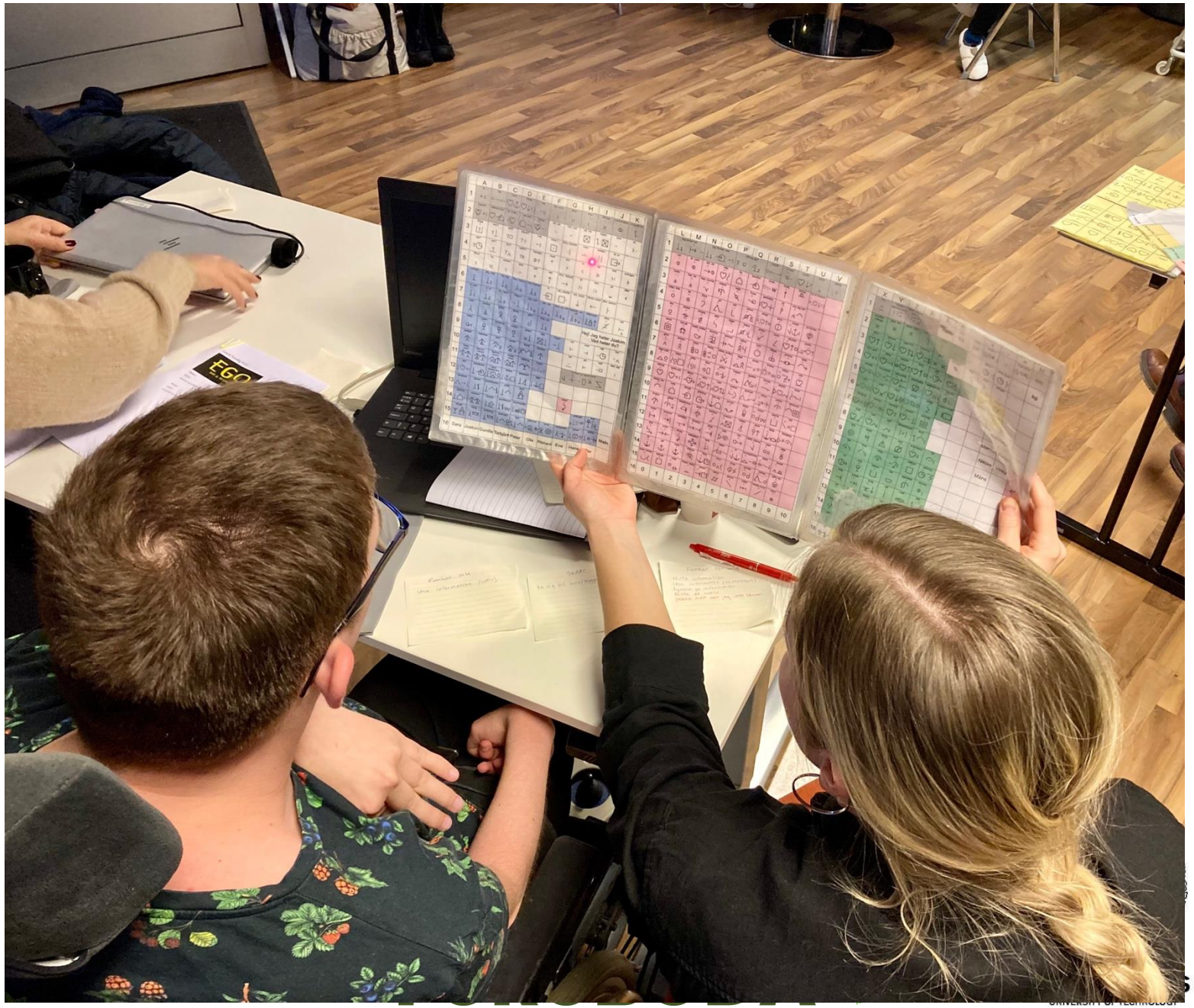
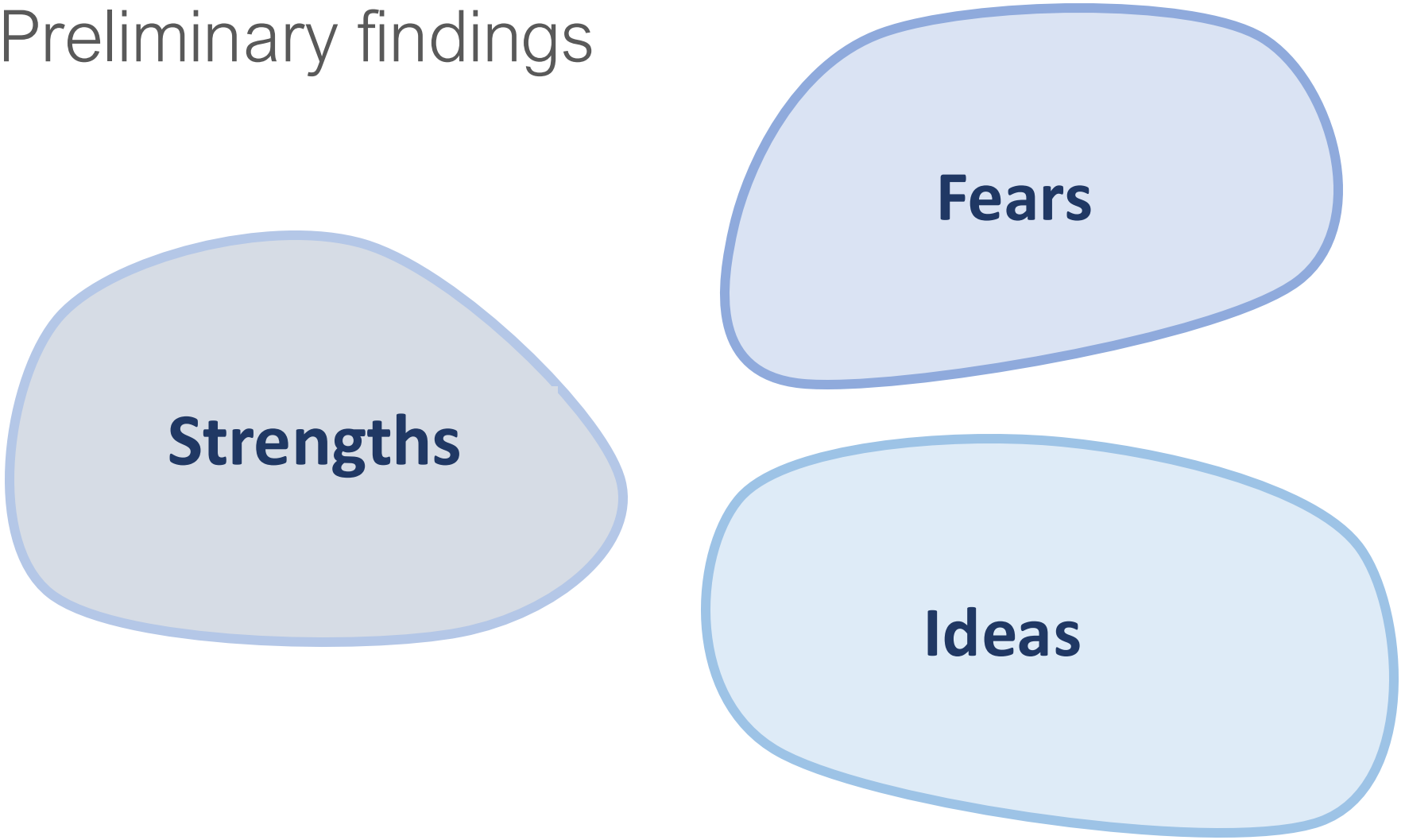
Skånetrafiken


INFORMATION TILL SVERIGES INVÅNARE
OM KRISEN
ELLER KRIGET
KOMMER



Preliminary findings



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Preliminary findings: strengths

Became clear during pandemic!

- Strong sense of trust: family, staff, organizations
- Strong social connection within the Bliss community
- Strong sense of mutual responsibility within disability organizations
- Tight bond with family and staff – they are gatekeepers

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Quotes on strengths

My whole life has been a crisis, so I am prepared.

They are our family, we would never abandon them in an emergency.

With them [the personal assistants] we can do anything. Without them we can do nothing.

One becomes set on finding a solution.

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Preliminary findings: fears

- Do not trust society or service providers to know about them
- Even a small crisis could be life threatening (e.g. electricity for breathing)
- Communication requires time, knowledge, and, preferably, a personal relationship.

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Preliminary findings: ideas

- Disability organizations could function as hubs of knowledge and contacts – need to be invited to the big discussions!
- Not all people with severe physical disabilities receive services – they risk falling through the safety net
- Keep basic AAC material at all crisis centres and meeting points

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Conclusion

- Bliss communicators experience difficulties independently accessing crisis information
- Bliss symbolics as a language is infinite, but the Swedish standard vocabulary is limited and largely excludes words relating to crisis
- Bliss users can provide important input to crisis management planning – but accessing their viewpoints require specific AAC skills
- Problematic to be excluded from discussions on a topic because the vocabulary to participate doesn't exist – especially when the topics discussed are a matter of life and death.

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Thank you!

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