Exploring the Benefits of Assistive Communication

A health economic study conducted in Sweden by Augur and Health Economist John Moshtaghi-Svensson, commissioned by Tobii Dynavox.

2024

augur

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Glossary of key terms

AAC

A tool, strategy, support or any form of communication used in addition to, or in place of, the spoken word. Helps people who are unable to use verbal speech to communicate. Stands for augmentative and alternative communication.

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.

Three main perspectives and themes we've explored in this study

USERS

How and to what extent assistive communication can improve and elevate the lives of those using it

NETWORK

How assistive communication affects the lives of people in proximity to those using it – such as family and caregivers

SOCIETY

How assistive communication can lead to higher quality of life and increased cost efficiency for society at large

The combination of methods we've used

1. QUALITATIVE PRE-STUDY
(in-depth interviews)

With the qualitative pre-study, we explored:

- Subjective **needs, behaviors and feelings**
- **Context and differences** that are not possible to detect using a solely quantitative approach
- Added **depth and meaning** to what is measurable, allowing us to focus on what is most relevant

KEY QUESTIONS

***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 **where/when** do they manifest themselves?*

2. QUANTITATIVE STUDY
(online survey)

With the quantitative study, we were able to:

- Gather larger volumes of data in order to **measure and understand shared attitudes and behaviors among target groups**
- **Compare differences across target groups**

KEY QUESTIONS

***To what extent** do users/family members/relatives experience the different benefits?*

***Which benefits** are particularly enhanced and which groups experience them most?*

3. HEALTH ECONOMIC MODEL
(modeling and calculation)

+/−

With the health economic model, we were able to:

- **Calculate the costs and gains for society** following the introduction of high-tech AAC tools*
- **See the results** across three diagnostic groups: cerebral palsy, autism and ALS

KEY QUESTIONS

*What are **the costs and return on investment** from a societal perspective per patient, based on increased work ability for users and caregivers, as well as reduced healthcare utilization.*

*specially designed computers and software controlled by alternative access methods, (e.g., eye tracking or touch screens).

Qualitative study participants

Fieldwork: June-September 2023

USERS AND CAREGIVERS

12 physical or digital interviews in Sweden with users of various brands of high-tech AAC solutions and/or caregivers/assistants (24 participants total):

- 4 with cerebral palsy
- 1 with autism
- 1 with autism & cerebral palsy
- 4 with ALS
- 1 with Rett syndrome
- 1 with a neurological condition similar to MS

SPEECH THERAPISTS

5 interviews with Swedish speech therapists who all prescribe high-tech AAC tools.

RECRUITMENT

The participants were recruited through contacts of Tobii Dynavox as well as through posts made by Augur on various social media forums. Any AAC tool from any manufacturer could be used.

Quantitative study participants

Fieldwork: December 2023-February 2024

USERS AND CAREGIVERS

81 online interviews in Sweden with users of various brands of high-tech AAC solutions and/or caregivers/assistants:

- 17 with cerebral palsy
- 26 with autism
- 25 with ALS

See table below for the diagnosis overlap:

Diagnosis	Total	CP	Autism	ALS
Cerebral palsy	21%	100%	15%	
Autism	32%	24%	100%	
ALS	31%			100%
Stroke	1%			
MS	1%			
Parkinson's				
Rett syndrome	4%			
Angelman syndrome	1%			
Intellectual disability	36%	47%	73%	
Other	21%	12%	27%	

In total, there were 21 users, 41 caregivers, 16 assistants and 3 users + their caregivers answering together.

Quantitative study methodology

SURVEY STRUCTURE

Depending on target group, different sets of questions were asked:

- **Users and assistants** were asked *mandatory* questions about their tool, their current and estimated health care use and work ability with and without their high-tech AAC tool, and *optional* questions about the perceived benefits of their tool as well as well as their usage of it.
- **Caregivers** were asked the same questions about the user, and additional questions about the network's work ability 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 Tobii Dynavox through Tobii Dynavox's own social and web channels, as well as by posts by Augur in various social media forums. Any AAC tool from any manufacturer could be used.

Target group: high-tech AAC users in Sweden

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

1 RESPONDENT

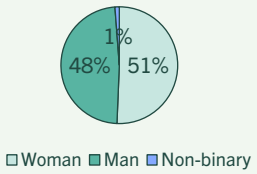
Role in answering ----------> *if caregiver*

User	26%
Caregiver	51%
Assistant	20%
User and caregiver together	4%

Parent	*77%*
Sibling	*5%*
Partner	*9%*
Child	*7%*
Other	*2%*

2 DEMOGRAPHICS (user)

Gender



Age

0-5 years	10%
6-11 years	18%
12-17 years	10%
Over 18 years	62%

Location

Blekinge	3%
Dalarna	1%
Gotland	-
Gävleborg	6%
Västra Götalandsregionen	24%
Halland	1%
Jämtland Härjedalen	1%
Jönköpings län	3%
Kalmar län	-
Kronoberg	3%
Norrbotten	3%

Skåne	12%
Stockholm	27%
Sörmland	1%
Uppsala	4%
Värmland	1%
Västerbotten	3%
Västernorrland	1%
Västmanland	3%
Örebro län	1%
Östergötland	3%
Don't know	1%

Base: high-tech users and/or caregivers, n = 81

3 DIAGNOSIS

Diagnosis ----------> *if...*

Cerebral palsy	21%
Autism	32%
ALS	31%
Stroke	1%
MS	1%
Parkinson's disease	--
Rett syndrome	4%
Angelman syndrome	1%
Intellectual disability	36%
Other diagnosis (open answer)	21%

Average age

First symptom of diagnosis: 27,5 years

Diagnosis set: 25 years

Speech disabilities started: 32,5 years

Cerebral palsy (type)

Spastic CP	*53%*
Dyskinetic CP	*29%*
Atactic CP	*6%*
Don't know	*12%*

Autism (level)

Level 1	*8%*
Level 2	*35%*
Level 3	*39%*
Don't know	*19%*

Intellectual disability (degree)

Mild	*17%*
Moderate	*35%*
Severe	*28%*
Profound	*14%*
Don't know	*7%*

4 AAC SOLUTIONS

Type of AAC tools used

Low-tech AAC tools, e.g. communication boards/books etc.	36%
Eye-controlled communication aid	53%
Touch-controlled communication aid	51%
Gestures, sign language	17%
Other (open text answer)	15%

Average starting age with AAC

25,9 years

Specific communication tools used

iPad	37%
Computer	17%
TD I-Series	15%
Mobile phone	15%
SC Tablet / SC Tablet Mini	10%
Other Tobii Dynavox model	10%
Grid Pad	9%
TD I-110	9%
Other (open text answer)	9%
PC Eye with Windows tablet or computer	7%
TD Pilot	7%
Jabla Tellus	1%
Other Smartbox model	1%
Hiru	-
Don't know /none of the above	3%

Communication software/program used

TD Snap	42%
Communicator 5	27%
TD Control	10%
Other (open text answer)	10%
TD Talk	9%
Grid 3	6%
Widget Go	6%
e-Pod	5%
Predictable	4%
TD Browse	4%
Grid for iPad	3%
TD Phone	3%
AssistiveTouch on iPhone/iPad	1%
Go Talk Now	1%
Easyclick	1%
Mind Express	1%
Proloquo2Go	1%
Proloquo4Text	1%
Don't know / none of the above	16%

Sub-group: cerebral palsy

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

1 RESPONDENT

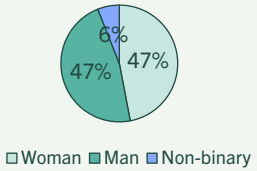
Role in answering ------> *if caregiver*

User	18%
Caregiver	41%
Assistant	29%
User and caregiver together	12%

Parent	*89%*
Sibling	*11%*
Partner	-
Child	-
Other	-

2 DEMOGRAPHICS (user)

Gender



Age

0-5 years	-
6-11 years	12%
12-17 years	24%
Over 18 years	65%

Location

Blekinge	-
Dalarna	-
Gotland	-
Gävleborg	6%
Västra Götalandsregionen	18%
Halland	-
Jämtland Härjedalen	-
Jönköpings län	6%
Kalmar län	-
Kronoberg	-
Norrbotten	6%

Skåne	6%
Stockholm	24%
Sörmland	6%
Uppsala	12%
Värmland	-
Västerbotten	6%
Västernorrland	-
Västmanland	6%
Örebro län	-
Östergötland	6%
Don't know	-

Base: high-tech users with CP and/or caregivers, n = 17

3 DIAGNOSIS

Diagnosis ---------> *if...*

Cerebral palsy	100%
Autism	24%
ALS	-
Stroke	-
MS	-
Parkinson's disease	-
Rett syndrome	-
Angelman syndrome	-
Intellectual disability	47%
Other diagnosis (open answer)	12%

Average age

First symptom of diagnosis:	0,3 years
Diagnosis set:	0,8 years
Speech disabilities started:	1,0 years

Cerebral palsy (type)

Spastic CP	*53%*
Dyskinetic CP	*29%*
Atactic CP	*6%*
Don't know	*12%*

Autism (level)

Level 1	-
Level 2	*25%*
Level 3	-
Don't know	*75%*

Intellectual disability (degree)

Mild	*38%*
Moderate	*25%*
Severe	*25%*
Profound	-
Don't know	*13%*

4 AAC SOLUTIONS

Type of AAC tools used

Low-tech AAC tools, e.g. communication boards/books etc.	59%
Eye-controlled communication aid	82%
Touch-controlled communication aid	24%
Gestures, sign language	18%
Other (open text answer)	24%

Average starting age with AAC

9,3 years

Specific communication tools used

TD I-Series	24%
iPad	24%
PC Eye on Windows tablet or computer	18%
Another model from Tobii Dynavox	18%
Computer	12%
Grid Pad	12%
Other (open text answer)	12%
TD I-110	6%
Mobile phone	6%
TD Pilot	6%
Hiru	-
Jabla Tellus	-
SC Tablet / SC Tablet Mini	-
Another model from Smartbox	-
Don't know / none of the above	-

Communication software/program used

Communicator 5	53%
TD Snap	35%
TD Control	24%
Grid 3	18%
TD Talk	12%
Other (open text answer)	12%
e-Pod	6%
Grid for iPad	6%
Mind Express	6%
AssistiveTouch on iPhone/iPad	-
Go Talk Now	-
Easyclick	-
Predictable	-
Proloquo2Go	-
Proloquo4Text	-
TD Browse	-
TD Phone	-
Widget Go	-
Don't know / none of the above	-

Sub-group: autism

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

1 RESPONDENT

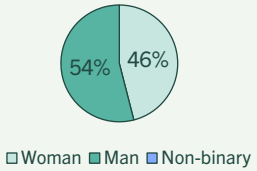
Role in answering - - - - - - → *if caregiver*

User	12%
Caregiver	77%
Assistant	12%
User and caregiver together	-

Parent	*100%*
Sibling	-
Partner	-
Child	-
Other	-

2 DEMOGRAPHICS (user)

Gender



Age

0-5 years	19%
6-11 years	35%
12-17 years	15%
Over 18 years	31%

Location

Blekinge	-
Dalarna	-
Gotland	-
Gävleborg	12%
Västra Götalandsregionen	35%
Halland	4%
Jämtland Härjedalen	-
Jönköpings län	4%
Kalmar län	-
Kronoberg	-
Norrbotten	-

Skåne	-
Stockholm	23%
Sörmland	-
Uppsala	4%
Värmland	-
Västerbotten	4%
Västernorrland	-
Västmanland	4%
Örebro län	4%
Östergötland	4%
Don't	4%

Base: high-tech users with autism and/or caregivers, n = 26

3 DIAGNOSIS

Diagnosis - - - - - - - - - →

Cerebral palsy	15%
Autism	100%
ALS	-
Stroke	-
MS	-
Parkinson's disease	-
Rett syndrome	-
Angelman syndrome	-
Intellectual disability	73%
Other diagnosis (open answer)	27%

Average age...

First symptom of diagnosis: 1,5 years

Diagnosis onset: 3,6 years

Speech disabilities started: 1,3 years

if...

Cerebral palsy (type)

Spastic CP	*25%*
Dyskinetic CP	*25%*
Atactic CP	*25%*
Don't know	*25%*

Autism (level)

Level 1	*8%*
Level 2	*35%*
Level 3	*39%*
Don't know	*19%*

Intellectual disability (degree)

Mild	*21%*
Moderate	*37%*
Severe	*21%*
Profound	*16%*
Don't know	*5%*

4 AAC SOLUTIONS

Type of AAC tools used

Low-tech AAC tools, e.g. communication boards/books etc	39%
Eye-controlled communication aid	12%
Touch-controlled communication aid	89%
Gesture, sign language	31%
Other (open text answer)	12%

Average starting age with AAC

7,2 years

Specific communication tools used

iPad	62%
TD I-110	15%
SC Tablet / SC Tablet Mini	15%
Computer	12%
Mobile phone	12%
Grid Pad	8%
TD I-Series	8%
TD Pilot	8%
Jabla Tellus	4%
Another model from Tobii Dynavox	4%
Another model from Smartbox	4%
Other (open text answer)	4%
Hiru	-
PC Eye on Windows tablet or computer	-
Don't know / none of the above	4%

Communication software/program used

TD Snap	65%
Other (open text answer)	12%
e-Pod	8%
Grid for iPad	8%
Widget Go	8%
Communicator 5	4%
Grid 3	4%
Easyclick	4%
Predictable	4%
Proloquo2Go	4%
Proloquo4Text	4%
AssistiveTouch on iPhone/iPad	-
Go Talk Now	-
Mind Express	-
TD Browse	-
TD Control	-
TD Phone	-
TD Talk	-
Don't know / none of the above	8%

Sub-group: ALS

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

1 RESPONDENT

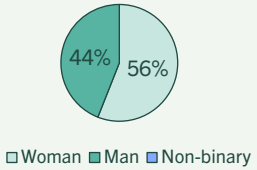
Role in answering ------> *if caregiver*

User	48%
Caregiver	32%
Assistant	20%
User and caregiver together	-

Parent	-
Sibling	*13%*
Partner	*50%*
Child	*38%*
Other	-

2 DEMOGRAPHICS (user)

Gender



Age

0-5 years	-
6-11 years	-
12-17 years	-
Over 18 years	100%

Location

Blekinge	4%
Dalarna	
Gotland	
Gävleborg	
Västra Götalandsregionen	16%
Halland	
Jämtland Härjedalen	
Jönköpings län	
Kalmar län	
Kronoberg	8%
Norrbotten	4%

Skåne	32%
Stockholm	32%
Sörmland	
Uppsala	
Värmland	
Västerbotten	
Västernorrland	4%
Västmanland	
Örebro län	
Östergötland	
Don't know	

Base: high-tech users with ALS and/or caregivers, n = 25

3 DIAGNOSIS

Diagnosis ---------->

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

Average age

First symptom of diagnosis: 53,7 years

Diagnosis onset: 54,0 years

Speech disabilities started: 56,5 years

if...

Cerebral palsy (type)

Spastic CP	-
Dyskinetic CP	-
Atactic CP	-
Don't know	-

Autism (level)

Level 1	-
Level 2	-
Level 3	-
Don't know	-

Intellectual disability (degree)

Mild	-
Moderate	-
Severe	-
Profound	-
Don't know	-

4 AAC SOLUTIONS

Type of AAC tools used

Low-tech AAC tools, e.g. communication boards/books etc.	16%
Eye-controlled communication aid	88%
Touch-controlled communication aid	20%
Gestures, sign language	
Other (open text answer)	12%

Average starting age with AAC

55,7 years

Specific communication tools used

Computer	28%
iPad	24%
Mobile phone	24%
Another model from Tobii Dynavox	16%
Other (open text answer)	16%
TD Pilot	12%
TD I-Series	8%
PC Eye on Windows tablet or computer	8%
Grid Pad	4%
Hiru	-
TD I-110	-
Jabla Tellus	-
SC Tablet / SC Tablet Mini	-
Another model from Smartbox	-
Don't know / none of the above	4%

Communication software/program used

Communicator 5	40%
TD Talk	16%
TD Control	12%
Other (open text answer)	12%
Predictable	8%
TD Browse	8%
TD Phone	8%
TD Snap	8%
AssistiveTouch on iPhone/iPad	4%
Go Talk Now	4%
Widget Go	4%
e-Pod	-
Grid 3	-
Grid for iPad	-
Easyclick	-
Mind Express	-
Proloquo2Go	-
Proloquo4Text	-
Don't know / none of the above	40%

The main user benefits of high-tech AAC

Express needs and preferences

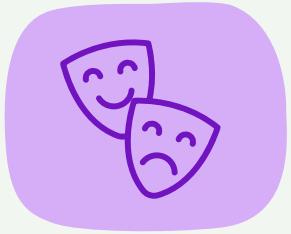
86%

Encouraged to communicate

72%

Form and maintain social relationships

69%



Express one's personality

68%

Learn and work

55%

Increased independence

34%

USERS

High-tech AAC's impact on quality of life

World Health Organization measures Quality of Life (WHOQOL) via four instruments, all of which can be said to be impacted by high-tech AAC.

PHYSICAL 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 discomforts, leading to more comfort in everyday life.

SOCIAL RELATIONSHIPS

The ability to communicate spontaneously and independently without the need for interpretation by others leads to improved social relations. This means stronger social bonds with your immediate family, as well as the ability to form relationships with people outside your inner circle and to be a participant in a variety of social situations.

PSYCHOLOGICAL HEALTH

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

ENVIRONMENTAL HEALTH

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. Calling for help (to someone nearby and to an alarm center) as well as being able to open doors, adjust temperature, and turn appliances on/off lead to greater environmental health.

USERS

For those with cerebral palsy, autism & ALS, high-tech AAC acts as an enabler and facilitator

CP

BEING PERCEIVED AS “JUST ANOTHER PERSON”

For people born with a diagnosis that hinders typical communication, such as severe CP, high-tech AAC improves their communicative abilities to an extent that can be life changing.

High-tech users can more easily express their personality and capabilities. This diminishes the role their disability plays in forming their identity and how they are perceived. For some, high-tech AAC can open a door to education and employment.

AUTISM

ESTABLISHING A MUTUAL INTERACTION

For these users, high-tech AAC provides a communication tool that is constant and predictable, with symbols, photos and sounds, that makes it possible to tailor the tool to their own life and interests.

This encourages communication, even outside of the closest family.

ALS

MAINTAINING INDEPENDENCE AND DIGNITY

People with ALS experience a loss of speech and body movement over time. High-tech AAC enables them to continue participating in life to the best of their abilities given the repeated "new normals" they face as their disease progresses.

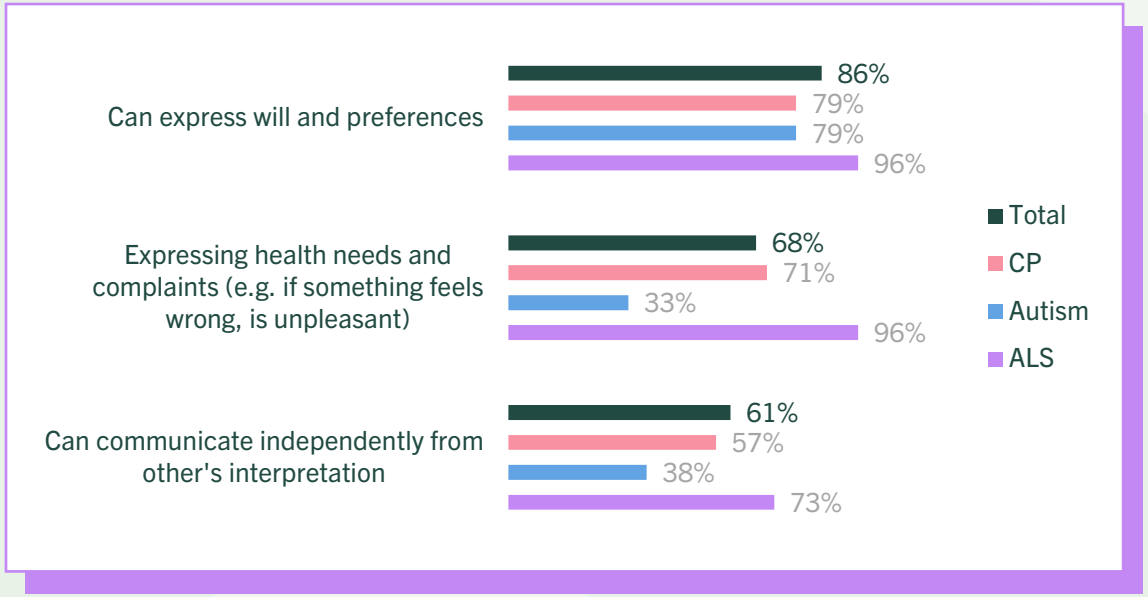
It also allows them to process and deal with the fact that they are dying. Thanks to AAC, they can take part in support groups and share their emotions, fears and experiences with others.

USERS

The ability to express one's will and preferences is the most recognized benefit of high-tech AAC

This is the most recognized benefit among the three diagnoses in focus, as stated by both users and caregivers.

Compared to low-tech AAC, this means **independent communication** that does not depend on anyone's guesses or a choice among a given set of options. This also means the ability to initiate communication and express health issues in a precise way.



Q: What are the main benefits of communication aids for [the user]? Base: high-tech AAC tool users and/or caregivers, n = 71 (CP: 14, autism: 24, ALS: 22)

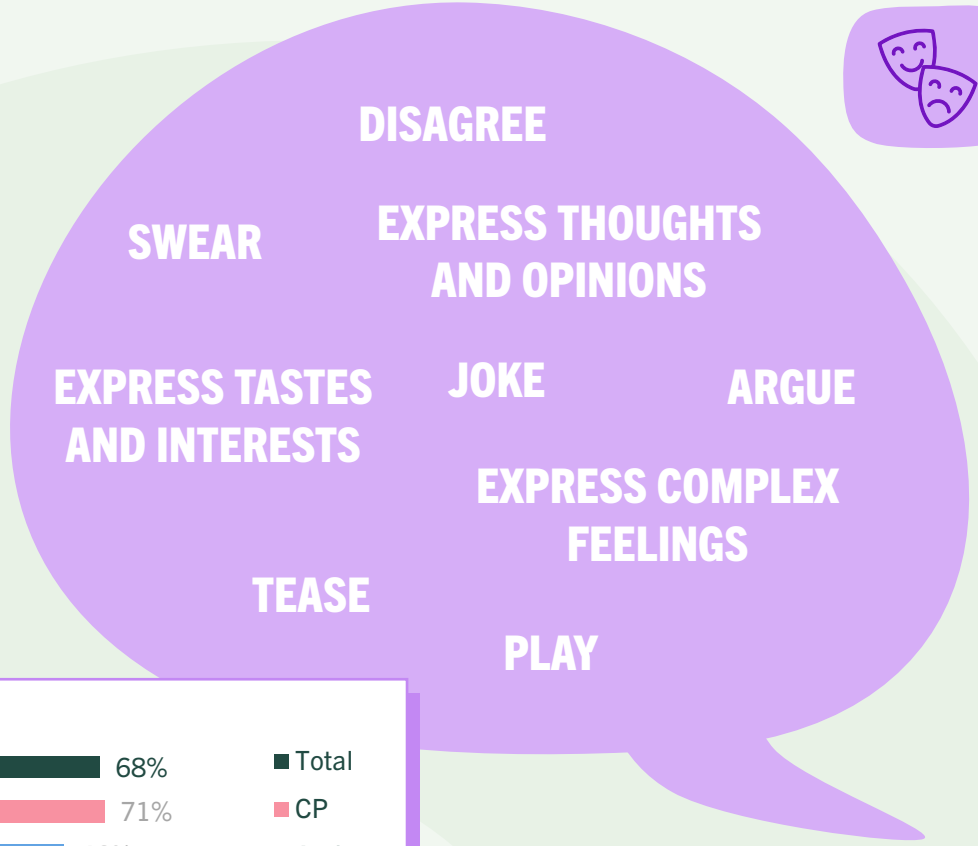
USERS CP ALS

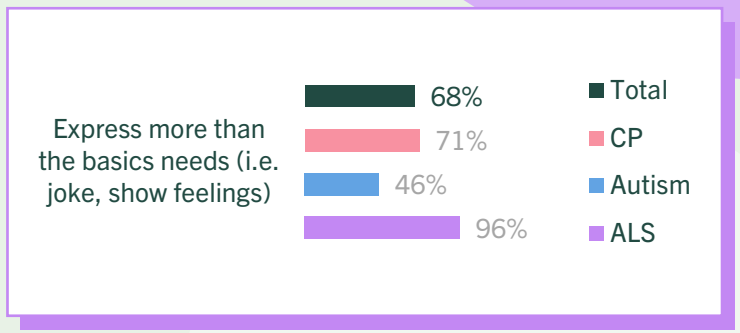
With high-tech AAC you can express your whole personality

Communication initiated independently by high-tech users means the ability to be a social participant, able to express more than just the basics. It provides an opportunity to start discussions, disagree, joke, swear, tease and play.

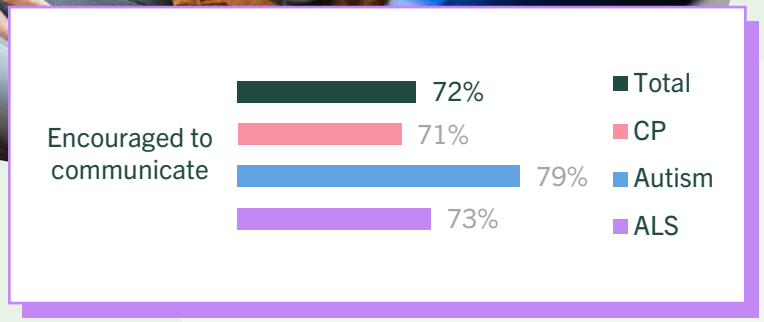
It means the ability to express your whole personality as you choose. It provides a means of showing people around you that you are human just like everybody else.

This is a more prominent benefit for users without intellectual disabilities, and more commonly mentioned by those with CP and ALS than autism.





Q: What are the main benefits of communication aids for [the user]? Base: high-tech AAC tool users and/or caregivers, n = 71 (CP: 14, autism: 24, ALS: 22)



USERS AUTISM

For autistic people, high-tech AAC is a way of encouraging communication

For autistic users, high-tech AAC provides a predictable tool to communicate with symbols, photos and sounds, making it possible to personalize for their own life and interests.

This enables a reliable means of conversation with more than just the members of their care circle. Overall, it also offers the possibility to communicate in a much more versatile way than with just low-tech AAC tools, such as symbol-based communication books and boards.

Q: What are the main benefits of communication aids for [the user]? Base: high-tech AAC tool users and/or caregivers, n = 71 (CP: 14, autism: 24, ALS: 22)

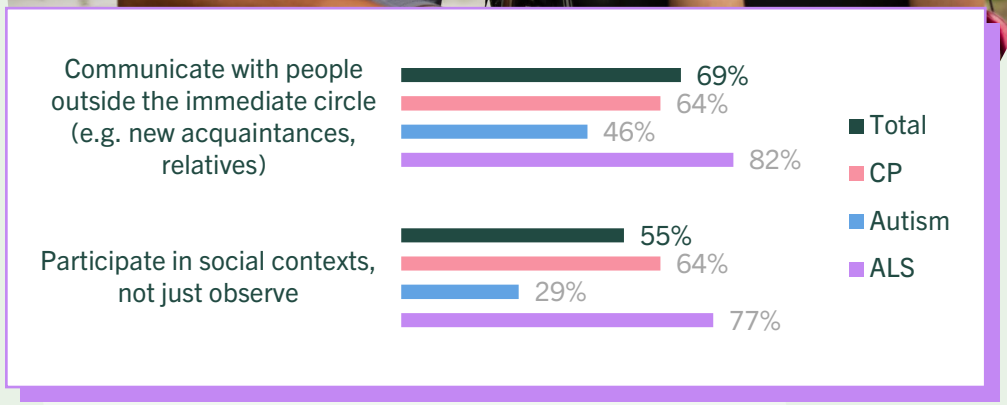
USERS

High-tech AAC users can 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/continue to know you on a deeper level
- You can communicate independently with those outside of the closest network (without having family or assistants needing to interpret). This mostly applies to people with CP or ALS, but also autism to a certain extent
- You can actively participate in and contribute to social situations, not just as an observer
- For users with ALS, this means the ability to keep up personal relationships even when you can no longer speak with your own voice

Q: What are the main benefits of communication aids for [the user]? Base: high-tech AAC tool users and/or caregivers, n = 71 (CP: 14, autism: 24, ALS: 22)



USERS CP ALS

They can also access modern digital tools

One benefit that comes with high-tech AAC tools is the possibility of communicating digitally. For those born with a condition such as **CP**, 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.

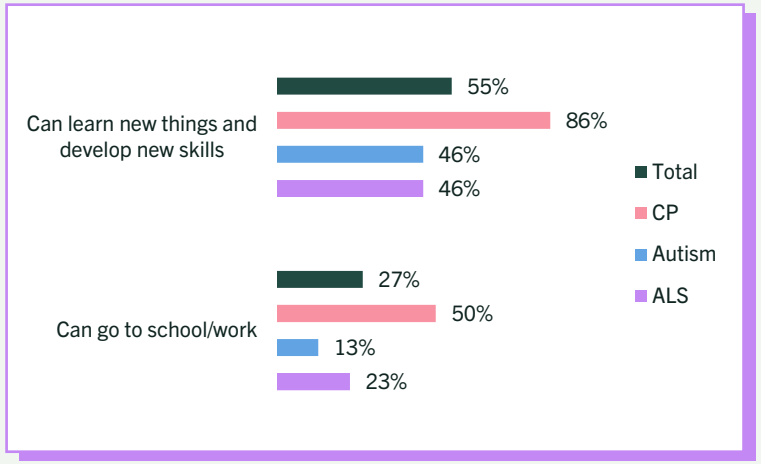
Q: What are the main benefits of communication aids for [the user]? Base: high-tech AAC tool users and/or caregivers, n = 71 (CP: 14, autism: 24, ALS: 22)

USERS CP

High-tech AAC enables learning, attending school and working

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

For some, it can also open the doors to work and to continue developing new skills throughout life. This also partly holds true for people with ALS, but the disease may complicate working due to factors other than communication difficulties.



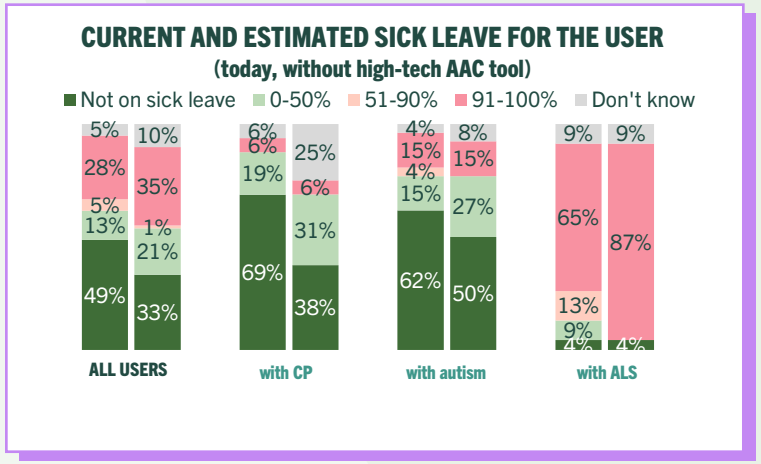
Q: What are the main benefits of communication aids for [the user]? Base: high-tech AAC tool users and/or caregivers, n = 71 (CP: 14, autism: 24, ALS: 22)

USERS

Without high-tech AAC tools, absenteeism is estimated to be 7% higher

High-tech AAC tools enable work or school life in a number of ways: it makes it possible to communicate with those outside the immediate family, to talk and write independently, to perform computer tasks, and much more. It also improves overall health, leading to more motivation and energy.

Without their AAC tool, 16% fewer respondents estimate that they would work/attend school full time, and a further 7% estimate that they would stop working/attending school altogether. That equates to a jump in the absenteeism rate from 38% to 45% (excluding 'don't know' responses). The biggest difference is in the ALS user group, where the sick leave rate is estimated to increase by 10%.



Q: If [the user] is on sick leave, how much is the sick leave spread over the whole year? / Imagine what it would have been like if [the user] had not had access to a high-tech communication aid. How much sick leave do you think [the user] would have had over the whole year? Base: high-tech AAC tool users and/or caregivers, n = 81 (CP: 16, autism: 26, ALS: 23)

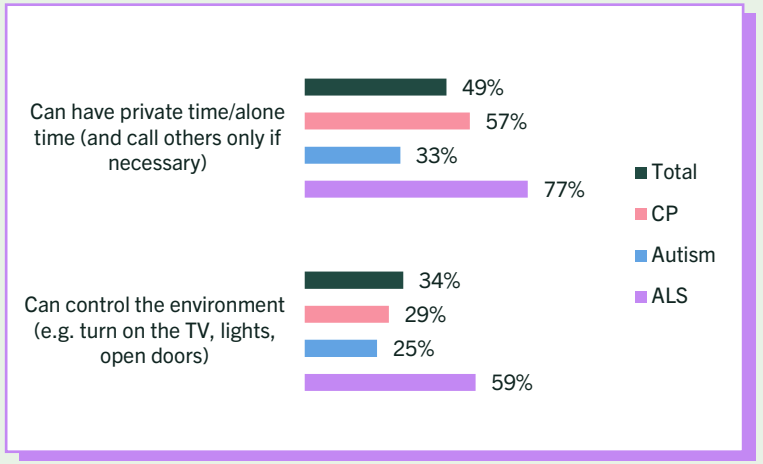
USERS CP ALS

The ability to control surroundings also enables independence and privacy

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 without others' help, or the ability to control one's environment (if the tool has smart home features), such as turning the TV, lights and stereo on and off, or opening doors.

The ability to control one's surroundings and call for help via the tool when needed means the possibility of maintaining privacy. It also enables digital privacy and the possibility to, for example, be in charge of one's own finances.



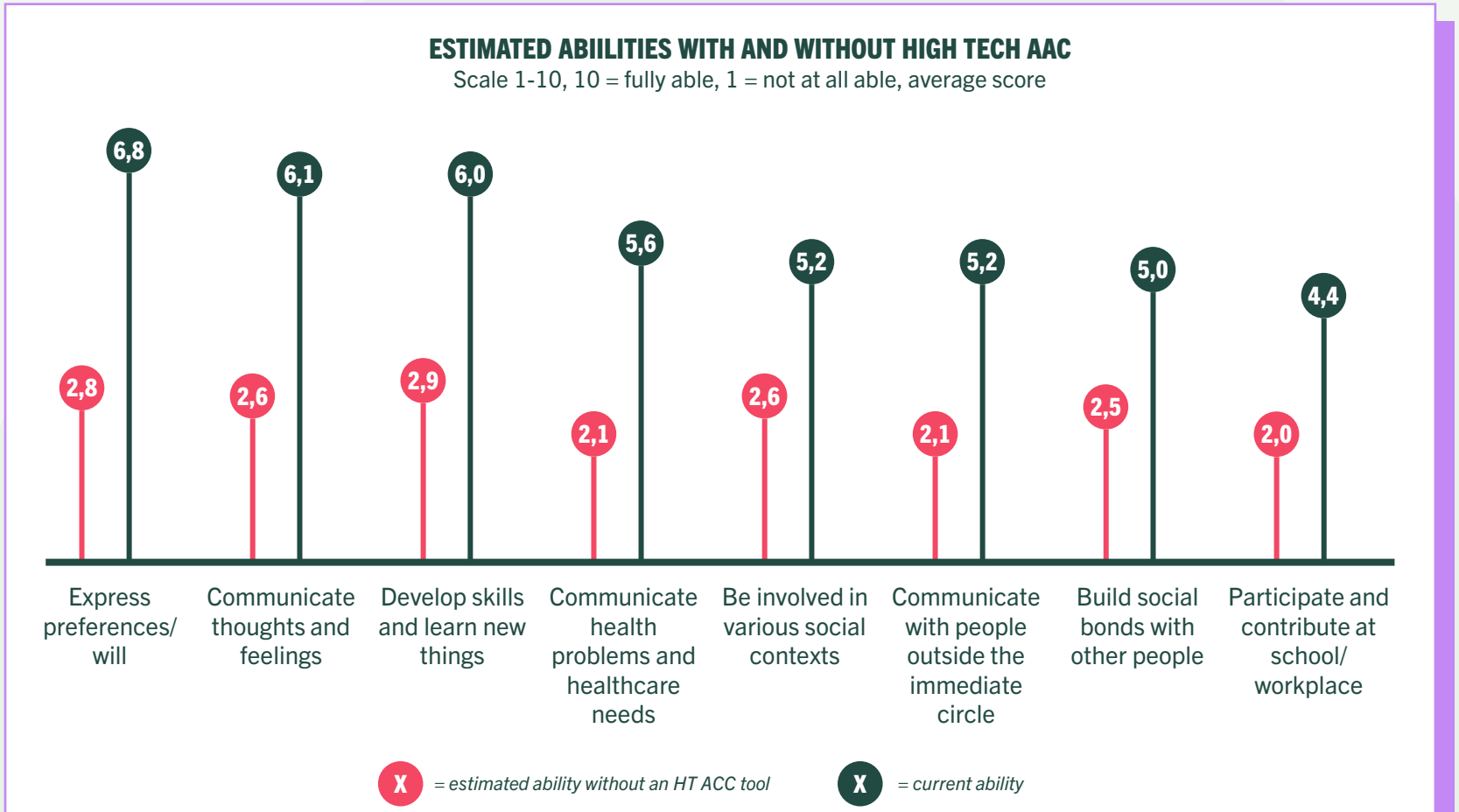
Q: What are the main benefits of communication aids for [the user]? Base: high-tech AAC tool users and/or caregivers, n = 71 (CP: 14, autism: 24, ALS: 22)

USERS

High-tech AAC is estimated to double important communicative and social capacities

The use of high-tech AAC is estimated to most improve the ability to express one's preferences and will, followed by being able to communicate thoughts and feelings.

Conversely, the abilities most estimated to be impacted by not using high-tech AAC are: explaining health problems and healthcare needs, communicating with people outside the immediate circle, and participating in school/workplace.



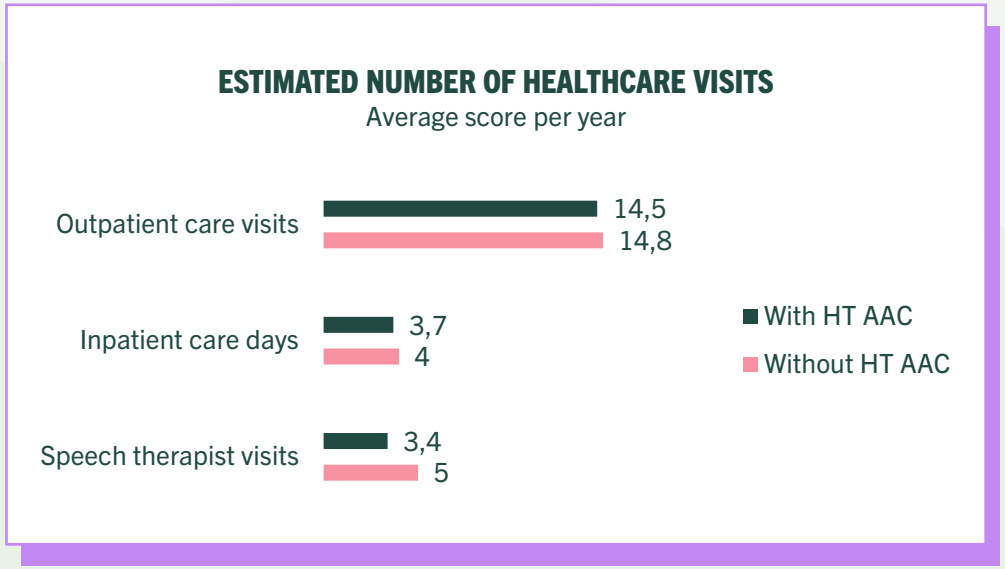
Q: To what degree do you feel that [the user] can do the following today? / Without [the user's] communication aid, how well do you think [the user] would be able to communicate the following/in the following situations? Base: high-tech AAC tool users and/or caregivers, n = 81 (CP: 16, autism: 26, ALS: 23)

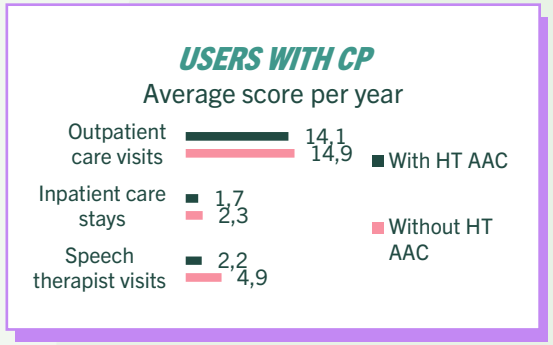
USERS

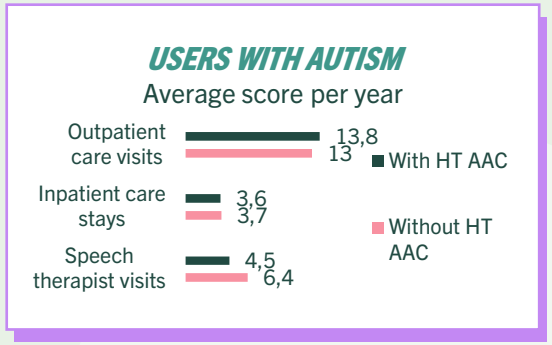
Needed health care is estimated to be slightly lower with a high-tech AAC tool

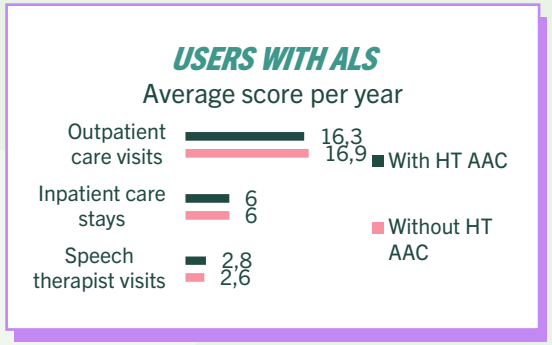
Without having access to their high-tech AAC tool, needed health care visits are estimated to be somewhat higher for users than when they do have access to it.

The need most estimated to increase is speech therapy, by almost two visits per year.









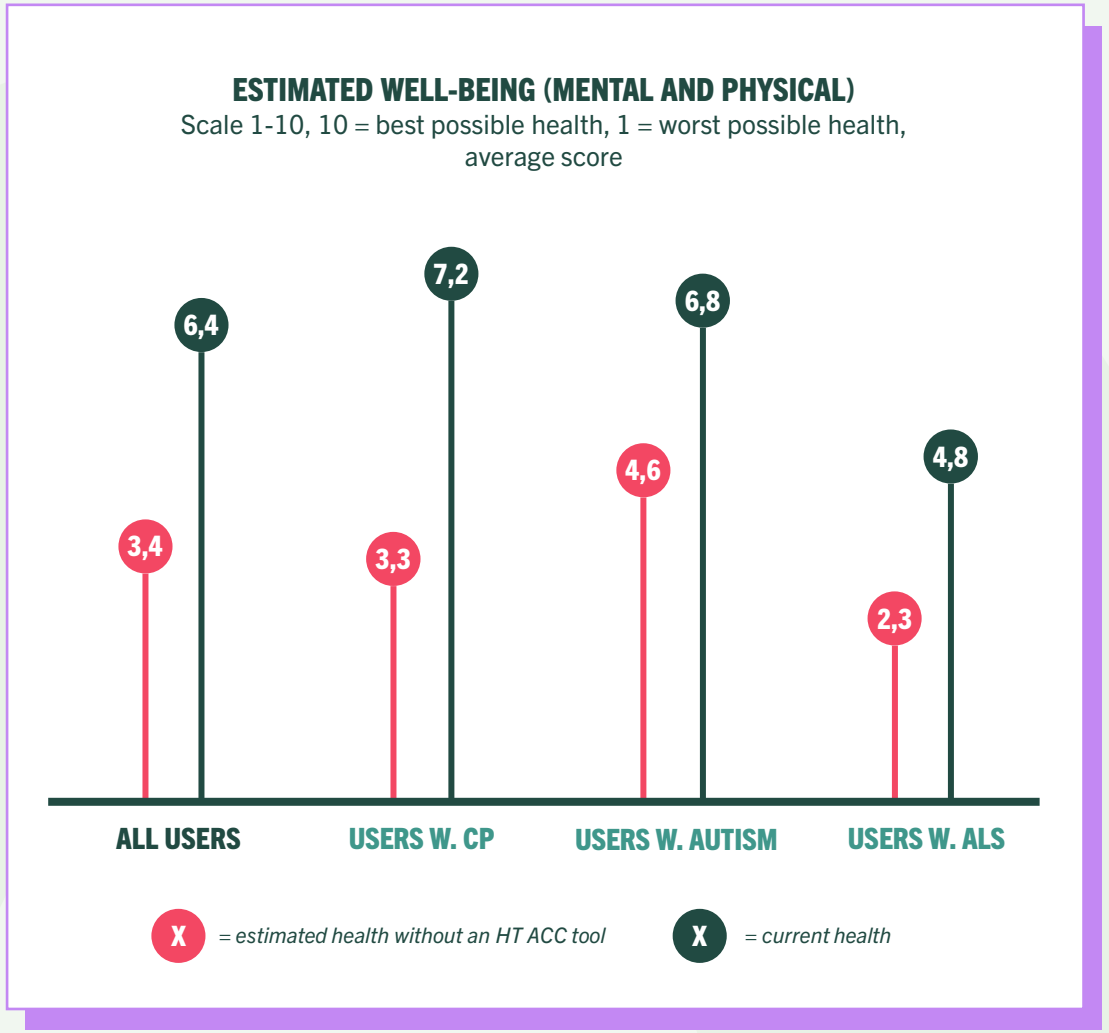
Q: Approximately, on how many occasions or days has [you/the user] been in need of the following types of care during the past 12 months? / Imagine again what it would have been like if [you/the user] had not had access to a high-tech communication aid. On how many occasions or days do you think [you/the user] was in need of the following types of care then? Base: high-tech AAC tool users and/or caregivers, n = 81 (CP: 16, autism: 26, ALS: 23)

USERS

A user's estimated total well-being is doubled with a high-tech AAC tool

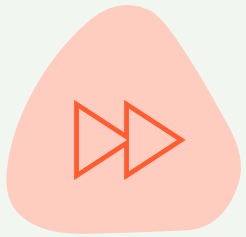
When asked to estimate overall well-being without access to their current high-tech AAC tool, most users estimate that one's well-being would be half of what it is today – from 6,4 on average to 3,3.

Users with CP or ALS are estimated to be more affected by the tool than autistic ones. Users with ALS actually estimate that their well-being would be decreased by roughly two-thirds without the tool.



Q: How would you rate [user's] overall health and well-being today on a scale of 1-10? 10 is the best health you can imagine, 1 is the worst health you can imagine. Consider both [the user's] mental and physical well-being. / Imagine what it would have been like if [the user] had not had access to a high-tech communication aid. How do you think the [user's] overall health would be today on a scale of 1-10? Base: high-tech AAC tool users and/or caregivers, n = 81 (CP: 16, autism: 26, ALS: 23)

The main caregiver benefits of high-tech AAC



More effective and precise communication

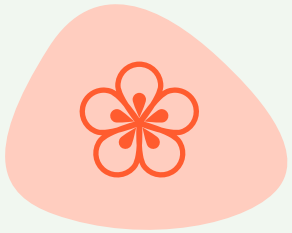
88%

Understand and meet the care recipient's needs

83%

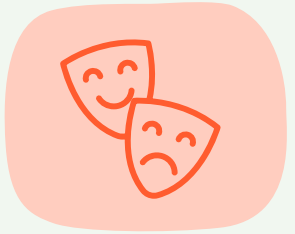
More independence for both

65%



Less stress and worry

48%



Can know the care recipient on a deeper level

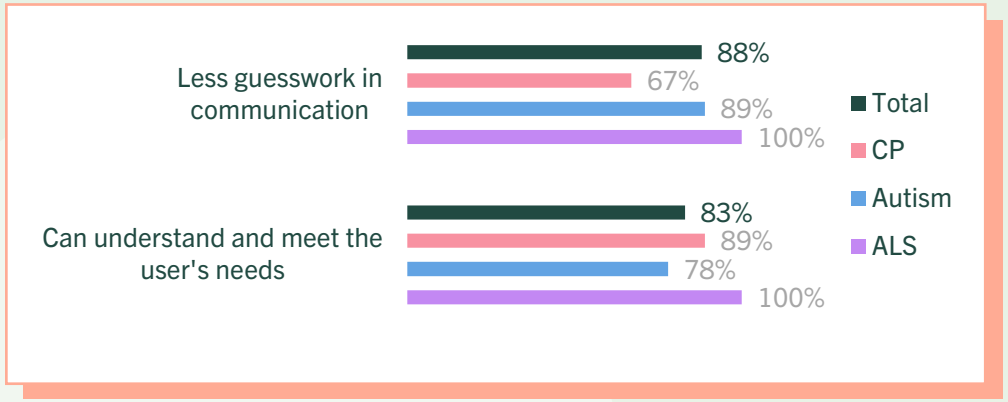
45%

Q: What do you feel are the greatest benefits of [user]'s communication aids for you as a relative? Base: caregivers of high-tech AAC tool users, n = 40 (CP: 9, autism: 18, ALS: 8)

NETWORK

Improved communication is the overall benefit of high-tech AAC to caregivers

High-tech AAC paves the way for exact communication with nuances and precision that is harder to obtain with low-tech tools. Less guesswork means being able to focus on understanding and meeting the user's needs, as well as leading to less frustration for both parties.

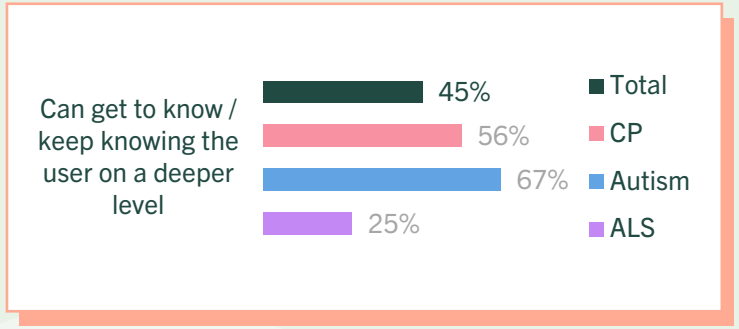


NETWORK CP AUTISM

For parents, it means getting to know your child on a deeper level

For parents to children born with a condition such as CP 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.

This benefit is most strongly expressed by parents of autistic children, as these tools might be the key to actually getting your child to communicate at all.



Q: What do you feel are the greatest benefits of [user]'s communication aids for you as a relative? Base: caregivers of high-tech AAC tool users, n = 40 (CP: 9, autism: 18, ALS: 8)

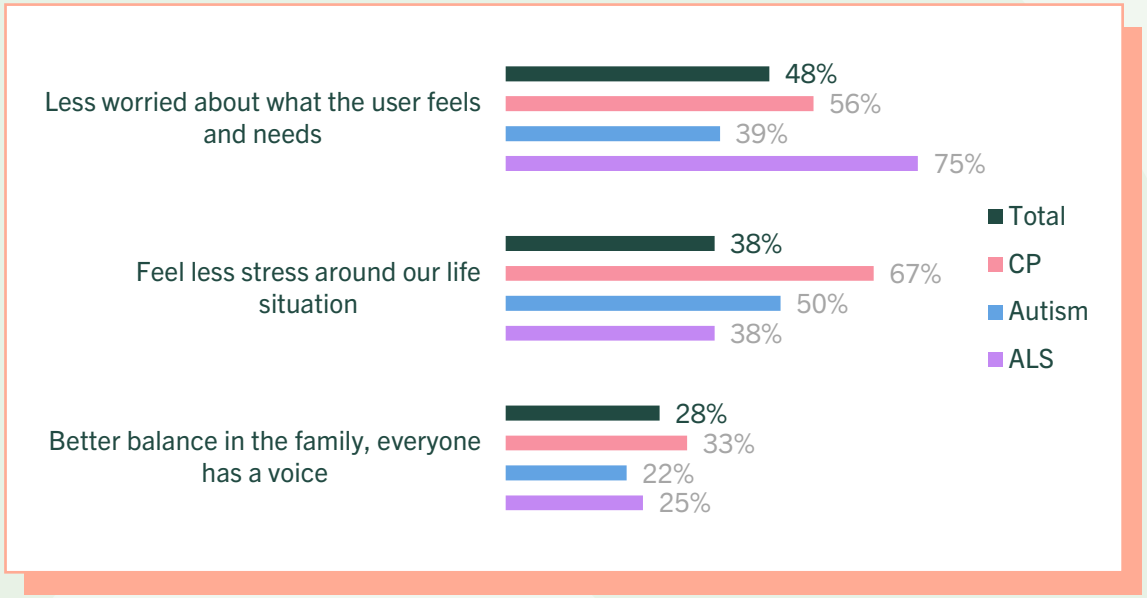
NETWORK

High-tech AAC tools can lead to less stress and worry for the caregiver

The benefits high-tech AAC tools provide in improving communication, enabling the user to express their needs, and the increased independence for everyone involved, result in less stress and worry for the caregivers.

For people with ALS, this means less worry about their needs and feelings being understood and met by their caregiver.

It also means being able to extend the supporting network, where more people can be involved in helping the user. This lessens responsibility for caregivers and makes for a less stressful life situation.



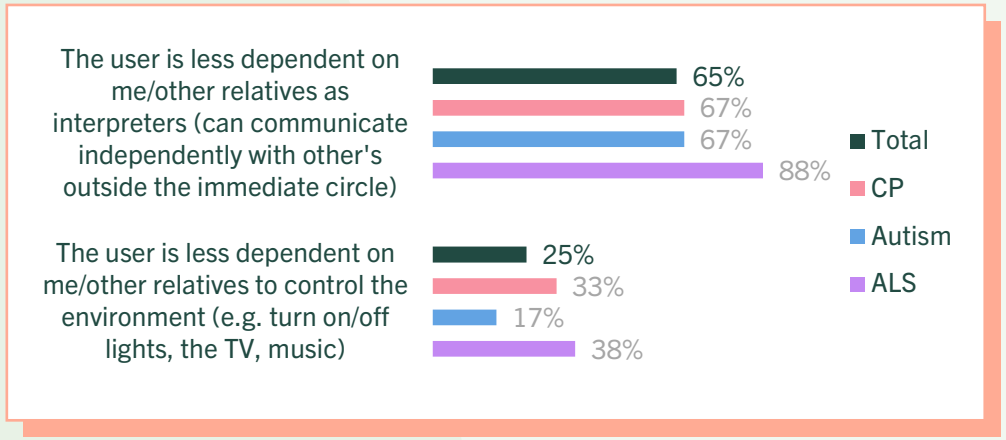
Q: What do you feel are the greatest benefits of [user]'s communication aids for you as a relative? Base: caregivers of high-tech AAC tool users, n = 40 (CP: 9, autism: 18, ALS: 8)

NETWORK

High-tech AAC gives increased independence for both the user and caregiver

The universality of the language spoken via high-tech AAC tools (especially for those communicating via spoken words 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.

The user's ability to control their environment also paves the way for independence for the caregiver, although to a lesser extent.



Q: What do you feel are the greatest benefits of [user]'s communication aids for you as a relative? Base: caregivers of high-tech AAC tool users, n = 40 (CP: 9, autism: 18, ALS: 8)

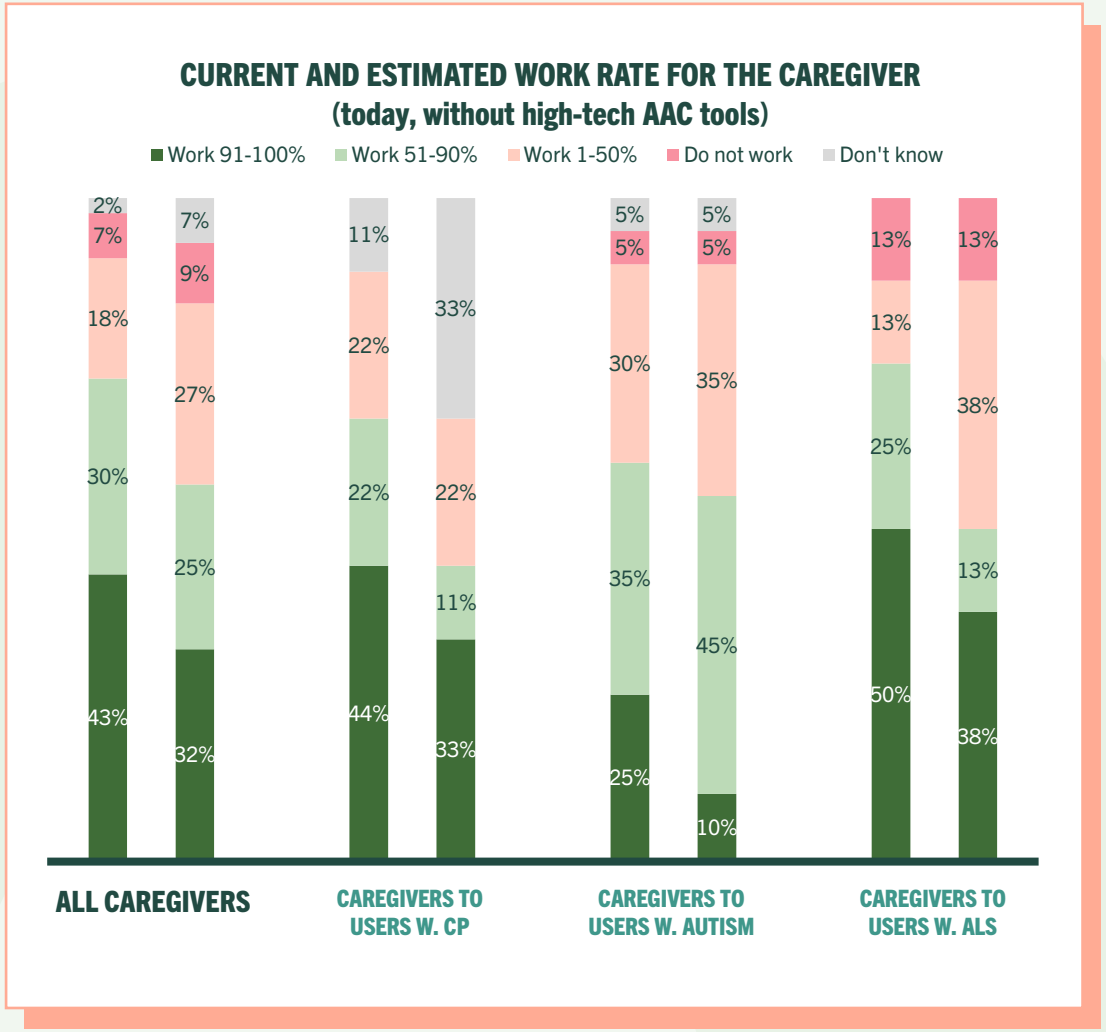
NETWORK

High-tech AAC leads to higher work ability of the network

Overall, primary caregivers estimate a 7% decrease in their work rate if the person they care for does not use a high-tech AAC tool (excluding those answering *don't know*). And 11% fewer estimate that they would be able to work full-time without the tool.

This is based on a number of factors, both psychological and practical. With a high-tech AAC tool, the user is less dependent on the closest caregivers and it's easier to leave them with other family members or assistants.

But it also means better mental health thanks to less stress and anxiety about meeting the user's needs, and the overall life situation.

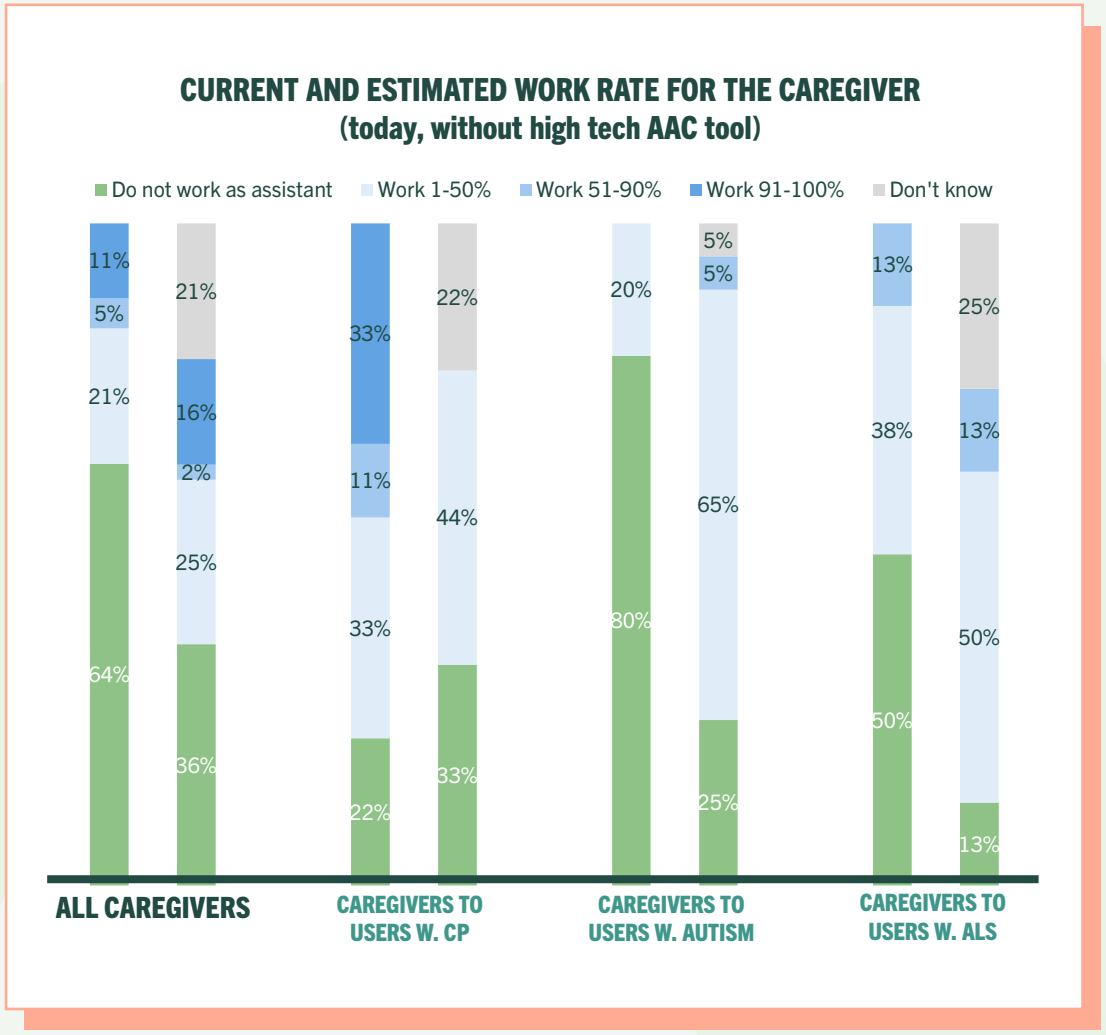


Q: To what degree have you worked in the past 12 months? / Imagine what it would have been like if [the user] had not had access to a high-tech communication aid. To what degree do you think you had worked then? Base: caregivers of high-tech AAC tool users, n = 44 (CP: 9, autism: 20, ALS: 8)

NETWORK

Without high-tech AAC, caregivers estimate taking on a 16% increase in duties normally done by assistants

Today, 64% of the responding caregivers do not take on the additional workload usually done by assistants. However, without the use of a high-tech AAC tool, they estimate that the work rate would increase by 16% (excluding those who answer *don't know*). A further 5% estimate that they would need to do the equivalent work of a full-time assistant, in addition to their caregiver duties, if the user did not have a high-tech AAC device.



Q: To what extent do you work as an assistant for [user]? Calculate as an average over the entire year. / Imagine what it would have been like if [the user] had not had access to a high-tech communication aid. To what extent do you think you had worked as an assistant to [user] then? Calculate as an average over the entire year? Base: caregivers of high-tech AAC tool users, n = 44 (CP: 9, autism: 20, ALS: 8)

Having access to a high-tech AAC tool on average has the potential to save society approx. 320 000 SEK per user over a 5-year period

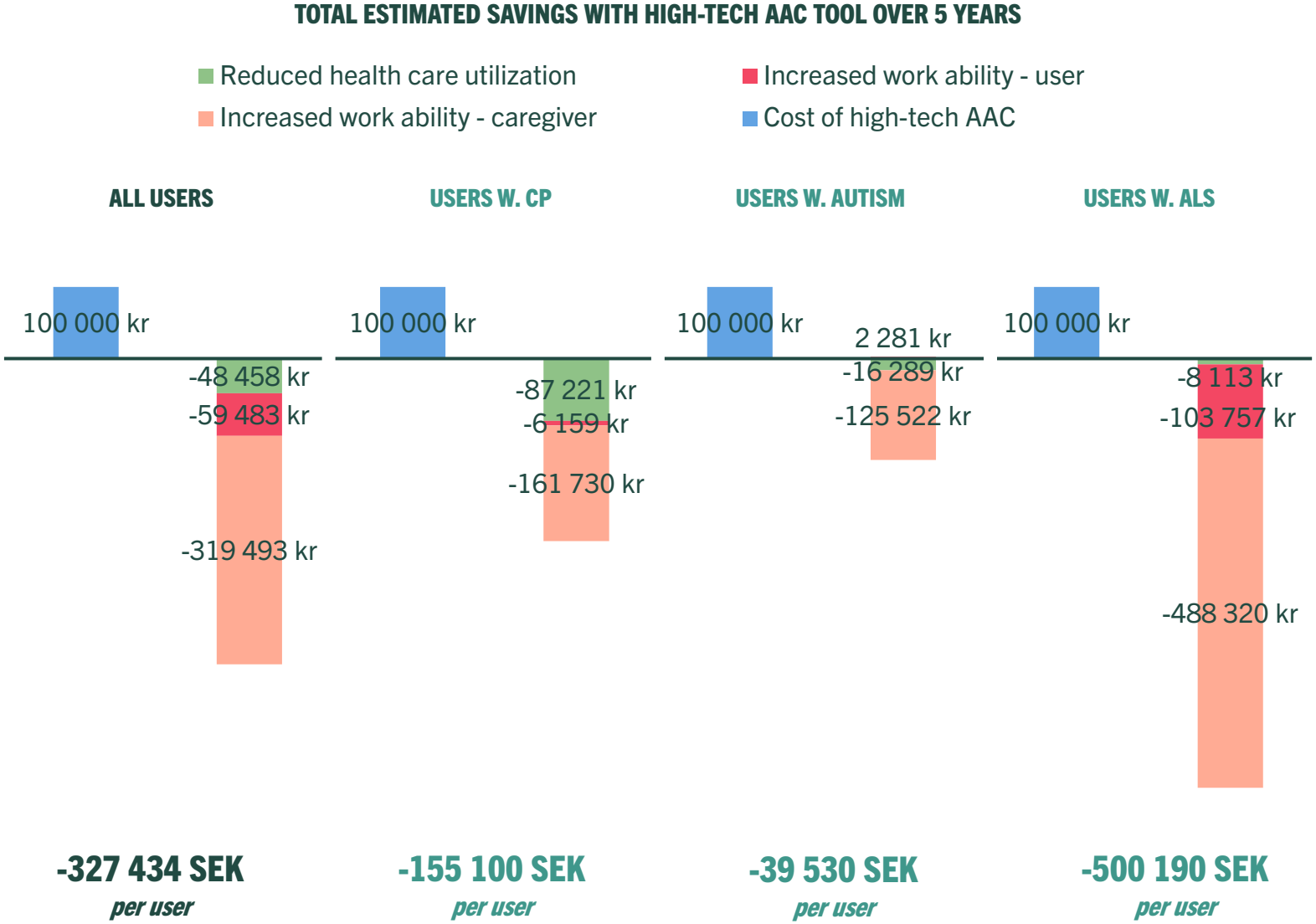
SOCIETY

High-tech AAC tool access shows potential for significant savings to society

Over a 5-year period, having access to a high-tech AAC tool shows societal savings of about 300k SEK per user, *after* the cost of the tool has been deducted.

The largest savings come from caregivers' increased ability to work, especially among the group caring for people with ALS.

For details on the figures and assumptions the health economic model is based, please consult Elin Pettersson at Tobii Dynavox.



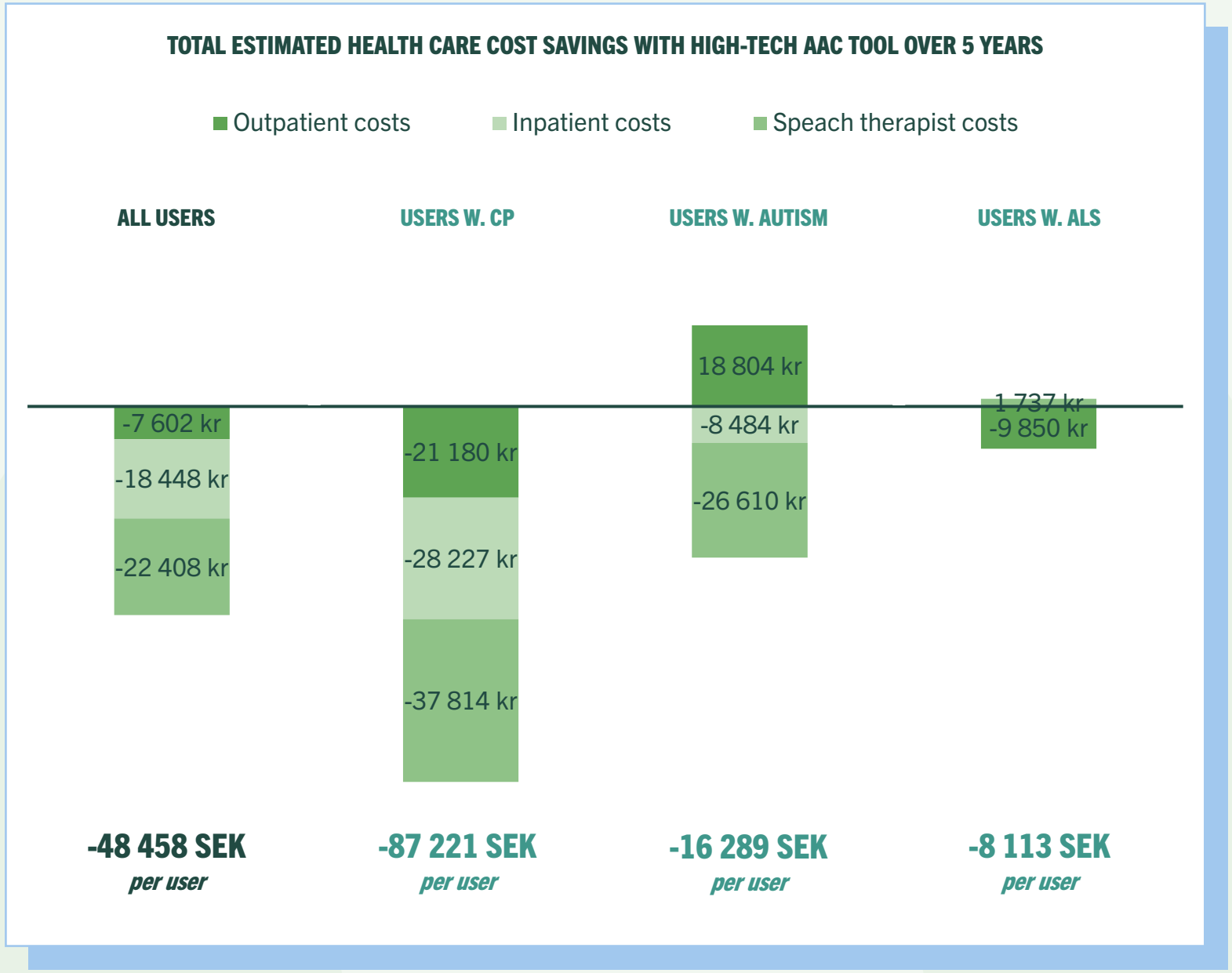
SOCIETY

Health care savings estimated to be highest for users with CP

Overall, the health care cost savings is estimated to decrease by about 50k SEK per user over a 5-year period.

The largest savings are estimated for the group with CP, where a high-tech AAC tool greatly improves precision in communicating symptoms and getting the right treatment for the user's medical needs. The greatest savings are estimated to be speech therapy costs, where there is a predicted decrease in the need to meet them as frequently.

For people with ALS who use a high-tech AAC tool, the estimated savings for health care is small, probably due to the severity and progressive nature of the disease.

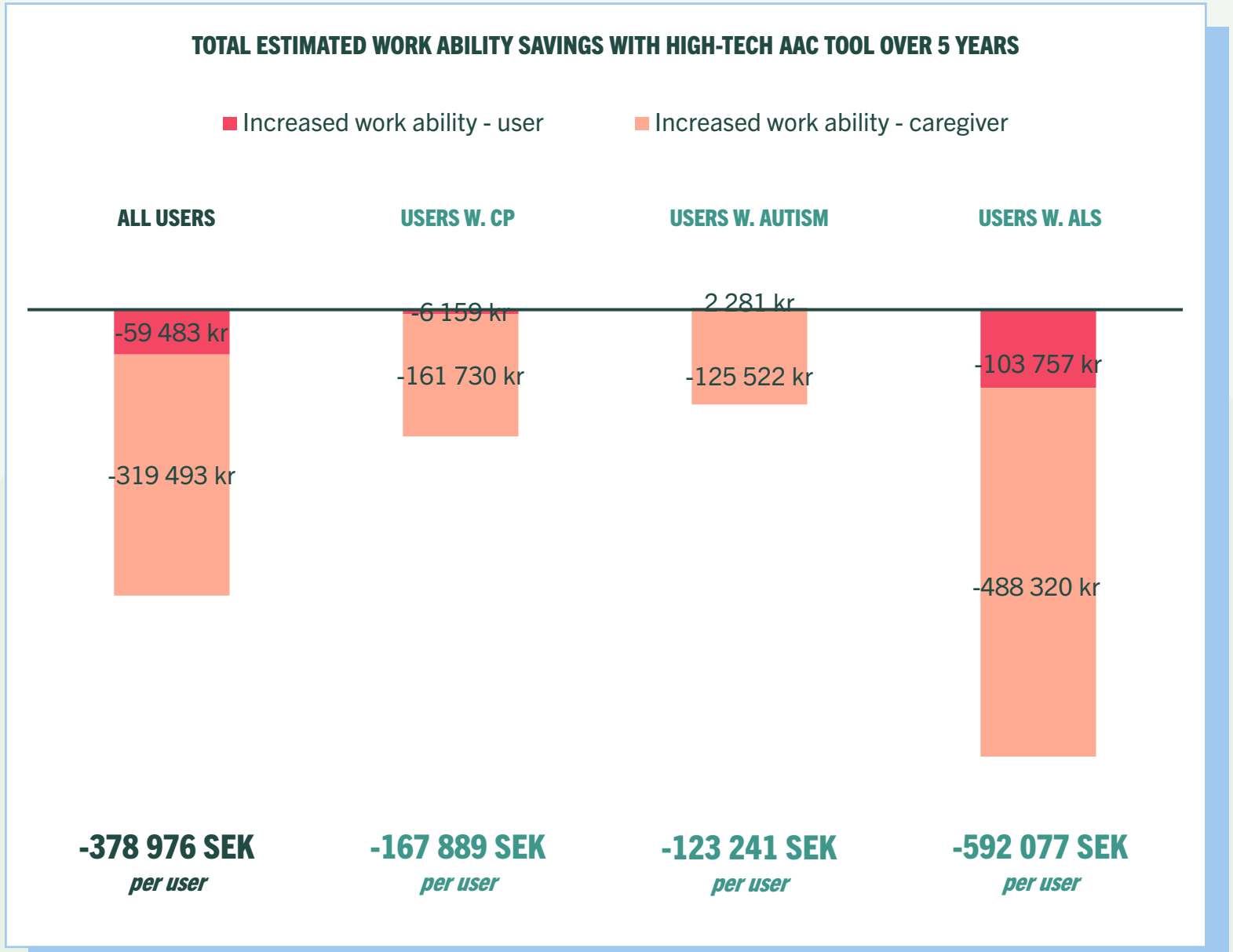


SOCIETY

Largest savings from increased work ability for the ALS group

The largest savings are to come from the increased work ability for the caregivers, who with the help of the tool, can feel safe in leaving the user in the hands of others and be sure they will understand the user's needs. The largest savings are estimated to come from the ALS group, who to the largest extent can communicate with a nuanced written language that is easily understood by others.

This is also the group who estimate the largest increased work ability for the user, where adults can continue doing their job for a while longer thanks to the tool.



The main challenges with using high-tech AAC tools

FOR USERS

1.	Difficult to use in all environments	62%
2.	Lack of patience from others	49%
3.	Dependency of others for usage	45%
4.	Time consuming and tiring to use	35%
5.	The network find it difficult to understand and use the tool	32%

FOR CAREGIVERS

1.	Need to teach others how to use it	53%
2.	Time consuming to manage the tool	40%
3.	Requires time and patience to use	35%

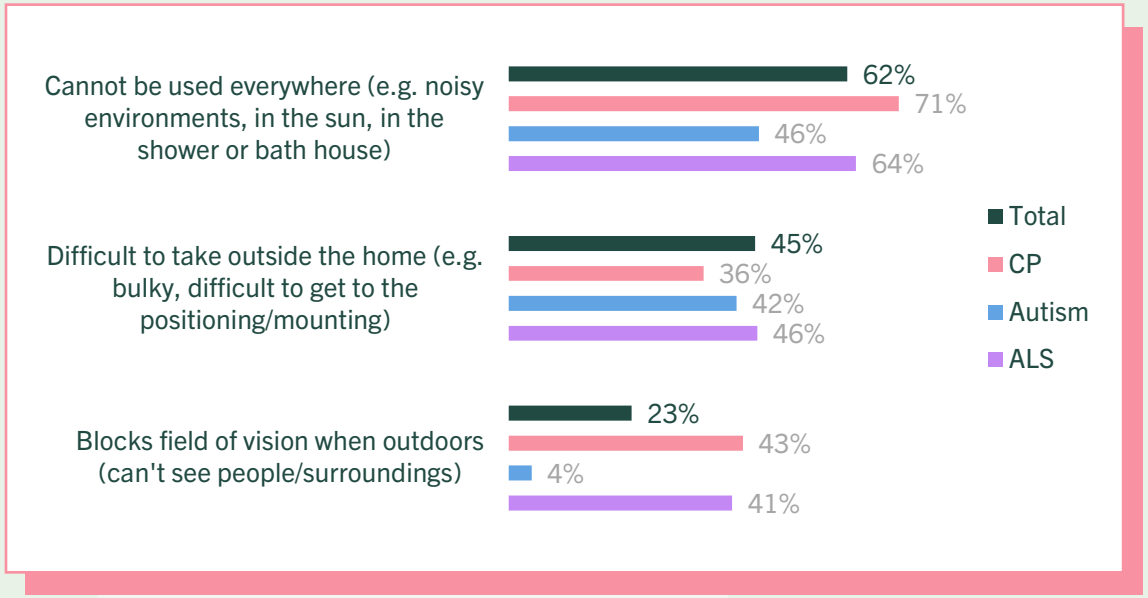
Q: What are the main disadvantages or barriers to using the communication aid for [you/the user]? Base: high-tech AAC tool users and/or caregivers, n = 71 (CP: 14, autism: 24, ALS: 22)
Q: What do you feel are the biggest disadvantages or barriers of [user]'s communication aids for you as a relative? Base: caregivers of high-tech AAC tool users, n = 40 (CP: 9, autism: 18, ALS: 8)

USERS

Difficulty of use in all environments is the biggest challenge with high-tech AAC tools

Many users and caregivers experience limitations with the time and place that high-tech AAC tools can be used. Most mentioned are the difficulties in taking a tool outside, which can make it more difficult to use eye-tracking, and the challenge of positioning the tool correctly when moving on an uneven surface.

For people using eye tracking, the tool can also block their field of vision, meaning it can be a trade-off between taking your tool with you on walks and being able to more freely look around. Many choose the latter, as getting outside stimuli is seen as more important than being able to communicate in that instance.



Q: What are the main disadvantages or barriers to using the communication aid for [you/the user]? Base: high-tech AAC tool users and/or caregivers, n = 71 (CP: 14, autism: 24, ALS: 22)

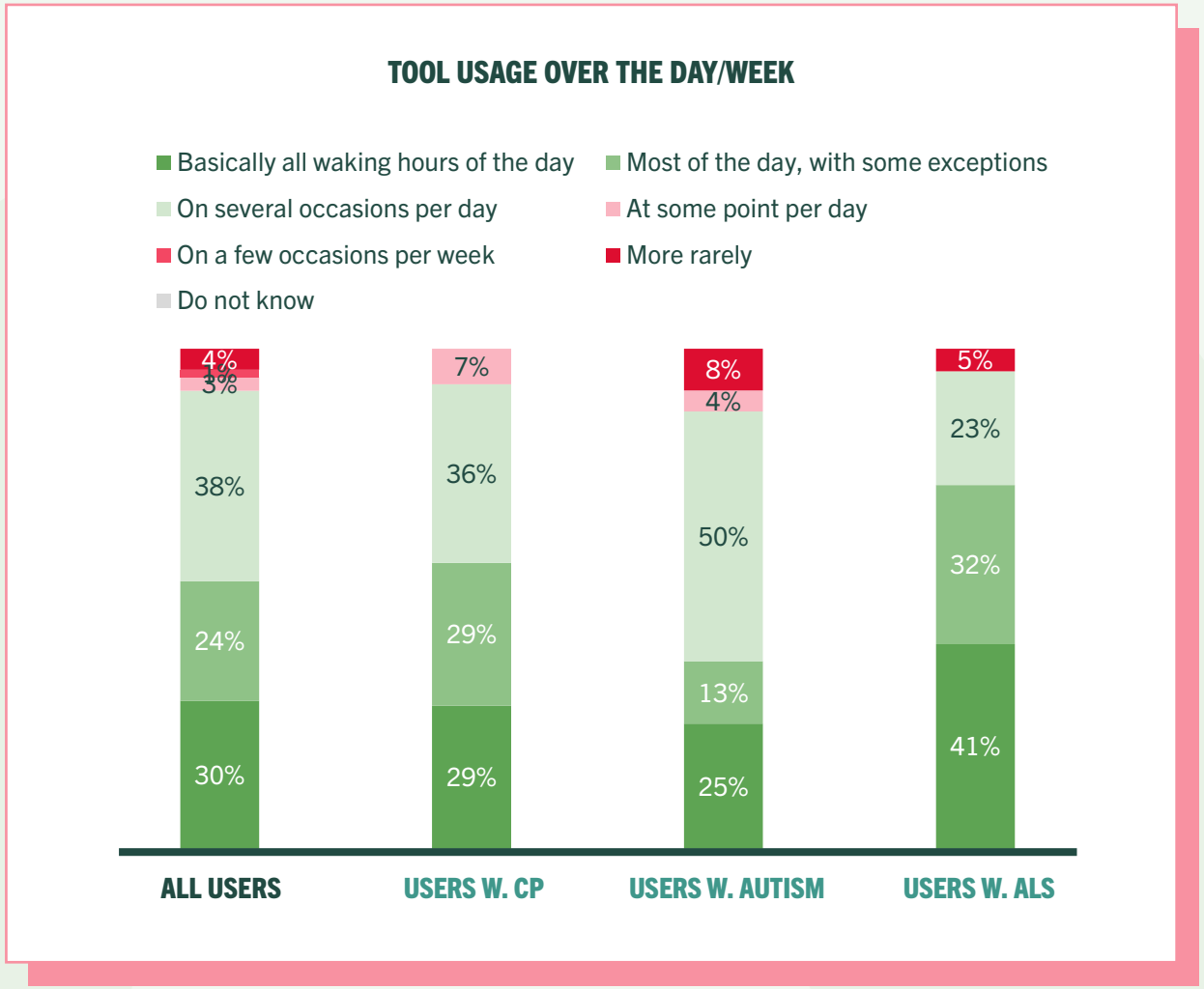
USERS

These challenges lead to the tool not being used all of the time…

About half of all high-tech users need their tool most of the day, and among them, half basically use it all waking hours.

People with ALS use their tool the most, possibly because they were accustomed to a high level of communication before getting their disease.

Autistic people use their tool the least, possibly due to being less dependent on the tool for performing daily tasks such as going to the bathroom or getting a snack. They are probably also more likely to use other forms of communication, like speech and low-tech AAC.



Q: How much does [the user] use [his/her] communication aid? Make an estimate for a typical day/week. Base: high-tech AAC tool users and/or caregivers, n = 71 (CP: 14, autism: 24, ALS: 22)

USERS

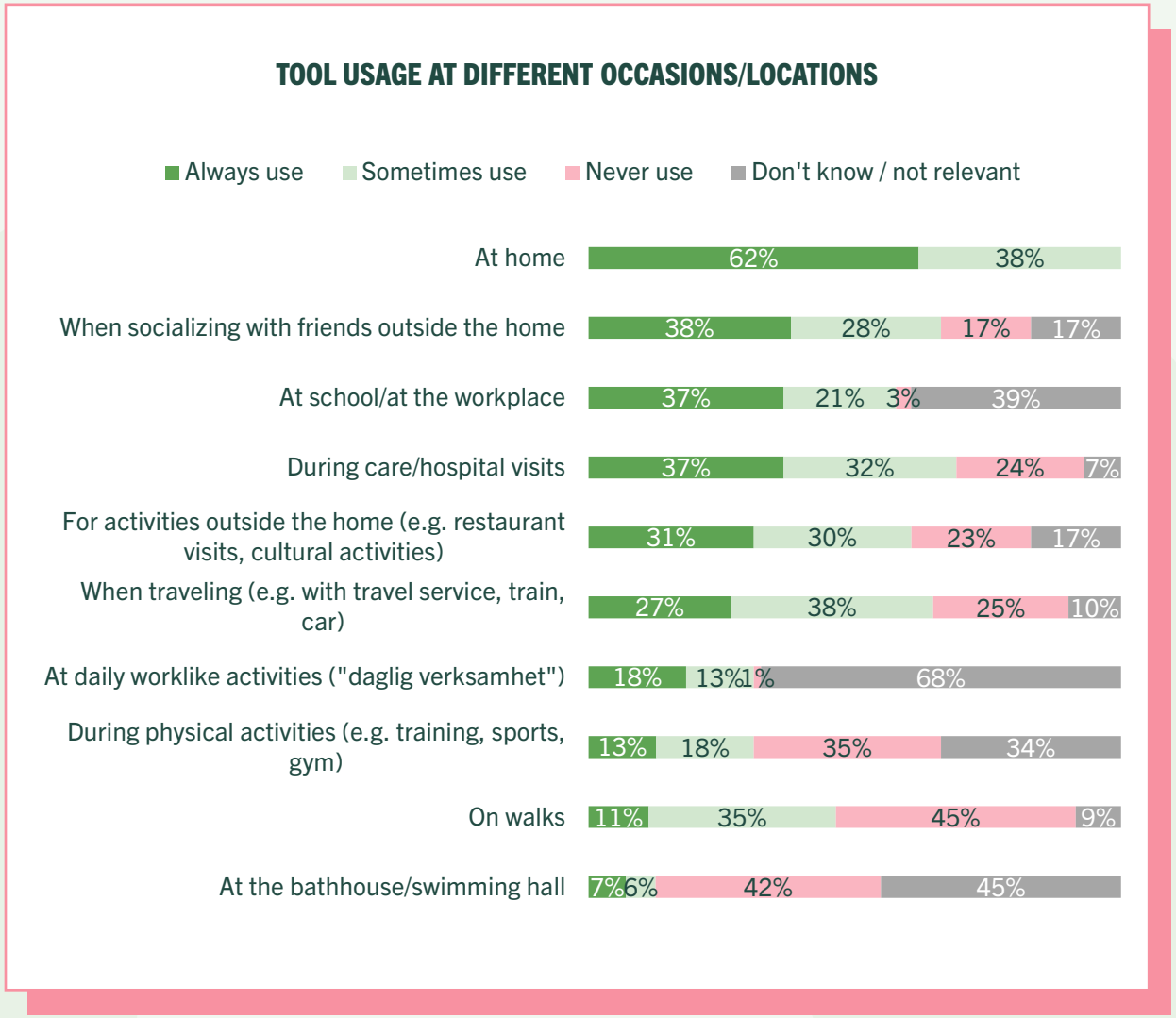
...nor in all places where time is spent most

High-tech AAC tools are mostly used at home, where conditions are optimal. They are also often used at other places indoors, such as in acquaintances' homes or at school/work.

Only about two-thirds use their tool at care or hospital visits. They are most commonly used in such locations by those with ALS, and less commonly so by those with CP.

The tool is also used less frequently for activities that require moving around or being outdoors, for reasons previously mentioned, related to difficulty of use. In such situations, they would probably use low-tech AAC as a supplementary tool, in addition to speech for those who have the ability to do so.

Q: In what situations does/doesn't [the user] use the communication aid? Base: high-tech AAC tool users and/or caregivers, n = 71 (CP: 14, autism: 24, ALS: 22)



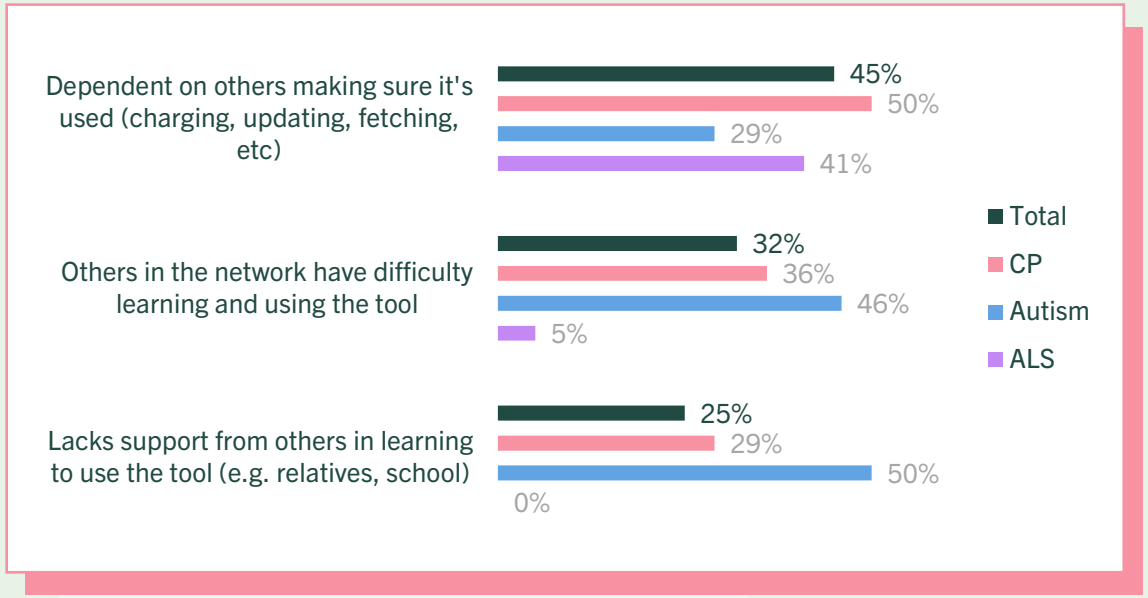
USERS

The dependency of others also limits usage of the tool

Being dependent on others to use a high-tech AAC tool is also a prominent barrier.

For those with CP and ALS, the practical barriers are the strongest ones: depending on others to manage the tool (charging, updating etc.) and physically getting the tool to the user.

For autistic users of high-tech AAC, there is a larger barrier. It's incumbent upon caregivers to educate the network about the purpose of the tool and to actively get them to help in using it. This is due to the difficulty many people have in understanding the benefits for autistic users, who can often communicate in ways other than direct speech. As such, the caregiver is often required to educate the network and to ensure that the AAC tool is used actively.

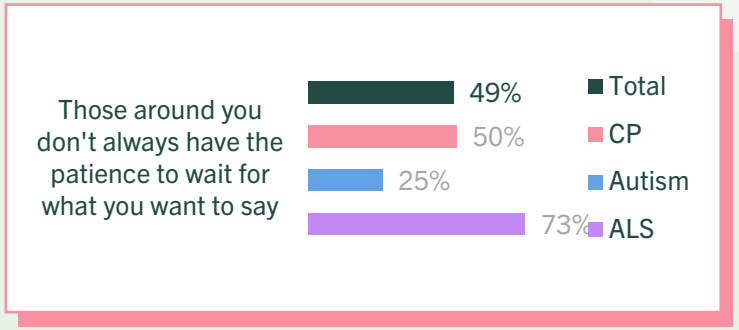


Q: What are the main disadvantages or barriers to using the communication aid for [you/the user]? Base: high-tech AAC tool users and/or caregivers, n = 71 (CP: 14, autism: 24, ALS: 22)

USERS ALS

The patience of others is the biggest challenge for users with ALS

High-tech users with ALS have gone from a life of unlimited ability to speak, to a life where speaking takes a long time, making them much more dependent on the patience of others. This might be why the lack of patience in others is the most mentioned barrier by this group.



Q: What are the main disadvantages or barriers to using the communication aid for [you/the user]?
Base: high-tech AAC tool users and/or caregivers, n = 71 (CP: 14, autism: 24, ALS: 22)

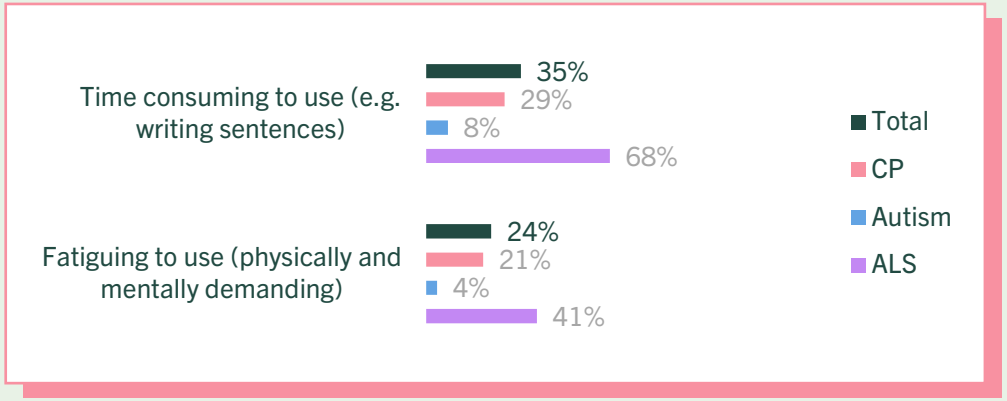
USERS NETWORK

Usage is physically tiring and takes time

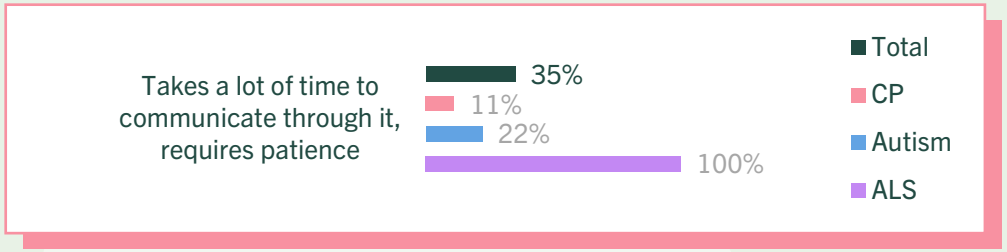
Compared to other barriers, the time and effort required to use a high-tech AAC tool is considered less of a problem.

However, it's commonly mentioned as a barrier by those with ALS and their caregivers, for the same reasons as mentioned previously: this group is used to being able to communicate without limitations, but now need to find a new pace when speaking to each other. This is both frustrating and tiring.

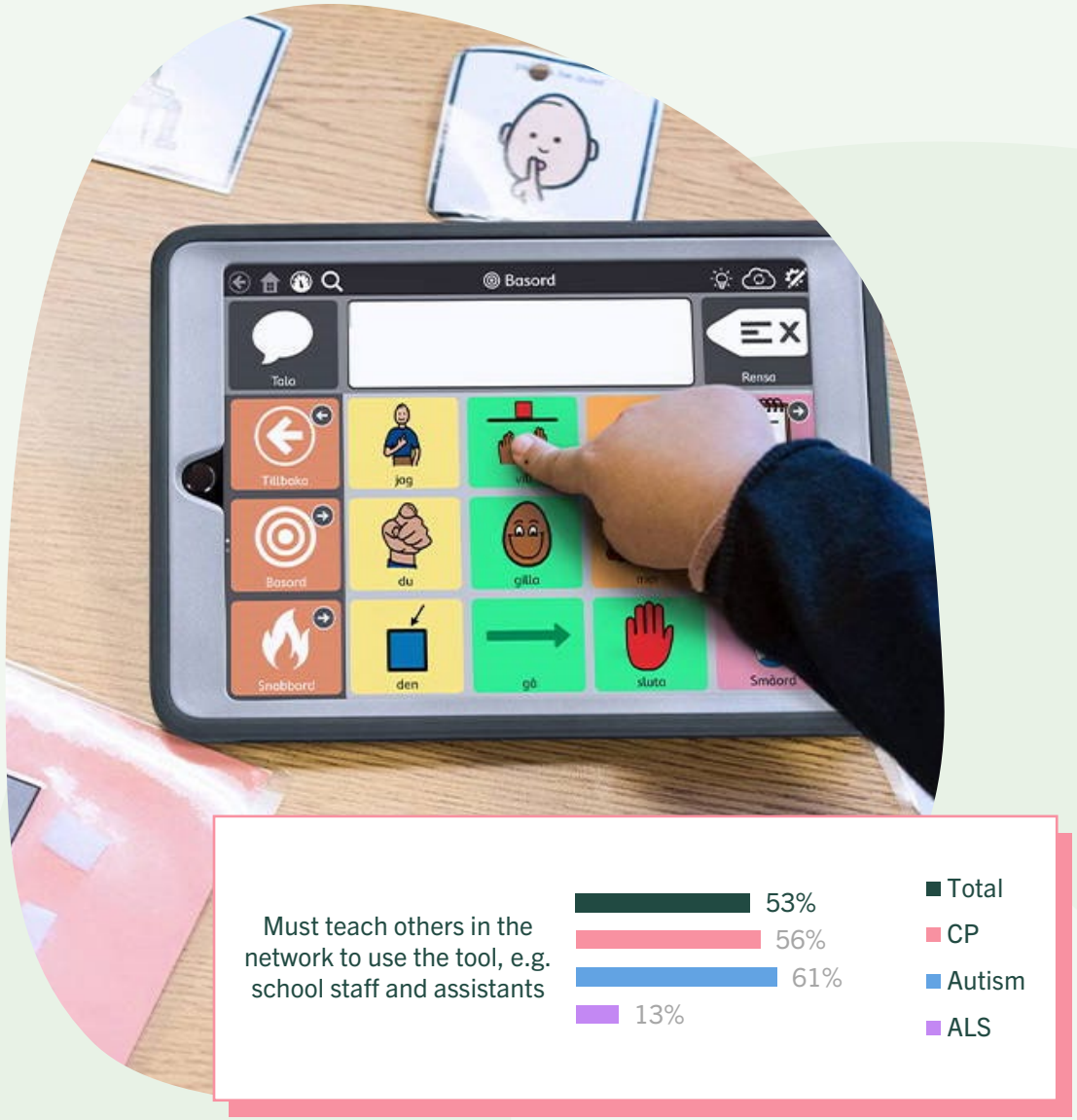
USERS



CAREGIVERS



Q: What are the main disadvantages or barriers to using the communication aid for [you/the user]? Base: high-tech AAC tool users and/or caregivers, n = 71 (CP: 14, autism: 24, ALS: 22)
Q: What do you feel are the biggest disadvantages or barriers of [user]'s communication aids for you as a relative? Base: caregivers of high-tech AAC tool users, n = 40 (CP: 9, autism: 18, ALS: 8)



NETWORK

For caregivers, educating the surrounding network creates the biggest challenge

Caregivers often feel responsible for educating the user's network in using the high-tech AAC tool. Even though they get initial support from their speech therapist, this does not extend beyond the user.

Educating both involves showing others how the tool works, and also making sure that others in the network use the tool as often as possible.

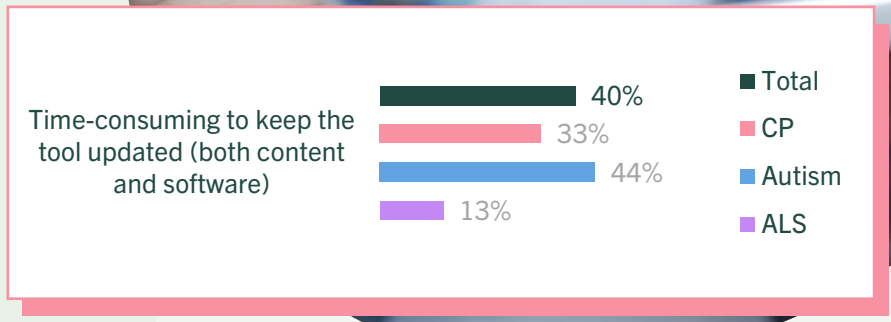
Q: What do you feel are the biggest disadvantages or barriers of [user]'s communication aids for you as a relative? Base: caregivers of high-tech AAC tool users, n = 40 (CP: 9, autism: 18, ALS: 8)

NETWORK

Managing the tool can also be a challenge for caregivers

A tech-savvy network with a natural interest and openness to new technology can mean a real difference in both attitude and actual usage of high-tech AAC. A more tech-reluctant network will need more external support to be able to reach the same results.

Those who feel they are less technical might worry about damaging the tool if doing something wrong. This can result in the tool not being updated or leaving many features unused.



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USERS NETWORK

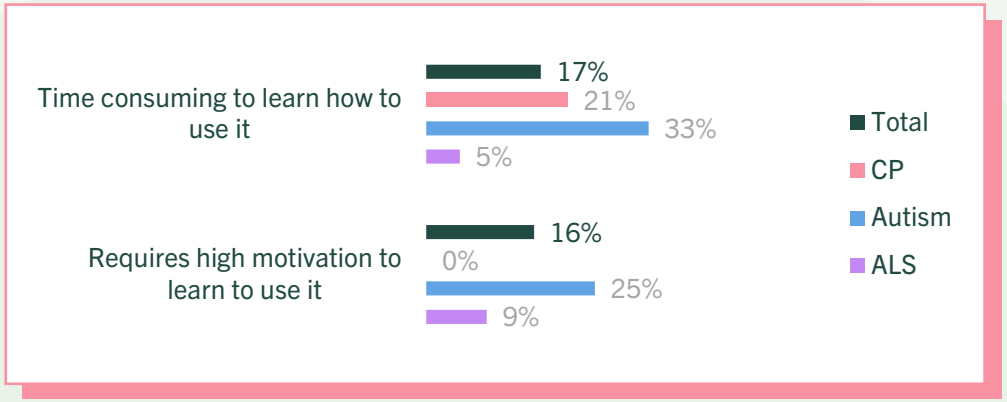
Starting to use high-tech AAC requires high motivation and effort from both the user and caregiver

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.

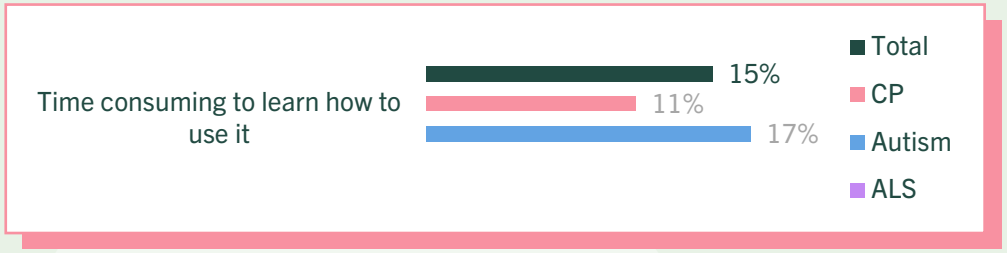
You need patience, both in teaching and while communicating, i.e., leaving the user enough time to take part in the conversation, and not changing the subject or making presumptions. You also need to model usage for the user, to help them learn.

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

USERS



CAREGIVERS



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SOCIETY

The effort required for efficient high-tech AAC usage is a barrier to prescription

The speech therapists interviewed in this study have all been very pro high-tech AAC for users of all ages and suitable diagnoses. However, the challenges of using these tools in a good way create some barriers to prescribing them. It's mostly related to the network surrounding the person in need of AAC, who have to be motivated and willing to put in the time for these tools to be effective.

From parents, we have also heard about speech therapists not wanting to prescribe AAC tools to children until they have started to show other signs of being willing and able to handle them. This is especially limiting for autistic children, where the AAC tool is described as being the thing *needed* to build motivation – a catch 22 situation.

Questions?
Please reach out!

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For inquiries regarding Tobii Dynavox, please contact Elin Pettersson at elin.pettersson@tobiidynavox.com.