EXPLORING
THE BENEFITS
OF ASSISTIVE
COMMUNICATION



A health economic study conducted in Germany in 2025 by Augur and Prof. Dr. Tom Stargardt, Hamburg Center of Health Economics, University of Hamburg commissioned by Dynavox Group AB.



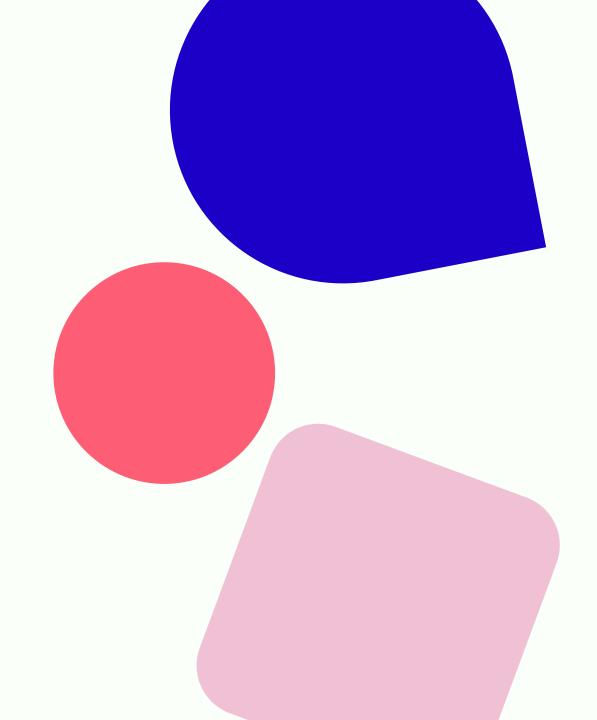
### Introduction

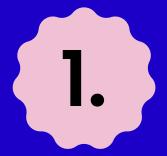
Although assistive communication, also known as AAC, has been available for several decades, it remains a relatively new and unfamiliar concept for many people. To enhance awareness and accessibility, Dynavox Group has commissioned this study, conducted by Augur, to explore how AAC can benefit individuals and society.

The purpose of this report is to improve access to AAC with evidence-based research. Feedback from individuals is deeply valued, as shared experiences help drive progress, foster innovation, and expand the reach of AAC. The continued exchange of insights and perspectives ensures that more people can benefit from improved AAC solutions in the future.

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### ABOUT THE STUDY

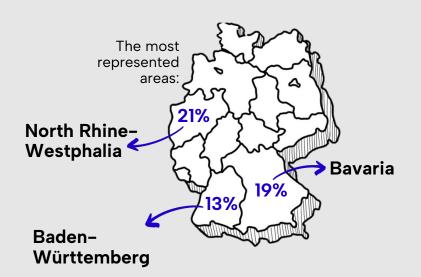
### The voices represented



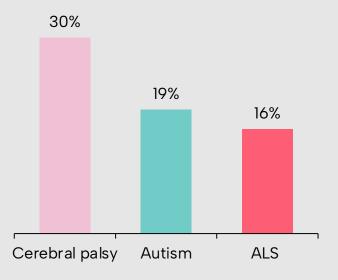
### 188 respondents in total

35 users / 81 caregivers / 8 users & caregivers answering as a pair / 64 assistants

### Users and/or caregivers from all over Germany



### Focus on three main diagnoses but more participated



### A wide range of AAC solutions



**LoGoFoXX** 

**Minispeak** 

## About the study

This is a study done in three parts, using multiple methods, for a holistic understanding of the value high-tech AAC tools bring.

The study started with a qualitative pre-study using in-depth interviews from October - November 2024. This was followed by an online survey from December 2024 - February 2025.

The interviews and online survey were conducted by the market research company Augur.

The results from the online survey, together with external output data, set the foundation for the health economic model, done in March 2025.

The model was done by Prof. Dr. Tom Stargardt, Hamburg Center of Health Economics, University of Hamburg.

### In-depth Interviews

A series of qualitative digital interviews with 12 high-tech AAC users and/or caregivers and 6 professionals, exploring subjective needs, behaviors and feelings of using assistive communication technology. Users and caregivers were located all over Germany.

By Augur Oct. - Nov. 2024

### **Online Survey**

An open-access online survey to high-tech AAC users, caregivers and assistants exploring the current user situation and a hypothetical scenario without high-tech AAC tool access. See participant details on the next page.

By Augur Dec. 2024 - Feb. 2025

### Health economic model

A health economic model measuring the costs and gains for society following the introduction of high-tech AAC tools, for users overall and across three diagnostic groups: cerebral palsy, autism and ALS.

By Prof. Dr. Tom Stargardt, Hamburg Center of Health Economics, University of Hamburg in Mar. 2025

## A short intro to AAAC



Augmentative and alternative communication (AAC) is a tool, strategy, support or any form of communication used in addition to, or in place of, the spoken word.

It helps people who are unable to use speech to communicate.

AAC can be categorized into two main types:

- Light-tech AAC: Non-electronic methods such as picture boards and communication books.
- High-tech AAC: Digital communication tools like speech generating devices, AAC apps, eye tracking systems, and text-tospeech software.

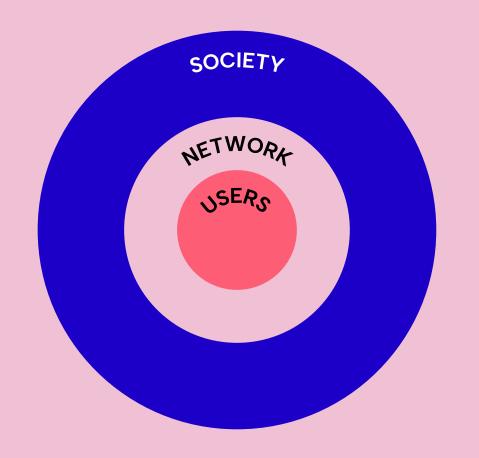
### **GLOSSARY OF KEY TERMS**

**Assistive communication:** Another way to describe AAC. This term is still relatively new but catching on as it is easier to understand for non-clinicians.

**Caregiver:** A person who has primary care responsibilities for an individual with a disability. Usually refers to a parent, spouse, close relative or friend.

**Assistant:** A person who is usually paid to help the person with a disability, offering 1:1 support on daily life tasks, such as bathing, eating, mobility, etc.

**Network:** A group of people in the user's network of support, including caregivers, assistants, educators, clinicians and anyone who interacts with them on a regular basis.



What this study shows:

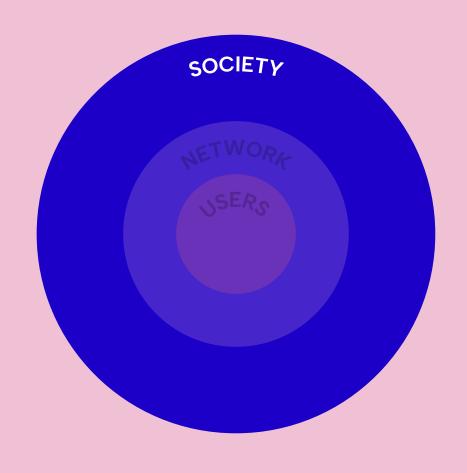
High-tech AAC brings significant value to users, their supporting network, and society.



"For my quality of life, this tool has had a distinct impact. It enabled me to get a higher education, to commit to and get respect for political topics regarding disabled people and to also talk with friends.

It's a major part of my life and has made me a different person than if I didn't have this communication tool." 2.

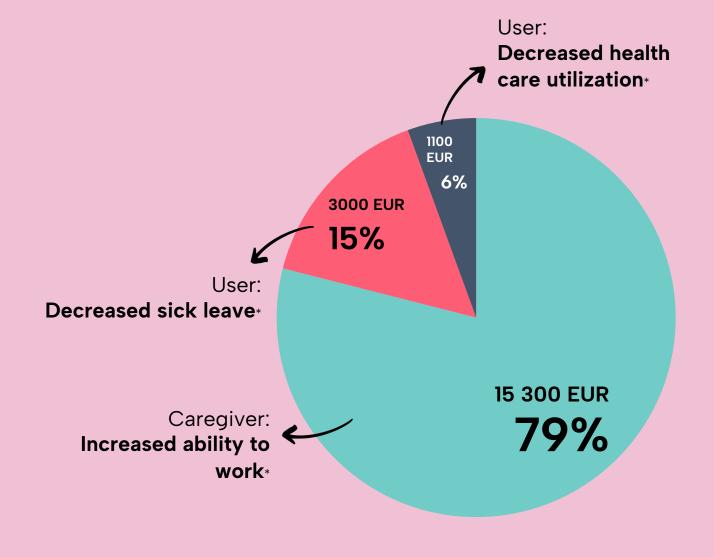
# THE VALUE OF HIGH-TECH AAC ON SOCIETY



By providing hightech AAC tools, society can see an average 11 300 EUR, or 1.4x, return on investment per user over a five-year period.\*

<sup>\*</sup>average savings for all diagnoses

The savings come from increased ability to work and decreased health care utilization thanks to hightech AAC access.



### For the three diagnoses in focus, the savings are even larger\*

74 500 EUR

Autism

- 93% caregiver ability to work
- 5% health care costs
- 2% user ability to work

30 800 EUR

**ALS** 

• 100% caregiver ability to work

16 300 EUR

### **Cerebral Palsy**

- 86% caregiver ability to work
- 8% user ability to work
- 6% health care costs

<sup>\*</sup>Calculated over a five-year period

## Thanks to the communication device, caregivers estimate an increased ability to work

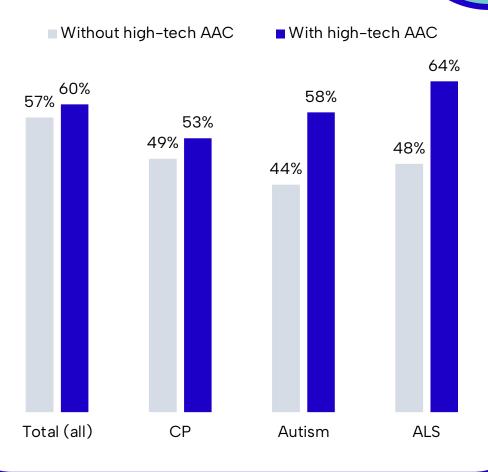
The largest savings come from caregivers' increased ability to work. With a high-tech AAC tool, they can feel secure leaving the user in the hands of others who they can be sure will understand the user's needs.

The tool also helps in reducing stress around one's life situation, decreasing the risk of depression or other illnesses.

### Estimated ability to work for caregivers

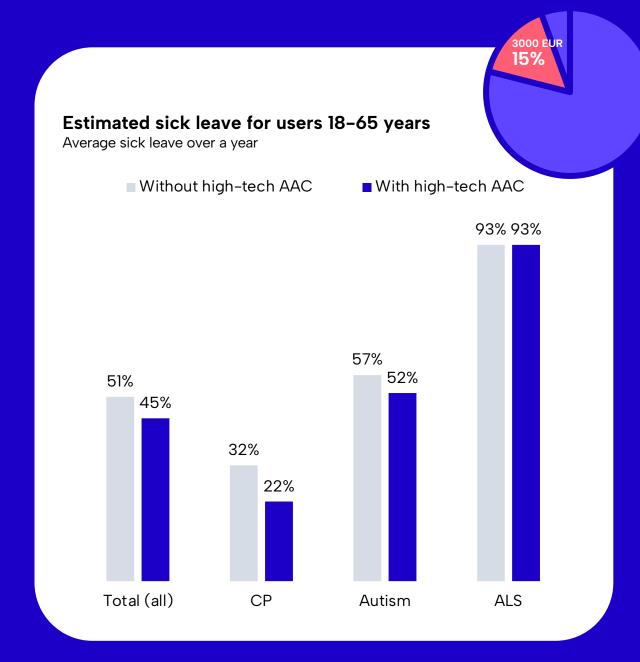
Estimated yearly work rate for up to four caregivers per user, average per caregiver





## An estimated lower sick leave for users lead to additional savings

A smaller part of the savings come from users being able to work to a higher extent, instead of being on sick leave. With the help of the tool these users can gain a higher degree of independence and control of their surroundings, communicate more efficiently, and learn and develop new skills, which in turn support the ability to work and to communicate health concerns.

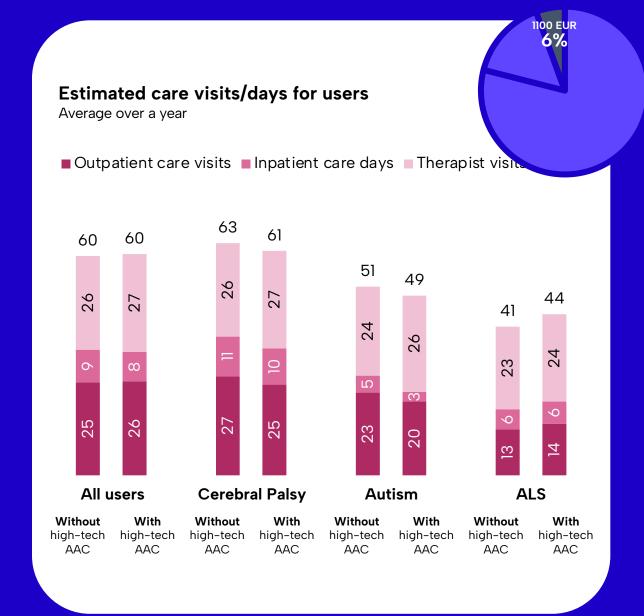


### A smaller part of savings comes from decreased health care utilization

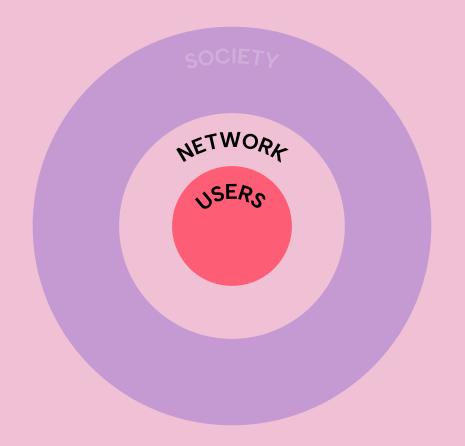
For some users, the tool can improve precision in communicating symptoms and getting the right treatment for the user's medical needs. This can lead to fewer outpatient visits and inpatient days, thanks to getting the right care more quickly.

However, for most users the needed health care is estimated to remain at constant levels. For people with ALS, this is probably due to the severity and progressive nature of the disease.

The calculated savings, despite no overall decrease, come from a decrease in inpatient care, which is more costly than therapist visits and outpatient care.



### 3. THE VALUE OF HIGH-TECH AAC TO USERS AND NETWORK



Zooming in on users and the supporting network:

High-tech AAC improves quality of life



### **Psychological**

Related to positive feelings, thinking, learning, self-esteem, body image etc.



### **Physical**

Related to general health, pain and discomfort, energy and fatigue, mobility, sleep and rest, work capacity, etc.



### Social

Related to social support, relationships, sexual activity, etc.



### **Environmental**

Related to freedom, safety, financial resources, opportunities, participation, home environment, etc.

### Quality of life defined

The World Health Organization defines quality of life as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.

Quality of life is measured via four instruments: physical health, psychological health, social relationships and environmental quality of life.

This study does not use the WHOQOL measurements but is inspired by its building blocks.

## Total well-being almost doubled through access to high-tech AAC

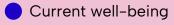
When asked to estimate overall well-being without access to their current high-tech AAC tool, most users estimate that one's well-being would be significantly lower than it is today – from 5.9 on average to 3.4.

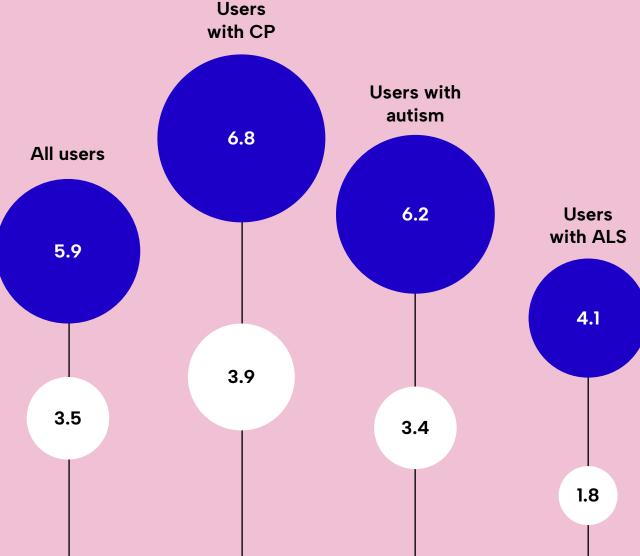
Users with ALS expect a very low well-being without the tool and estimate that access to the tool more than doubles their well-being.

Users with cerebral palsy and autistic users start on a higher level of well-being without the tool but still estimate it to improve their overall well-being by almost 50%.

### Estimated well-being (mental and physical) Scale 1-10, 10 = best possible health, 1 = worst possible health, average score

Estimated well-being without a high-tech AAC tool





### Improved selfexpression and ability to learn lead to better psychological health

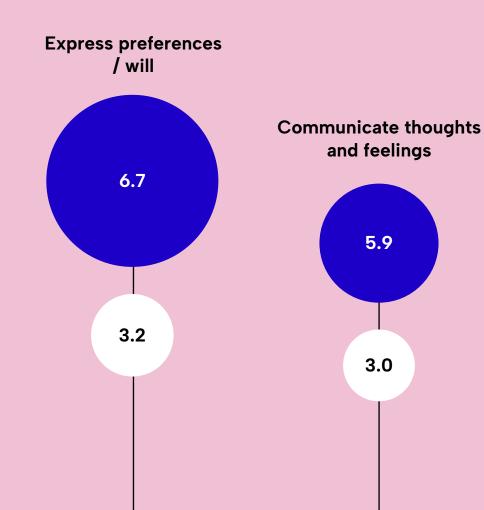
The ability to express one's personality, thoughts and feelings, and to develop skills and learn new things, are all improved with the use of high-tech AAC tools.

All these factors are related to better overall psychological health, due to being seen as a whole person with dreams and aspirations to a greater extent than without the tool.

78%
see the ability to
express one's will
and preferences
as an advantage of
high-tech AAC

Estimated abilities with and without high-tech AAC Scale 1-10, 10 = fully able, 1 = not at all able, average score

- Estimated ability without a high-tech AAC tool
- Current ability



66%

see the ability to express more than the basic needs as an advantage of high-tech AAC 53%
consider being able to express your whole personality as an advantage of high-tech AAC

### Disagree

Play Express thoughts and opinions

Express tastes and interests

Argue

Joke

Express complex Swear feelings

Tease

# With high-tech AAC, you can express your whole personality

Communication initiated independently by high-tech AAC users means the ability to be a social participant who is able to express more than just the basics.

It provides an opportunity to start discussions, disagree, joke, swear, tease and play.

It means the ability to express your whole personality as you choose. It provides a means of showing people your humanity.

# Usage helps with reduced stress and anxiety

By being able to express your needs and desires on your own, high-tech AAC improves users' mental health, lowers the risk of depression, and strengthens relationships through better understanding and fewer conflicts.

Clearer communication reduces misunderstandings, which makes for smoother daily life where you feel seen and heard.

Additionally, high-tech AAC simplifies daily life by allowing active participation and independent decision-making.



50%

say that reducing stress and anxiety is an advantage of high-tech AAC

### Better communication and more independence lead to less stress and worry for caregivers

High-tech AAC tools provide improvement in communication resulting in less stress and worry for caregivers. They feel secure in the user's needs and feelings being understood and met by their supporting network.

It also means being able to extend the supporting network, allowing more people to be involved in supporting the user. This lessens responsibility for caregivers and makes life less stressful. "When parents see that their children can express their needs, they feel much less stressed and more secure in their parenting."

Special education teacher

44%

of caregivers say that feeling less worry about what the user wants and needs is a benefit of high-tech AAC





She can tell me what she wants, so I can take better care of her, and she can clarify her wishes, which benefits me too.

Not being able to communicate, especially with ALS, is incredibly frustrating. Without the device, there are times, like in the shower or when it's unavailable, when it's really difficult.

It's a huge emotional relief that she can communicate effectively.



Partner to user with ALS

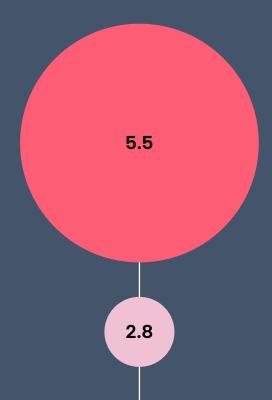
# Vastly improved ability to communicate symptoms and discomfort lead to better overall health

The ability to communicate health problems and other major needs is strongly improved by having access to a high-tech AAC tool.

This means an improved ability to get the right health care at the right time. It also means being able to express minor needs and discomfort, leading to more comfort in everyday life. Estimated abilities with and without high-tech AAC Scale 1-10, 10 = fully able, 1 = not at all able, average score

- Estimated ability without a high-tech AAC tool
- Current ability with a high-tech AAC tool

### Ability to communicate health problems and healthcare needs



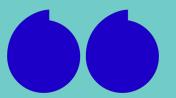
# More correct diagnostics and a stronger influence over one's health plan

In general, the need for healthcare remains the same but you can get more accurate, timely help with high-tech AAC.

It means that you can have a bigger say in the treatment you are given and impact your own health plan. You can ask the doctor questions, describe your symptoms more accurately, and influence the course of treatment or therapy. This makes for more efficient health care and a stronger sense of empowerment. 53%

say the ability to express health needs and issues and impact one's health plan is a benefit of high-tech AAC "If someone can't say 'I have stomach pain,' you lose the chance to catch something like appendicitis early or detect other serious issues."

Speech therapist



To express where I feel pain, that I am in pain, or that something is wrong, and to even feel pain properly, I need to be able to communicate.

If someone can't communicate their discomfort their entire experience of pain and discomfort is different.



Special education teacher

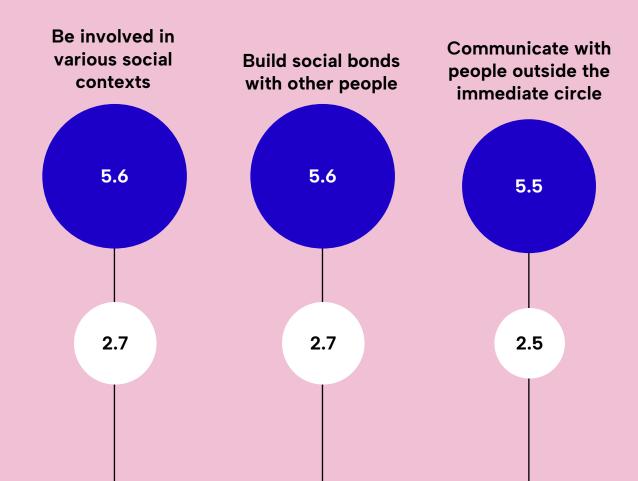
# High-tech AAC enables users to form social bonds and be active participants

High-tech AAC offers the opportunity for users to form social bonds with people around them, both their immediate family and other people in their network.

- You can be an active part of your family and people can get to know you and/or continue to know you on a deeper level
- You can communicate independently with those outside the closest network, without needing family or assistants to interpret
- You can actively participate in and contribute to social situations, not just observe

Estimated abilities with and without high-tech AAC Scale 1-10, 10 = fully able, 1 = not at all able, average score

- Estimated ability without a high-tech AAC tool
- Current ability with a high-tech AAC tool





Without the tool, [the user] wouldn't be able to communicate with outside people as he does today – chatting at events, talking to strangers. Without the tool, a stranger wouldn't know how to engage with him at all, thinking 'how am I supposed to communicate with this person'?



Digital platforms enable wider social connections

One benefit that comes with high-tech AAC tools is the possibility of communicating digitally.

For those born with a condition such as cerebral palsy, digital communication means the ability to meet new friends online and explore personal interests.

For those with an acquired condition such as ALS, digital communication is a means of remaining connected to people in your life and conversing with them privately.





"Today, during a consultation, a young boy was using a communication aid. The consultant was showing him how it worked: 'Press here, press there, try this.'

And then, the boy turned to his mother and said, 'I love you'. Before that, he had never been able to say it.

The impact of that moment — the child's radiant expression, the mother's tears — those are true goosebump moments.

They show just how much is missing, how much words matter, and how deeply painful it is when those possibilities don't exist.



## For caregivers, high-tech AAC helps in creating and maintaining deep and meaningful relationships

For parents of children born with a condition such as cerebral palsy or autism, the high-tech AAC tool means going from reactive communication to spontaneous and multifaceted communication, where children can show more sides to their personality and express preferences, opinions, and feelings.

For those who have a partner or family member living with ALS, the tool provides a way for the user to communicate in a nuanced way and express thoughts and feelings, which enables a continued and lasting relationship. 40%

of caregivers consider
the ability to get to know
and/or keep knowing
users on a deeper level a
benefit of high-tech AAC

46%

among caregivers to users with cerebral palsy



# High-tech AAC strengthens the ability to be an active and empowered part of society

High-tech AAC is key for users to be part of and interact with their surroundings, their network and society.

It gives users more opportunities to learn and develop new skills and enables them to work or attend school to a greater extent. It also gives them more opportunities to express themselves and be active participants in society.

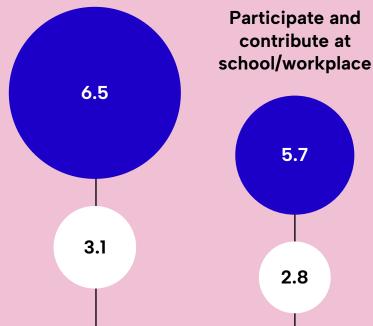
The ability to control and function more independently within one's home environment is greatly improved by having access to a high-tech AAC tool.

This, together with easier communication with those outside of the network, leads to improved independence for both users and caregivers.

**Estimated abilities with and without high-tech AAC** Scale 1-10, 10 = fully able, 1 = not at all able, average score

- Estimated ability without a high-tech AAC tool
- Current ability with a high-tech AAC tool





"When he and his grandmother went on a trip recently, he planned the whole route and picked out the campsites via his tool."

Parent to a child with cerebral palsy

## Access to high-tech AAC helps impact your life situation and express yourself



High-tech AAC enables everything from what leisure activities to do, to choosing the person who takes care of me, to deciding if I really want to go to Sardinia or when I want to call my mother.



Special education teacher



Some years ago, I was sexually assaulted. When I later got my first communication device, the first thing I did was go to the police and file a report, just before the statute of limitations expired. Without the communication device, I wouldn't have been able to take that step.



Autistic user

### **Enhanced learning** and developing new skills bring wider opportunities

62% see learning new

things and developing new skills as an advantage of high-tech AAC

For those with cerebral palsy, who most often are born with or are diagnosed very young, having early access to high-tech AAC can open the door to participating in school and following the same curriculum as classmates, asking complex questions, taking tests and writing essays.

This is also true for autistic people where high-tech AAC enables them to participate, learn and develop on their terms.

49% see being able to develop and enhance language skills as an advantage of high-tech AAC

60% among autistic users

this benefit is even more pronounced

# Control of your surroundings enables independence, privacy, security and entertainment

53%

see the ability to have private time as an advantage of high-tech AAC

High-tech AAC tools not only enable communication, but also a way to perform tasks independently.

This can take many forms, such as using digital tools like computers or phones to access information or entertainment without others' help, or the ability to control one's environment, such as turning the TV, lights and stereo on and off, or opening doors.

The ability to control one's surroundings via the tool means the possibility of maintaining privacy. It also enables digital privacy and the possibility to, for example, take charge of one's own finances. 47%

see independent access to entertainment

as an advantage of high-tech AAC

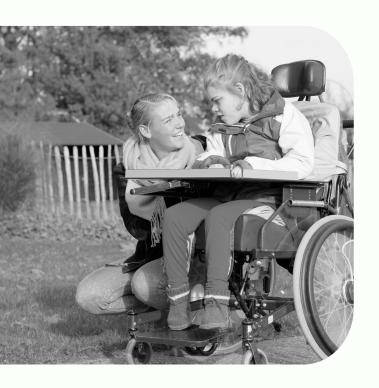
"That's independence, being able to decide, 'I'm lying in bed; it's summer; it's 9 PM; I'll lower the blinds because it's too bright.' Otherwise, you can't do that."

User with locked-in syndrome

## High-tech AAC paves way for higher independence for caregivers

62%

of caregivers feel that the user becoming less dependent on them as interpreters is a benefit of high-tech AAC



The universality of the language spoken via high-tech AAC tools (especially for those communicating via spelling rather than symbols) means people outside of the immediate circle can understand and meet the user's needs.

This enables people outside of the closest family members to be, for example, babysitters, assistants, and companions. This helps both the user and caregiver be more independent.

"Communication aids are crucial because they allow interaction with the environment, participation in different roles, and maintaining connections."

Special education teacher

## 4. THE MEANING OF HIGH-TECH AAC TO DIFFERENT USER GROUPS

# Enabling users with cerebral palsy to be seen as a whole person

"Thanks to this tool, we think our son will actually be able to have a job in the future. And not just any job, but one that he enjoys."

Parent to a child with cerebral palsy

For those with conditions that limit communication through speech, like severe cerebral palsy, high-tech AAC can be life-changing. It gives them a voice – one that truly reflects their personality, thoughts, and abilities.

This shifts focus away from their disability and toward who they are as individuals. In many cases, it even opens doors to education and employment, creating opportunities that might not have been possible otherwise.

## Users with cerebral palsy and their caregivers especially highlight AAC benefits such as:



Being encouraged to communicate



Learning new things and developing new skills



Having independent access to entertainment (e.g. play games, surf the Internet, watch movies, read on one's own)



Users being less dependent on the caregiver as interpreters



Less guessing
with communication,
getting it right faster
with
fewer misunderstandings

# Creating meaningful connections for autistic users

"With the communication device, we can prepare our son for things that cause anxiety, like a doctor's visit. We have symbols for that, so he knows what to expect."

For autistic users, high-tech AAC offers a reliable and adaptable way to communicate — using symbols, photos, and sounds that can be personalized to fit their life and interests.

This not only makes interaction easier but also encourages communication beyond their closest family, helping them connect with more people. Autistic users and their caregivers especially highlight AAC benefits such as:



Developing and enhancing language skills



Reducing anxiety and frustration



Providing a structured and predictable way to communicate



Understanding and meeting the care recipient's needs



Less guessing with communication, getting it right faster with fewer misunderstandings

Parent of an autistic child

# Helping users with ALS preserve their voice and maintain adult roles

"Thanks to the tool, I can help in family life. I plan everything, handle our calendar and communicate with the school."

User with ALS

As ALS progresses, speech and movement gradually fade, but high-tech AAC helps individuals stay engaged in life despite these constant changes. It provides a way to express emotions, navigate difficult realities, and maintain connections. In addition, it helps in upholding routines and doing certain tasks, like handling your own finances or being involved in your child's school life.

Through AAC, people with ALS can participate in support groups, share their fears and experiences, and process the journey ahead with dignity.

## Users with ALS and their caregivers especially highlight AAC benefits such as:



Expressing health needs and impacting one's health plan



Participating in social contexts, not just observing



Communicating with others digitally (e.g., text messages, email, social media)



Increased security (e.g. can call for help)



Caregivers feeling less stressed about their life situation



Users being less dependent on the caregiver as interpreters



Caregivers feeling less worried about what the user wants and needs

## HIGH-TECH AAC CHALLENGES

# The main down-side with high-tech AAC is that it can't be used in all environments, thus limiting the user

70%

of users experience an inability to **use the device everywhere** as a challenge/disadvantage of high-tech AAC

"When I do sports or when I'm outdoors, communicating with my communication aid is not possible. Swimming definitely doesn't work. In those situations, my assistants must really know me well."

User with cerebral palsy

Since high-tech AAC solutions require a robust set-up that is sensitive to both liquids and light, it makes them hard to use in all environments and activities – even in basic daily tasks, such as taking a shower.

This limits the user, and they end up being presented with two options – either participating in the activity without one's main means of communication or not participating at all. Low-tech AAC plays an important role here but may limit communication opportunities and/or require caregiver support.

## High-tech AAC is always or most often used during...









Speech therapy

Home life

School/ work

Activities outside of home

## High-tech AAC is seldom or never used during...









Walks

Exercise

Beach

Swimming



## Effective hightech AAC requires support from the network

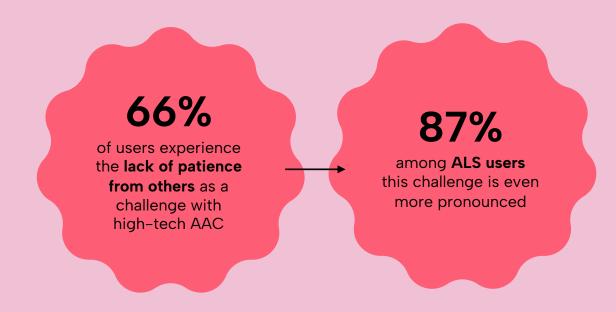
High-tech AAC is a tool that requires maintenance. This makes the user highly dependent on others to ensure that all parts are in place for it to work – mounted, charged, updated, etc. Without the support from the surrounding network, the user cannot use their tool.

Furthermore, it requires the entire network to be onboard and making the effort to learn how to use the tool. This requires high motivation from all involved – from close family members to schools and workplaces.

# Many lack the patience required to talk to high-tech AAC users, not giving them enough time to communicate what they want to say

"With people who don't know how to communicate with [the user], they may not wait or listen fully. It's a challenge. For example, we went to a music festival this year, and people were curious about his setup, with the monitor and wheelchair. They asked him how it felt to be there, and he wanted to write a response. But they were gone by the time he finished because they didn't know the process."

Caregiver



# Making sure everyone in the network is onboard can be a strain on the caregiver

In many cases the role of teaching others how to use and communicate with the user via their high-tech AAC tool often falls on the caregiver, something many of them experience as a barrier.

Caregivers can also experience a lack of engagement from people in the surrounding network, which doesn't make this task any easier.

At the same time, caregivers often experience a lack of external support from teachers, therapists, etc. to teach them how to use the tool.

"The school hasn't been using the device much, which we find challenging. We've noticed that the device's battery is full when he comes home, whereas it used to be quite drained in preschool. They are still taking a gentle approach as they get to know him, and maybe they think his nonverbal cues are enough for now."

Caregiver

67%

of caregivers see the need to teach others how to use high-tech AAC as a challenge

52%

of caregivers
lack engagement from
people in the
surrounding network

62%

of caregivers lack support from others in learning to use high-tech AAC tools

# The process of applying for and attaining a high-tech AAC tool can be quite an ordeal

There is often a part of the process where the health insurance companies reject things and then you have to juggle a bit, explaining why and why not [the device should be approved by insurance].



Speech therapist



Initially the insurance company rejected the application, partly due to a recent report claiming he wasn't 'smart enough' to use it. After we appealed and explained more clearly, we finally got approval.



Caregiver



"It was rather difficult to get to know the device and to make full use of it in a meaningful way. I think you need a little patience. It was really cool that we had the speech therapist on our side, who laid out the basic steps and gave the introduction and said that everything is fine, we'll start very slowly, no stress, it doesn't happen overnight."

# Learning to use the device takes a lot of time and patience for both users and caregivers

Many users and caregivers find the first period of usage challenging. It takes time to learn how to use the tool and communicate effectively for both parties. This is most strongly expressed by autistic users and their caregivers.

You need patience, both in teaching and while communicating, i.e., leaving the user enough time to take part in the conversation, and not changing the subject or making presumptions. You also need to model usage for the user to help them learn.

For most, the benefits of the tool vastly outweigh the effort required, while others find it more challenging.

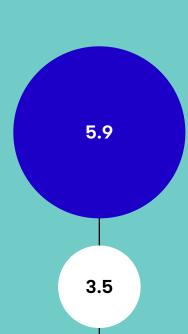
To sum up...

## High-tech AAC brings significant value to users' and caregivers' lives

## Estimated well-being (mental and physical)

Scale 1-10, 10 = best possible health, 1 = worst possible health, average score

- Estimated well-being without a high-tech AAC tool
- Current well-being with a high-tech AAC tool



High-tech AAC usage significantly improves users' overall wellbeing...

...as well as abilities related to a higher quality of life



#### Psychological health

- Express preferences/ will
- Communicate thoughts and feelings



#### Physical health

 Communicate health problems and healthcare needs



#### Social relationships

- Be involved in various social contexts
- Communicate with people outside the immediate circle
- Build social bonds with other people

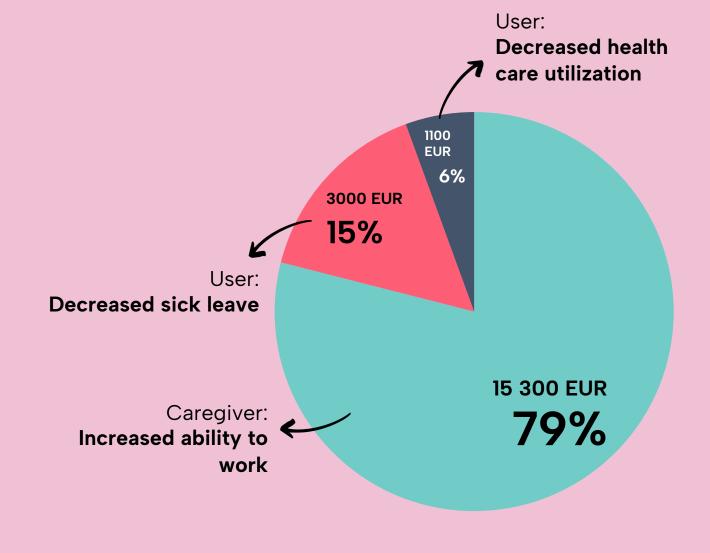


#### **Environmental quality of life**

- Participate and contribute at school/ workplace
- Develop skills and learn new things

To sum up...

In addition to all the benefits to users and caregivers, society can see an average II 300 EUR, or 1.4x, return on investment over a five-year period.\*



<sup>\*</sup>this represents a 1.4x average return on investment for all diagnoses, per high-tech AAC tool, per user

## Questions?

This health economic study is owned by Dynavox Group AB, having been commissioned through Augur AB.

Please reach out to Tove Lindén at <a href="mailto:tove@augur.se">tove@augur.se</a> with questions about this study.

For inquiries regarding Dynavox Group AB, please contact <a href="mailto:assistivecommunication@dynavoxgroup.com">assistivecommunication@dynavoxgroup.com</a>.

As the owner, Dynavox Group AB retains all rights and responsibilities associated with the report's content and dissemination, while Augur AB facilitated its production and delivery.

## APPENDIX: ABOUT THE SURVEY

## Qualitative study details



## **Participants**

#### **USERS AND CAREGIVERS**

12 digital interviews in Germany with users of various brands of hightech AAC solutions and/or caregivers/assistants:

- 4 with cerebral palsy
- 4 with autism
- 3 with ALS
- 1 with locked-in syndrome

#### **PROFESSIONALS**

 6 interviews with German clinicians and special education teachers who all prescribe/work with high-tech AAC tools.

#### RECRUITMENT

• The participants were recruited through contacts of Dynavox Group. Any AAC tool from any manufacturer could be used.

## <u>Methodology</u>

#### **APPROACH**

Digital interviews of 1–2 hours. Interviewees were sent a short version of the interview questions beforehand to prepare. Most interviews were conducted with users and caregivers/assistants together, while some were conducted with only the user or caregiver.

#### **KEY QUESTIONS**

In the interviews we explored subjective needs, behaviors and feelings and they helped shed light on context and differences that are not possible to detect using a solely quantitative approach. Key questions were:

- How are assistive communication solutions from a variety of suppliers experienced by users and those who are in contact with them?
- What are the greatest benefits and challenges, and where/when do they manifest themselves?

## Quantitative study details

## December 2024 -February 2025

## **Participants**

#### **USERS AND CAREGIVERS**

188 online survey respondents in Germany:

- 57 with cerebral palsy
- 35 with autism
- 30 with ALS
- 80 with another diagnosis

The role of the respondent differed:

- 35 users
- 81 caregivers
- 8 users & caregivers answering as a pair
- 64 assistants

For more details on the target group, see Appendix: Target group details.

## <u>Methodology</u>

Depending on target group, different sets of questions were asked in an online survey:

- Users and assistants were asked mandatory questions about their tool, their current and estimated health care use and ability to work with and without their high-tech AAC tool, and optional questions about the perceived usage and benefits of their tool.
- Caregivers were asked the same questions about the user, and additional questions about the network's ability to work with and without the user's high-tech AAC tool, and optional questions about the perceived benefits of the tool.

#### **FIELDWORK**

The participants were recruited through contacts to Dynavox Group through its own social and web channels, as well as by information sent out via different newsletters, fairs, social media groups and forums. Any AAC tool from any manufacturer could be used.

## Health economic model



### About the model

The model has been calculated by Prof. Dr. Tom Stargardt, Hamburg Center of Health Economics, University of Hamburg.

### Patient information and healthcare consumption

Questionnaires designed by Augur have been used to acquire information on patients and healthcare consumption. Details about the survey can be found on previous page.

### External data sources for posts in model

- Mortality rate: Pupillo E, Messina P, Logroscino G, Beghi E, Group S. Long-term survival in amyotrophic lateral sclerosis: a population-based study. Ann Neurol. 2014;75(2):287-297.
- Employment rate: Statistisches Bundesamt 2023
- Outpatient care: Muntendorf et al. (2024) inflated to 2023 by 7.1%
- Inpatient care: calculated according to PEPP/DRG
- Rehabilitation & Therapist visit: Muntendorf et al. (2024) inflated to 2023 by 7.1%

## **Methodology**

In the model, a user of HTAAC (HTAAC+) is compared against themselves in a hypothetical scenario without HTAAC (HTAAC-).

The model calculates costs per patient following the introduction of different high-tech AAC (HTAAC) tools for all patients and for three diagnostic groups: cerebral palsy, autism, and ALS.

The model simulates costs from a societal perspective for one patient.

Since the lifespan of the tools is five years, a time horizon of five years has been used. Half-cycle correction is conducted using the lifetable methods. Exponential discounting with a discount rate of 3% is applied.

The model includes costs based on healthcare utilization (outpatient visits, inpatient care, therapist visits) and production (change in ability to work) for both the user and the caregivers (may include multiple caregivers).

# APPENDIX: TARGET GROUPS DETAILS

Vorpommern

North Rhine-Westphalia (Nordrhein-Westfalen)

## High-tech AAC users in Germany

## An overview of the total segment (as per this sample)

Αv

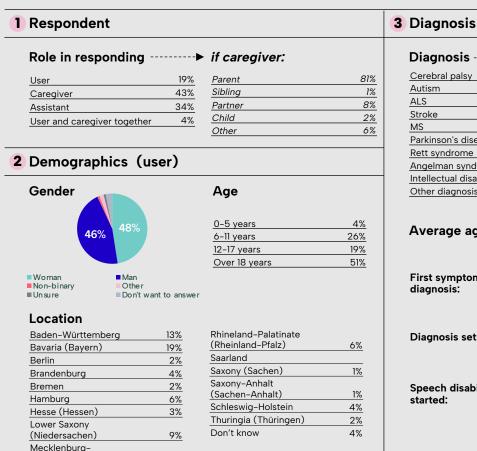
Firs

dia

Diagnosis set:

started:

Speech disabilities



5%

21%

Diagnosis	▶
Cerebral palsy	30%
Autism	19%
ALS	16%
Stroke	3%
MS	
Parkinson's disease	
Rett syndrome	11%
Angelman syndrome	1%
Intellectual disability	28%
Other diagnosis (open answer)	21%

erage age	
st symptom of	10.0
gnosis:	years

9.9	
years	

if...

CP (type)

Spastic CP

Atactic CP Don't know

Level 1

Level 2

Level 3

Don't know

(degree)

Moderate

Profound

Don't know

Severe

Mild

Dyskinetic CP

Autism (level)

Intellectual disability

### 4 AAC Solutions

52%

30%

9%

16%

9%

29%

26%

37%

6%

34%

30%

19%

11%

Low-tech AAC tools, e.g. communication boards/books	
etc.	33%
Eye-controlled communication aid	54%
Touch-controlled communication aid	54%
Gestures, sign language	29%
Other (open text answer)	11%

Type of AAC tools used

#### Specific communication tools used

iPad	43%
TD I-Series	29%
Computer	7%
PC Eye on tablet or computer	7%
Grid Pad	6%
Anybook Audiostift	6%
Mobile phone	6%
Accent	5%
TD Pilot	4%
SC Tablet/ SC Tablet Mini	4%
Accent w/ Look Eyetracking	2%
Nova Chat	2%
MyCore EyeControl	2%
TD I-110	1%
MyCore/MyCore 10	1%
Humankommunikator devices (touch)	1%
Lightwriter	1%
Seetech Pro Symbol 15	1%
Seetech Pro Key 15	1%
Seetech Mobile Key with eyetracking	1%
HE Kommunikator devices	1%
Basic X8, X10, X12,	1%
Konnex	1%
Other	13%

#### Average starting age with high-tech AAC

17.7 <sub>vears</sub>

#### Communication software/program used

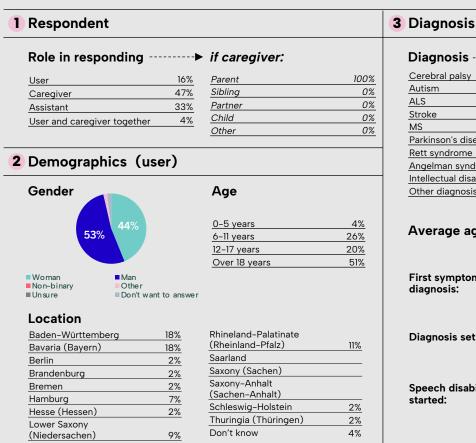
TD Snap	40%
Communicator 5	32%
Go Talk Now	26%
Metatalk	25%
TD Control	11%
Grid 2/3	6%
Minspeak	5%
TD Talk	4%
AssistiveTouch on iPhone/iPad	4%
Grid for iPad	4%
TD Browse	3%
LoGoFoXX (15/24/32/60/84)	3%
Mind Express	2%
Predictable	2%
TD Phone	2%
Windows Accessibilty	2%
Proloquo2Go	1%
Eloquence for Via	1%
Other	7%
Don't know	3%

Mecklenburg-Vorpommern

North Rhine-Westphalia (Nordrhein-Westfalen)

## High-tech AAC users with cerebral palsy

## An overview of the segment (as per this sample)



5%

19%

Cerebral palsy	100%
Autism	5%
ALS	
Stroke	2%
MS	
Parkinson's disease	
Rett syndrome	
Angelman syndrome	
Intellectual disability	30%
Other diagnosis (open answer)	12%
Other diagnosis (open answer)	12 /0

First symptom of

diagnosis:

Diagnosis set:

started:

Speech disabilities

0.2 years
0.9

if...

CP (type)

Spastic CP

Atactic CP

Don't know

Level 1

Level 2

Level 3

Don't know

(degree)

Moderate

Profound

Don't know

Severe

Mild

Dyskinetic CP

0.9
years

0.6	
years	

### 4 AAC Solutions

52%

30%

9%

16%

67%

33%

6%

29%

24%

24%

18%

Intellectual disability

Low-tech AAC tools, e.g. communication boards/books	
etc.	21%
Eye-controlled communication	
aid	68%
Touch-controlled	
communication aid	39%
Gestures, sign language	23%
Other (open text answer)	9%

Type of AAC tools used

### Average starting age with high-tech AAC

10.1 <sub>vears</sub>

#### Autism (level) Specific communication tools used

TD I-Series	44%
iPad	28%
PC Eye on tablet or computer	12%
Computer	9%
Anybook Audiostift	7%
Accent	7%
Grid Pad	5%
TD Pilot	4%
Accent w/ Look Eyetracking	4%
MyCore EyeControl	4%
MyCore/MyCore 10	4%
Mobile phone	2%
TD I-110	2%
Lightwriter	2%
Other	7%

#### Communication software/program used

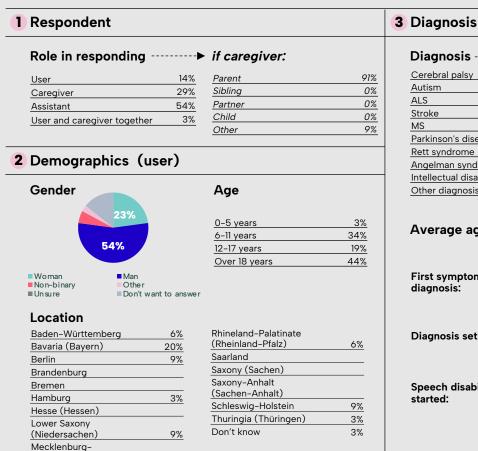
TD Snap	44%
Communicator 5	42%
Go Talk Now	19%
TD Control	16%
Metatalk	14%
Minspeak	9%
AssistiveTouch on iPhone/iPad	4%
TD Browse	4%
Mind Express	4%
Grid 2/3	2%
TD Talk	2%
Grid for iPad	2%
LoGoFoXX (15/24/32/60/84)	2%
Windows Accessibilty	2%
Other	7%
Don't know	4%

Vorpommern

North Rhine-Westphalia (Nordrhein-Westfalen)

## High-tech AAC users with autism

## An overview of the segment (as per this sample)



3%

31%

Cerebral palsy	9%
Autism	100%
ALS	
Stroke	3%
MS	
Parkinson's disease	
Rett syndrome	
Angelman syndrome	3%
Intellectual disability	49%
Other diagnosis (open answer)	29%

Average age...

Diagnosis set:

started:

Speech disabilities

First symptom of diagnosis:	1.4 years





if...

CP (type)

Spastic CP

Atactic CP Don't know

Level 1

Level 2

Level 3

Don't know

(degree)

Moderate

Profound

Don't know

Severe

Mild

Dyskinetic CP

Autism (level)

Intellectual disability

### 4 AAC Solutions

67%

33%

33%

9%

29%

26%

37%

12%

35%

29%

6%

18%

49%
3%
100%
54%
6%

Type of AAC tools used

#### Specific communication tools used

iPad	86%
SC Tablet/ SC Tablet Mini	119
Anybook Audiostift	99
Mobile phone	6%
Computer	3%
Accent	3%
Nova Chat	3%
Other	179

### Average starting age with high-tech AAC

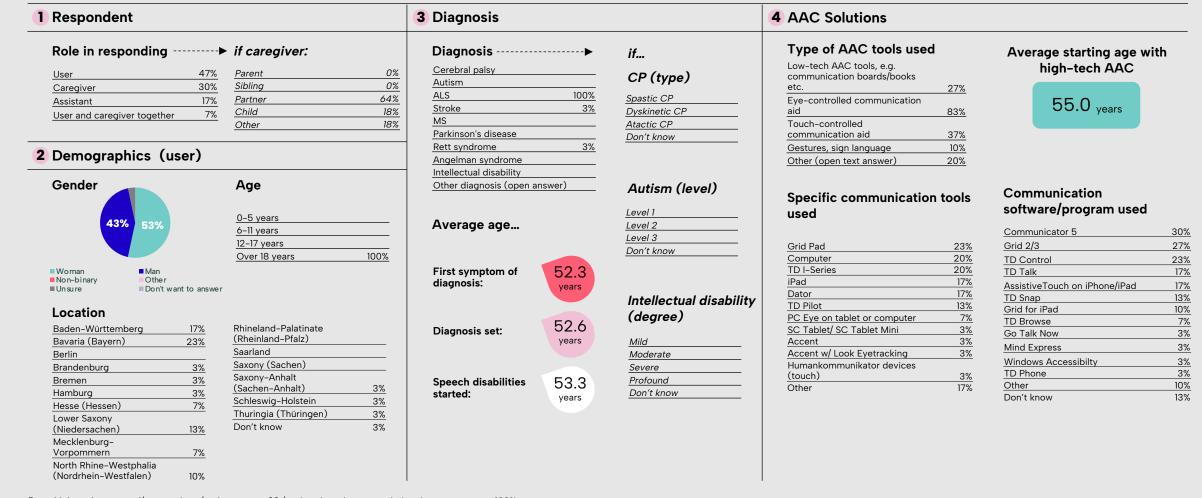
10.5 years

#### Communication software/program used

Metatalk	63%
Go Talk Now	57%
TD Snap	43%
LoGoFoXX (15/24/32/60/84)	9%
Minspeak	6%
Predictable	6%
Proloquo2Go	6%
Communicator 5	3%
Grid 2/3	3%
TD Talk	3%
Grid for iPad	3%
Eloquence for Via	3%
Other	11%
Don't know	

## High-tech AAC users with ALS

## An overview of the segment (as per this sample)



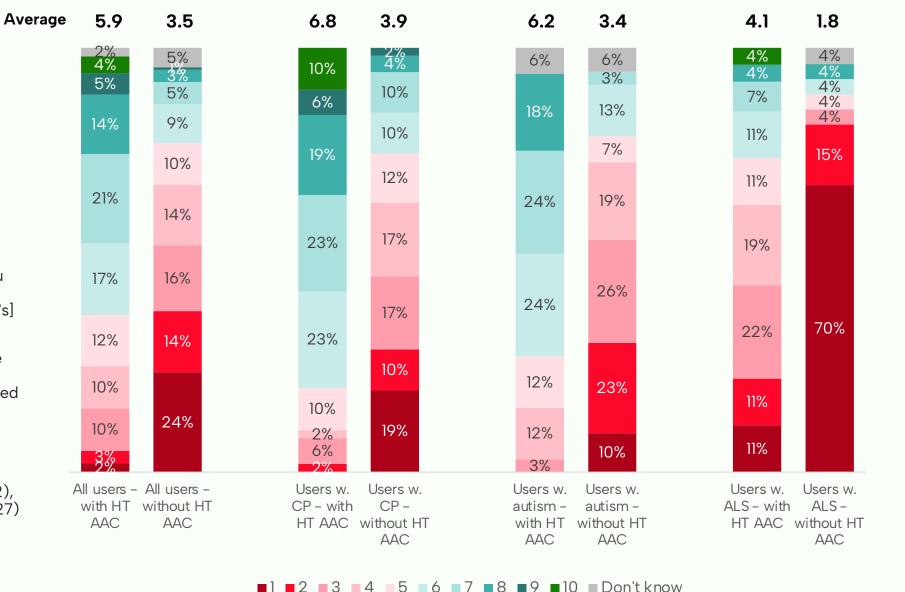
# APPENDIX: DETAILED DATA

## Total wellbeing

Q: How would you rate [your/the user's] overall health and well-being today on a scale from 1 to 10? 10 is the best health you can imagine, and 1 is the worst health you can imagine. Consider both [your/the user's] mental and physical well-being.

Q: Imagine what it would be like if [you/the user] did not have access to a high-tech communication tool (i.e. only communicated through blinking/picture boards/letter boards, etc.). If this was the case, how do you think [your/the user's] overall health would be today on a scale from 1 to 10?

Base: All users (n=174), Users w. CP (n=52), Users w. autism (n=33), Users w. ALS (n=27)

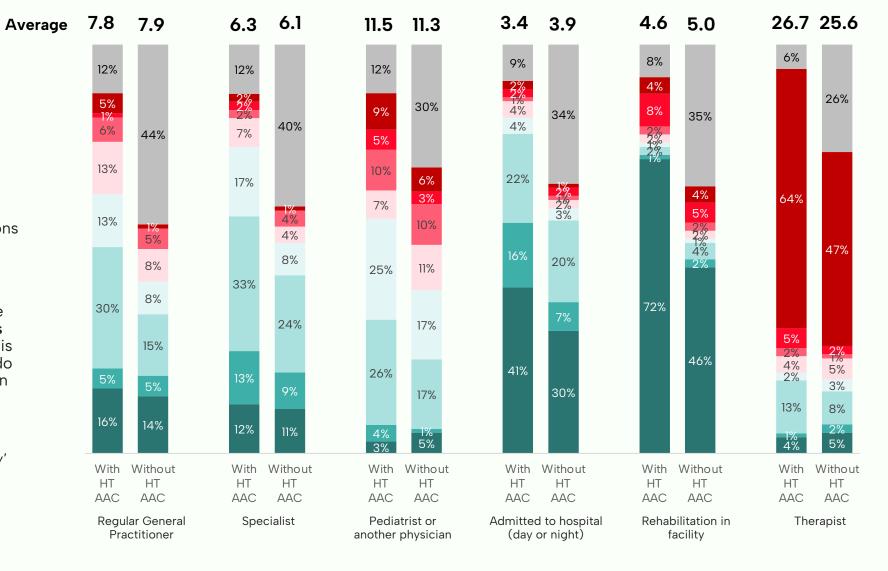


### **ALL USERS**

Q: Approximately, on how many occasions or days have [you/the user] needed the following types of care in the past 12 months?

Q: Once again, imagine what it would be like if [you/the user] did not have access to a high-tech communication tool. If this was the case, on how many visits/days do you think [you/the user] would have been in need of the following types of care?

Base: All users (n=167)

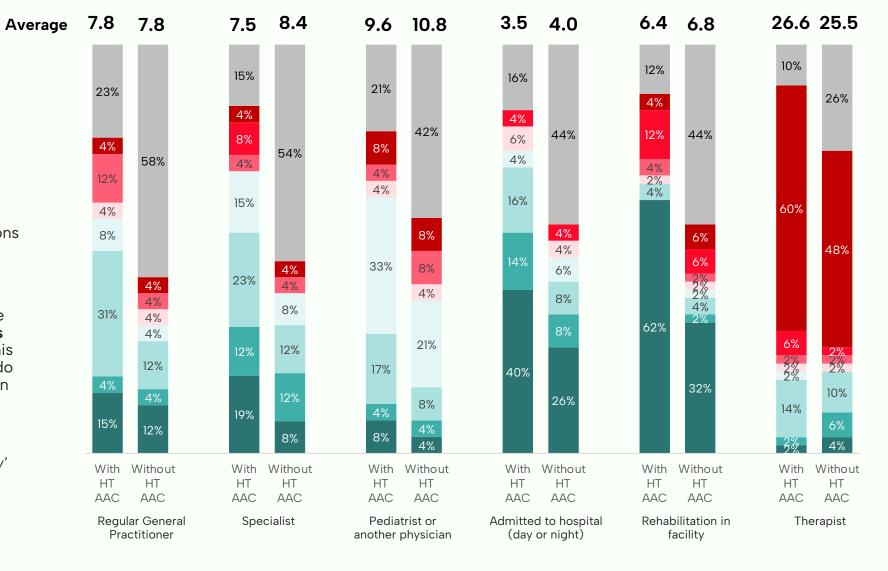


### **USERS W. CP**

Q: Approximately, on how many occasions or days have [you/the user] needed the following types of care in the past 12 months?

Q: Once again, imagine what it would be like if [you/the user] did not have access to a high-tech communication tool. If this was the case, on how many visits/days do you think [you/the user] would have been in need of the following types of care?

Base: Users w. CP (n=50)

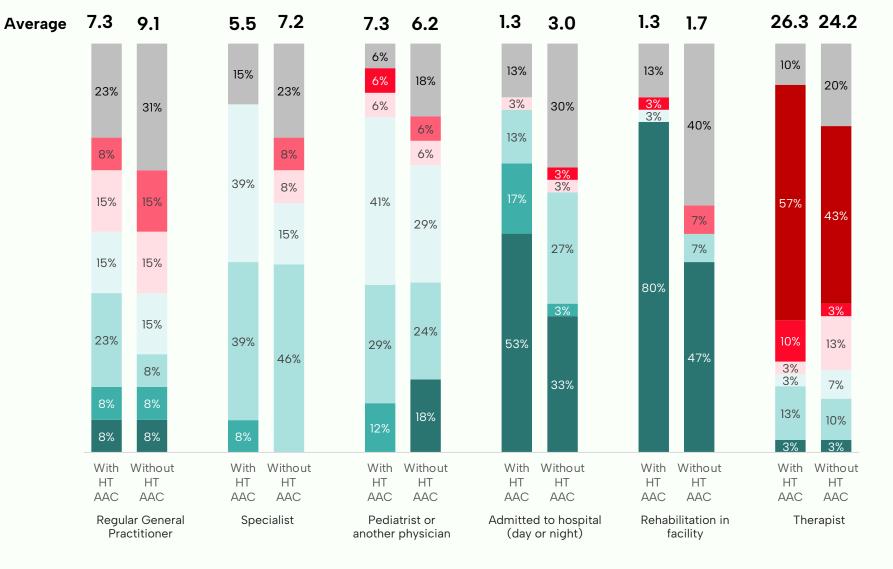


### **USERS W. AUTISM**

Q: Approximately, on how many occasions or days have [you/the user] needed the following types of care in the past 12 months?

Q: Once again, imagine what it would be like if [you/the user] did not have access to a high-tech communication tool. If this was the case, on how many visits/days do you think [you/the user] would have been in need of the following types of care?

Base: Users w. Autism (n=30)

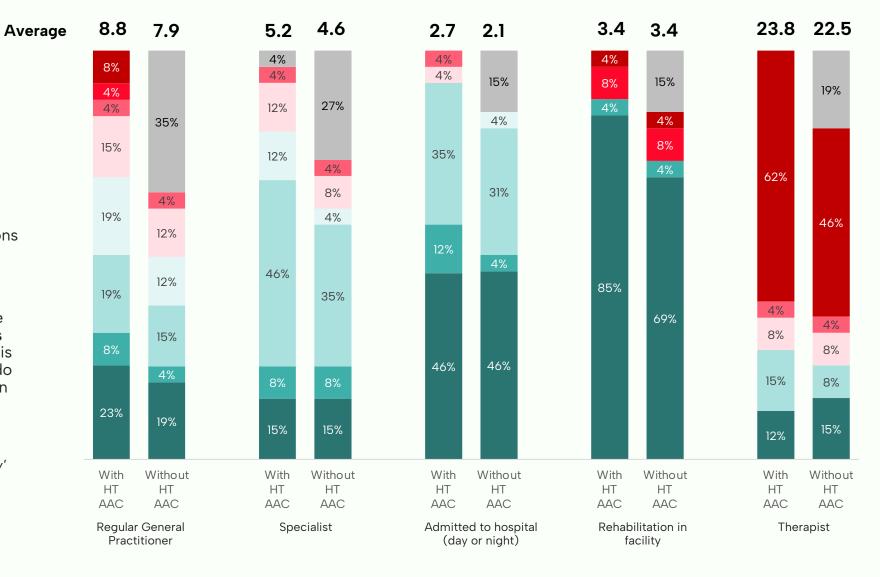


### **USERS W. ALS**

Q: Approximately, on how many occasions or days have [you/the user] needed the following types of care in the past 12 months?

Q: Once again, imagine what it would be like if [you/the user] did not have access to a high-tech communication tool. If this was the case, on how many visits/days do you think [you/the user] would have been in need of the following types of care?

Base: Users w. ALS (n=26)

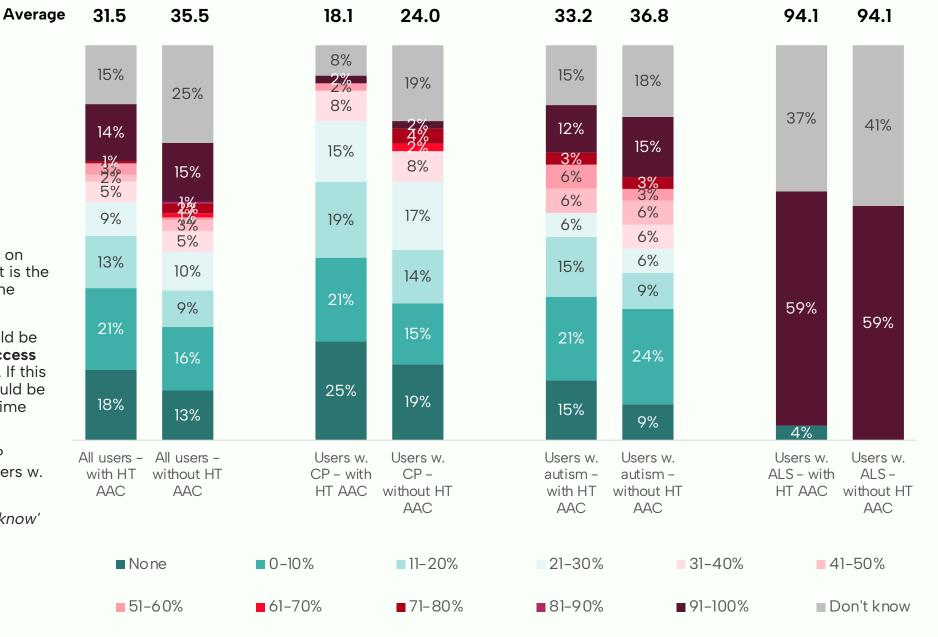


## Sick leave

Q: If [you are/the user is] have been on sick time in the last 12 months, what is the extent of the sick time taken over the entire year?

Q: Once again, imagine what it would be like if [you/the user] did not have access to a high-tech communication tool. If this was the case, what do you think would be the extent of [your/the user's] sick time taken over the entire year?

Base: All users (n=174), Users w. CP (n=52), Users w. autism (n=33), Users w. ALS (n=27)



Average 5.9 3.0

5.5 2.8 5.5 2.5 5.7 2.8 5.6 2.7 6.7

3.2

5.6 2.7 6.5 3.1

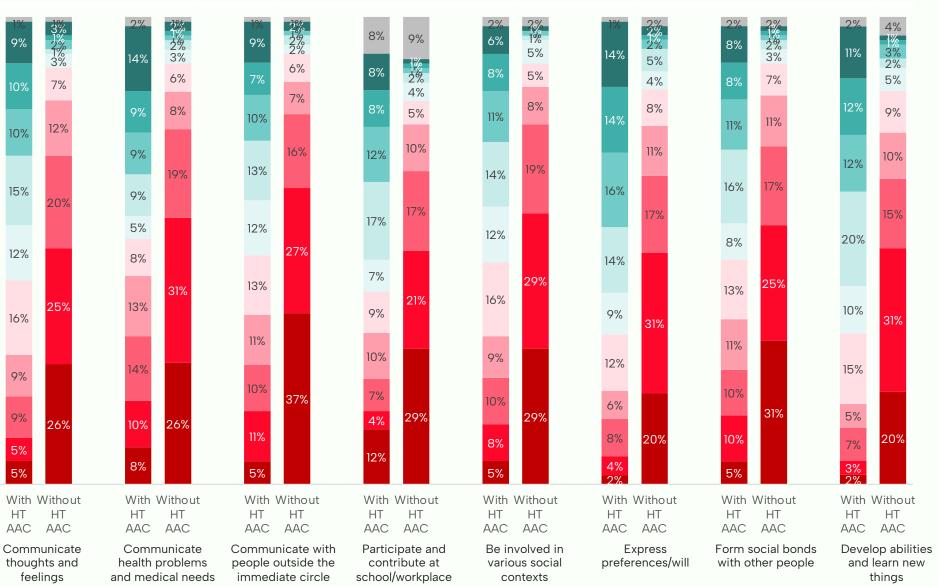
## **Abilities**

### **ALL USERS**

Q: To what extend do you feel that [you/the user] can do the following today?

Q: Without [your/the user's] communication tool, to what extent do you think [you/the user] would be able to do the following?

Base: All users (n=174)



Average 6.2 3.3

5.4 2.8

5.6 2.5

6.3 2.8

5.8 2

2.7

6.7 3.2

6.0 2.7

6.7 3.1

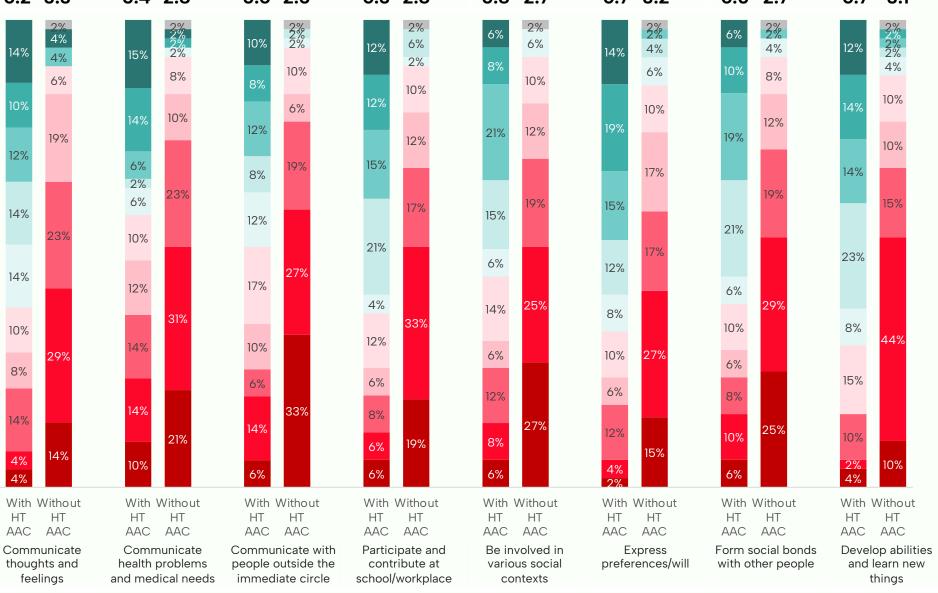
## **Abilities**

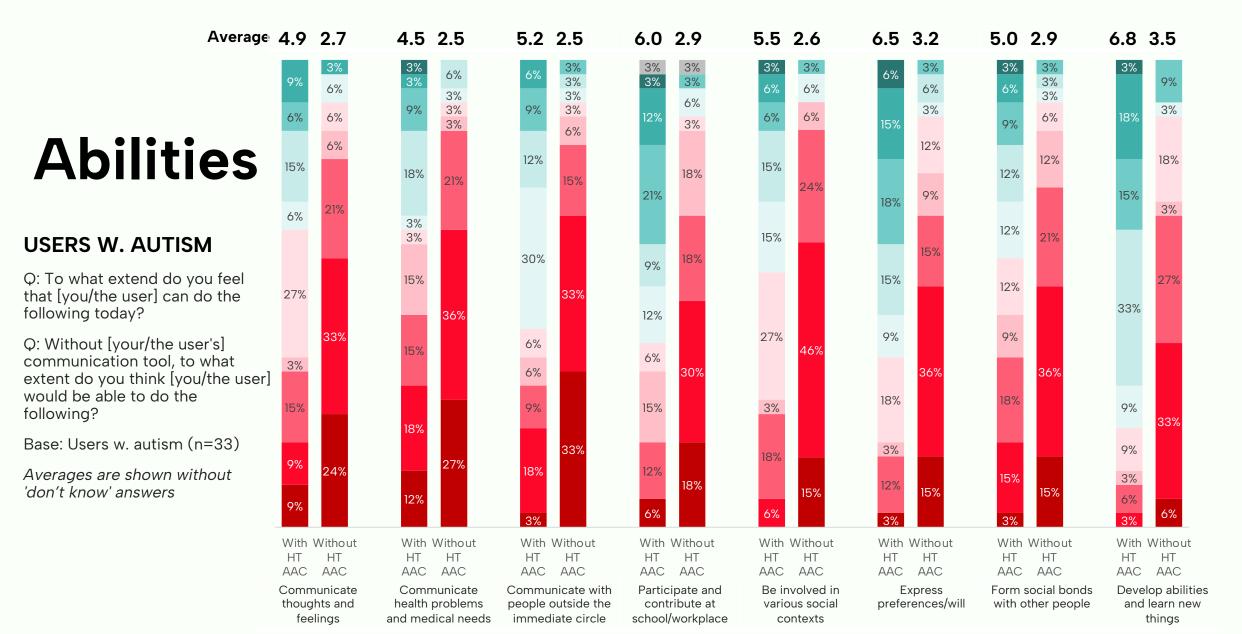
### **USERS W. CP**

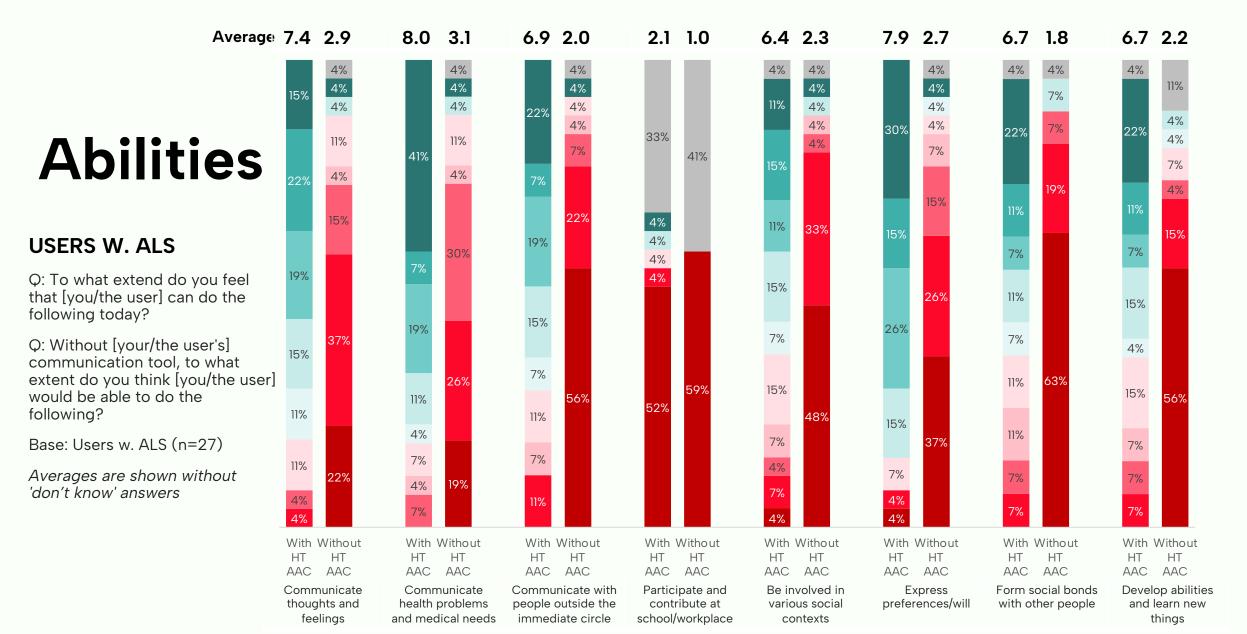
Q: To what extend do you feel that [you/the user] can do the following today?

Q: Without [your/the user's] communication tool, to what extent do you think [you/the user] would be able to do the following?

Base: Users w. CP (n=52)







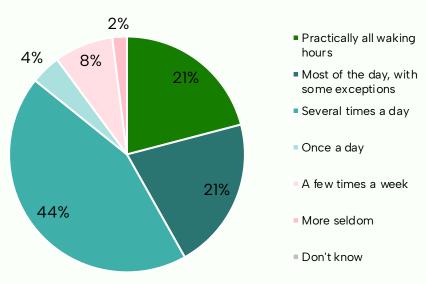
### **ALL USERS**

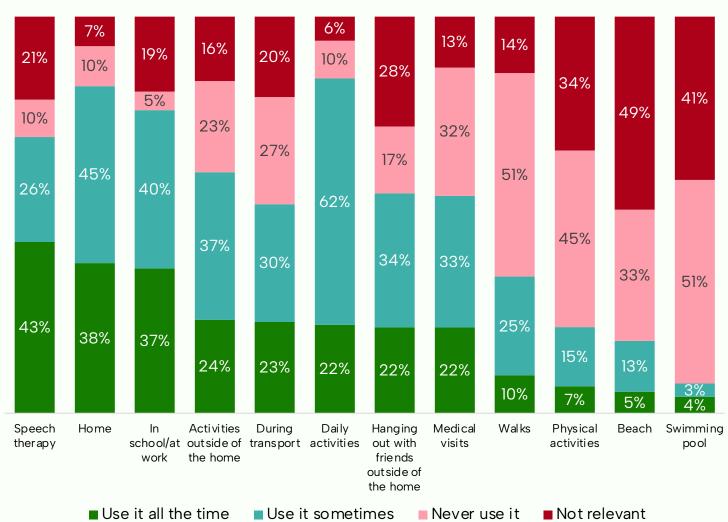
Q: How much [do you/does the user] use [your/his/her] communication tool? Make an estimate for a regular day/week.

Q: In what situations do/don't you/the user use your communication tool?

Base: All users (n=174)

### Usage during a regular day





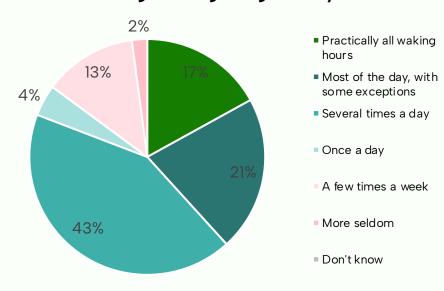
### **USERS W. CP**

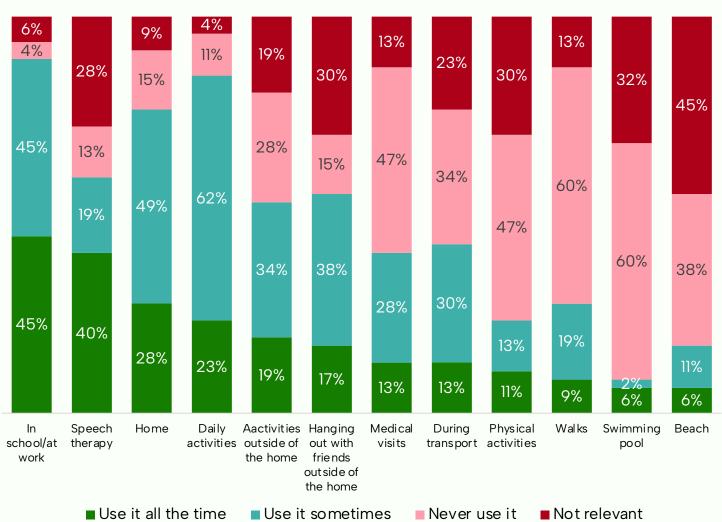
Q: How much [do you/does the user] use [your/his/her] communication tool? Make an estimate for a regular day/week.

Q: In what situations do/don't you/the user use your communication tool?

Base: Users w. cerebral palsy (n=52)

### Usage during a regular day





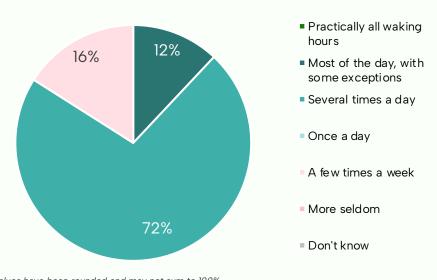
### **USERS W. AUTISM**

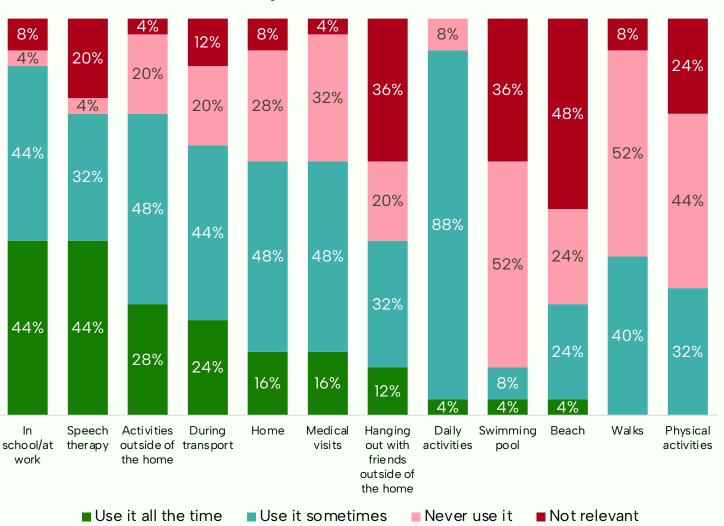
Q: How much [do you/does the user] use [your/his/her] communication tool? Make an estimate for a regular day/week.

Q: In what situations do/don't you/the user use your communication tool?

Base: Users w. autism (n=33)

### Usage during a regular day





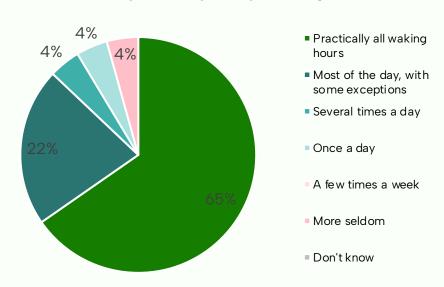
### **USERS W. ALS**

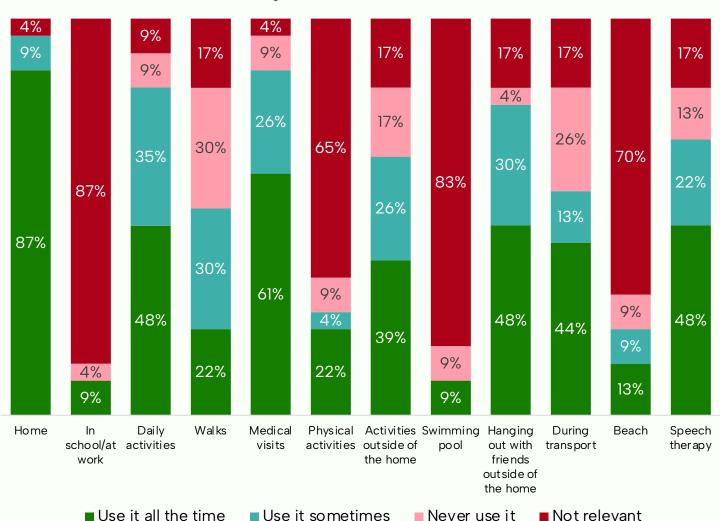
Q: How much [do you/does the user] use [your/his/her] communication tool? Make an estimate for a regular day/week.

Q: In what situations do/don't you/the user use your communication tool?

Base: Users w. ALS (n=27)

### Usage during a regular day

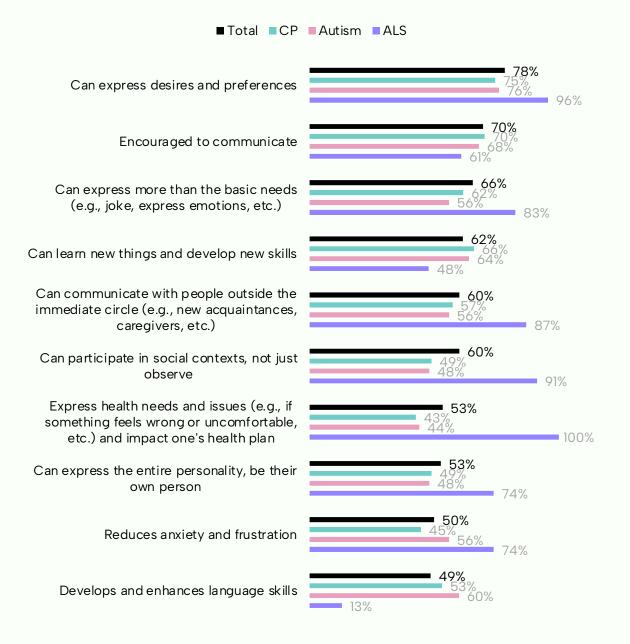




# Benefits of high-tech AAC to users (1)

Q: What are the greatest benefits with the communication tool for [you/the user]?

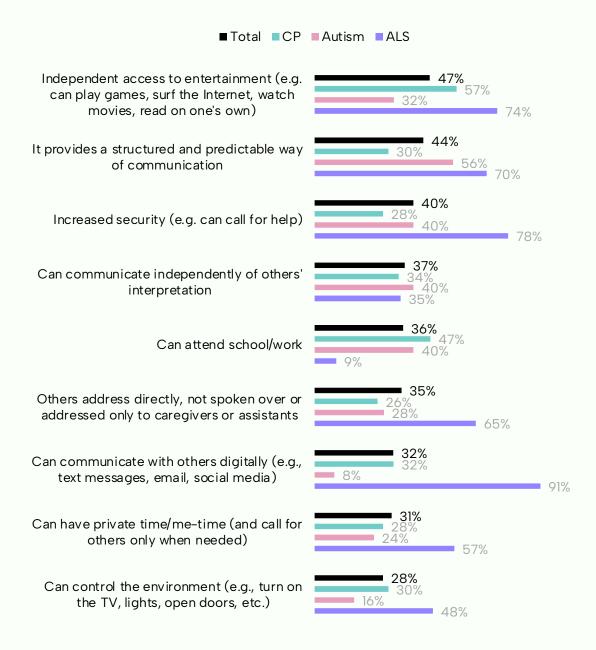
Base: high-tech AAC tool users and/or caregivers



# Benefits of high-tech AAC to users (2)

Q: What are the greatest benefits with the communication tool for [you/the user]?

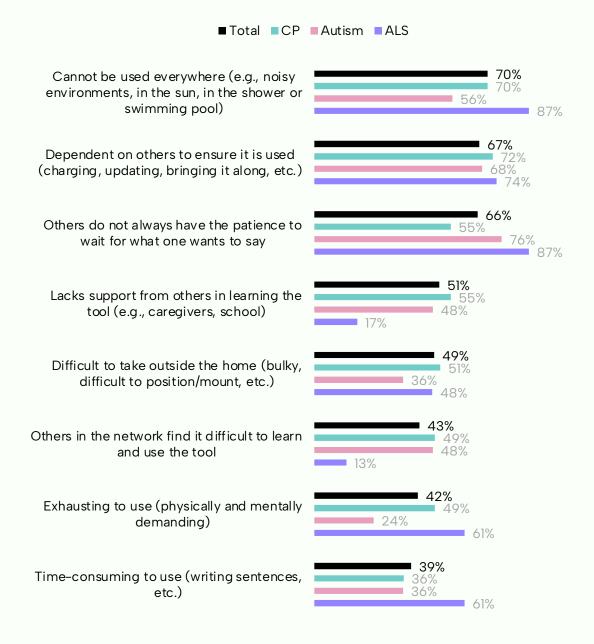
Base: high-tech AAC tool users and/or caregivers



# Disadvantages of high-tech AAC to users (1)

Q: What are the greatest challenges/disadvantages with the communication tool for [you/the user]?

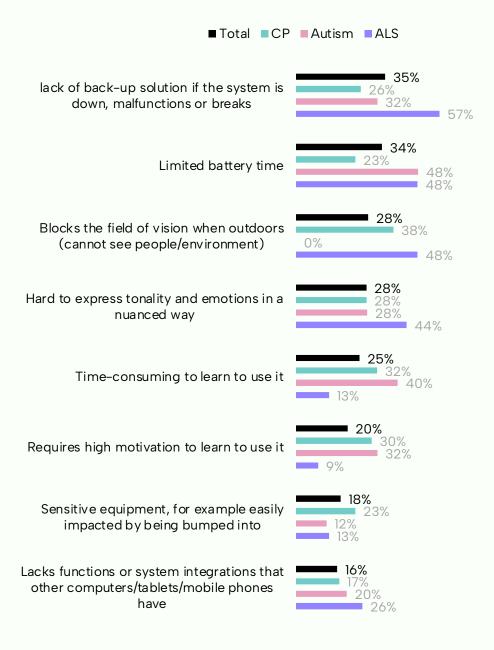
Base: high-tech AAC tool users and/or caregivers



# Disadvantages of high-tech AAC to users (2)

Q: What are the greatest challenges/disadvantages with the communication tool for [you/the user]?

Base: high-tech AAC tool users and/or caregivers

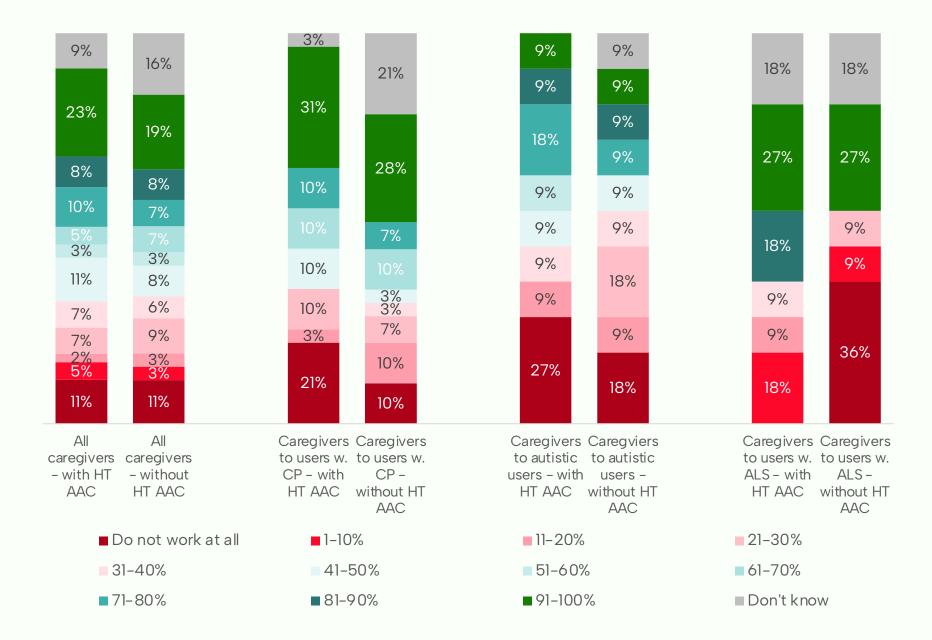


### Work rate caregiver

Q: To what extent have you worked in the last 12 months?

Q: Imagine what it would be like if [the user] did not have access to a high-tech communication tool (i.e., only communicated through blinking/picture boards/letter boards, etc.). To what extent do you think you would have worked then?

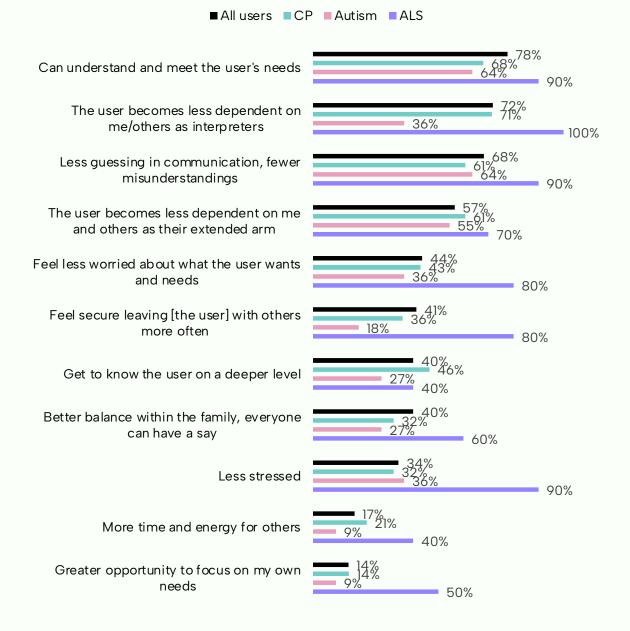
Base: All users (n=89), Users w. CP (n=29), Users w. autism (n=11), Users w. ALS (n=11)



# Benefits of high-tech AAC to caregivers

Q: What are the greatest benefits with the communication tool for [you/the user]?

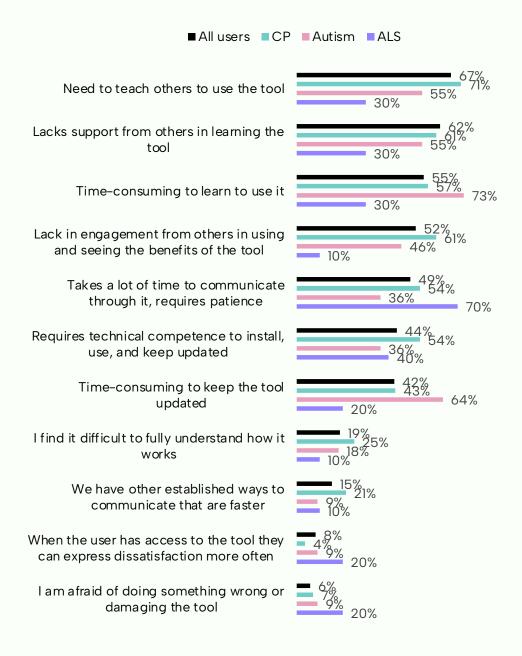
Base: high-tech AAC tool users and/or caregivers



# Disadvantages of high-tech AAC to caregivers

Q: What are the greatest challenges/disadvantages with the communication tool for [you/the user]?

Base: high-tech AAC tool users and/or caregivers



### Thank you