Volunteering with a speaking frog

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At least once a week I volunteer in a day activity centre, something that I much like to do. After a year spent to find my place and get to know everybody, another year was spent to study if speaking software with stored text has practical value.

On a first read, skip text in small font.

Our clients[1] are mostly adults with complex disabilities due to stroke, cerebral palsy or multiple sclerosis. About half of them are wheel chair dependent, some are completely speechless and many have dysarthria. Most clients come with special buses and many need assistance with eating and drinking. We offer painting, making clothes, embroidery, woodwork, music, theatre, cooking, internet, table tennis and board games.

Volunteers work with individuals or with small groups and try to be good company. All of us like art and like people and we often meet at lunch. It can be a challenge to talk with, not just to, our clients. Though several clients have speaking software available to them, they hardly use it functionally.

Our paid staff typically is responsible for several people simultaneously and must keep records too. This leaves little time or attention for one-to-one conversation. Clients need not *want* to talk much, apart from having trouble to do so. As a rule clients get along quite well and are happy to see other people. Some call it "my job". One is good at checkers and wins from everybody except the author who often achieves a draw.

Atmosphere

Staff and volunteers rarely discuss patients records that are succinct related to our history. Over forty years ago the centre was started by parents of kids with cerebral palsy on a piece of waste land between Amsterdam and Amstelveen. This also explains we have many volunteers and our management is less involved than elsewhere. Food was free there with excellent cooking staff and a retired programmer did some ict with clients. We refer to it as the good times of old.

There is little expertise on AAC (or Augmentative and Alternative Communication) and no low-tech communication aids are used. It is possible to consult with a speech language therapist or with an occupational therapist but this rarely happens. Some clients visited special education but their records are not shared with our centre, that does not usually share records with volunteers. A rare client is seen by a speech language therapist in private practice.

When I mentioned the low-tech AAC system Talking Mats this met with scepticism. Nobody wanted to learn it, "our patients have already been treated", "we usually get by with experience" and "we never saw much effect from these". When we moved because the organisation downsized a significant amount of expensive switches, special joysticks and keyboards of all sizes was found in a locker.

If AAC is not popular with us, neither is management that has a top down style. But art is, as is quality of life and client participation, there is a course entitled "the client in control". S, who is a client, found a small job to monitor quality of life in one of our institutions. Clients are encouraged to take part in meeting groups intended to give them a say and share responsibility. When I shared copies of Communication Matters, S showed interest, read some articles and considered to do a course on AAC.

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[1] ACB in Buitenveldert, Amsterdam, Netherlands, part of Amstelrade care organisation.

Speaking software with stored text

It took much time to get to know everybody. After about a year I proposed to use speaking software with stored text, a long standing interest of mine. In WriteEasy abbreviation expansion helps to keep a conversation going and contains some jokes. Stored text in menus allows to prepare things to say, text prediction limits keystrokes and Alternative Code is effective with a single switch.

Despite much research in the past and implementations in several speaking communication aids, stored text for rate enhancement is a technology in search of applications with a history of almost forty years, much of it in Dundee, Scotland. Though of impressive quality this research has not led to much functional use. This does not proof much because this type of thing takes time to get right and only rarely is new medical technology rapidly accepted.

Design of WriteEasy was informed by study of relevant scientific literature, by various models, by analysis of logfiles and by diverse experiments. Mostly with the author and with able bodied test subjects, but some with several disabled people. WriteEasy allows open conversations with two speaking computers and single switches as well as prepared conversations with stored text adapted for the occasion.

WriteEasy in the past

WriteEasy includes neither icons nor texting, nor internet access nor environment control by infrared. It appeared useful nevertheless but neither care givers nor distributors saw clients for it. One developer at a distributor rightly said "it can be hard to understand in what *small* a world most handicapped do live". Likewise, funding was impossible with reasons given "nobody needs this, really", "in our experience institutional embedding is required for adoption", "perhaps a rehabilitation doctor wants to do a thesis on this", "we have other priorities", "we only pay to affect quality of life for people with cp".

Many cerebral palsied people are slow readers and are therefore considered unfit for text based communication aids with text prediction. Results of WriteEasy and of related work with intended reading users were disappointing, several with cp indicated that they would rather spend their time otherwise. Clients with a progressive disease were rarely prepared to train or otherwise anticipate on a loss of communication ability. We could not say what *exactly* one might do with WriteEasy and kept wondering what content to store ahead of time and for what precise purpose(s).

Neither rate enhancement nor preparing messages ahead of time need fulfil socially accepted purposes. AAC is not a box of technologies that work out of the box but a field that requires expertise, support, time for assessment, debate, social skills, cooperation, involvement of family and care givers … and budget too.

Most AAC techniques have small and varied target groups and might be used to accomplish many different purposes. They need not be limited to the expression of needs, sympathy and social closeness or to show ones identity. From a technological point of view text based aids need not be restricted to communication with next of kin and care givers or to take part on social media.

Proposal

We needed a few months to agree no particular result could be guaranteed and case managers of involved clients would always be informed. That colleagues were reticent to cooperate is not amazing. Day centres are not paid for to study practical value of communication aids, I could not pay much and could not specify purposes for individual clients either. As I had announced my interest on arrival, to use speaking software was accepted. It had not been asked for and nobody proposed to asses clients' linguistic and cognitive abilities or to involve an SLT. As we had one I did demonstrate and shared info with the occupational therapist associated to our centre. Neither saw clients for WriteEasy.

Originally, I hoped to adapt stored text to specific activities and test practical value with switches and keyboard. See Diagram. To do this well I would have to known some clients well and volunteering elsewhere had convinced me that this was certainly feasible given my background in health care and interest in people and in board games. Possibly I would address unmet needs too. Both ideas rapidly failed. Clients would not take part at all in activities

that required more communication than they could effect and resistance by part of the staff could be clearly felt.
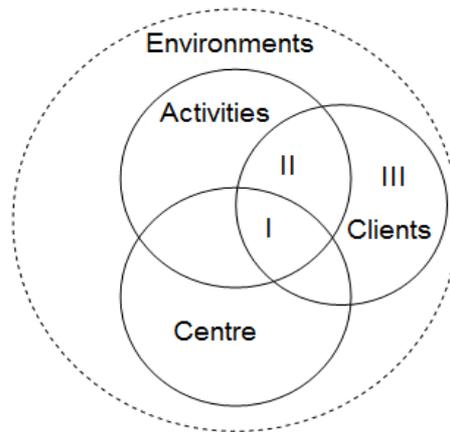
I means a client does some activity in some centre

II means a client does some activity outside a centre

III means a client does something else outside a centre

It is not easy to really understand context of use

Diagram   Circles try to visualize sets of possible contexts of use, leaving out the audience as well as the precise stored data and technology used.

A client using social media or a chess database at home in subset III of our Diagram will need other functions than the same client who tries to talk to other clients during an activity at a centre in subset I.

Embodied speech

When shown, WriteEasy did not have much appeal. To do something about it, a speaking frog was constructed. A blue tooth speaker sits in its belly and communicates with an external Windows tablet. Blue tooth switches are connected to switches leaving its mouth in Picture 1. The tablet also listens to a bluetooth keyboard and mouse and may listen to other switches.


Picture 1. Froggy talks if one knows how to use the switches leaving its beak.

Picture 2. Left and Right switches are connected to blue tooth switches, that sit in Froggy's belly with the blue tooth speaker.

Alternative Code is presented on screen of the tablet where codes can be looked up. Froggy embodies a voice and appeals to curiosity. As one may wonder to say what, to whom and in what context, Froggy does *not* embody a hypothesis that one might easily test. Likewise one may wonder what precisely stored text can do in conversation.

Picture 3 shows a speaking computer intended for motivated clients with dysarthria that can be accessed by touch. WriteEasy offers stored text in menus that can be linked to one another and can also be selected by rather subtle text prediction. On top of the screen an inverted edit line is projected to facilitate use in noisy environments.
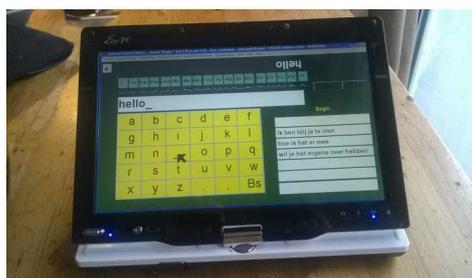
Picture 3. Speaking computer with touch screen and stored text.

Trying out Froggy

Picture 1 was posted on a whiteboard and Froggy was demonstrated, commented on games of chess and of checkers and voiced poetry written by a client, C. This created some interest and a severely dysarthric client that we shall call B chatted using Froggy. I used a mouse to encode and quote stored text, B used a keyboard to type, asked for its name and age, talked about herself too.

We had fun and I used stored text in menus Religion and Programming, also adapted a menu or two. B uses her own voice as much as she can to exercise it. Her passion is making clothes that she designs with evident talent and often uses texting. She declined further experiments with Froggy or with Picture 3 and explained that she wants to focus on her passion, as our clients are taught.

Another dysarthric client N never learned to read and write, among other reasons due to poor eye-sight. He kindly met with Froggy, advised to increase and also store the volume of the speech and we had a second conversation. I repeatedly proposed to learn to write either with encoding or with row-column scanning but he refused to because he feels writing is not for him.

I tried candid use, with the mouse hidden behind my back and talking about thought control. This again was fun to do but did not make people want to really *talk* with Froggy. I proposed to demonstrate active row-column scanning using RcScan to family of a severely handicapped cerebral palsied boy who had learned to read long ago. They declined this offer but we had an interesting mail exchange.

Froggy comments

I consulted with C, our poet, some staff, other volunteers and some other clients. We saw no immediate application for Froggy and little need for open conversations with switches. Assuming that it is a good thing to learn board games, we nevertheless continued our endeavour. Some speaking clients liked to combine playing and chatting with Froggy. We adapted abbreviation expansion to include texts like "tc = take care", "mt = my turn" or "yt = your turn". Character macros like "g = good" were not changed, had been designed to comment and keep in touch.

M has central deafness and uses dysarthric speaking, lip reading and gestures. Picture 3 served to comment on us playing chess with the inverted edit line. In a typical session of twenty minutes that Froggy spoke, it selected 228 characters, 150 of those by abbreviation expansion. Rate per minute varied between zero and sixty chars per minute and felt acceptable. We also used a bloc note and gestures for clarity, to tease and to have fun. Again, communication was multi-modal and not *all* text spoken had been stored beforehand.

When asked would he prepare texts to use himself, M answered he preferred vocalizing, gestures and lip reading. Later that he would rather write something down if people had trouble to understand him. Picture 3 however was fun to use and appeared quite effective too.

Learning with Froggy

Froggy gradually acquired more abbreviations like "gm = good move" and "wd = watch your defense". Patients would address it from time to time and a colleague asked if it could be kissed into a prince. We answered with stored text prepared in advance, "exercise breeds perfection", teasing a bit. We also threw some more jokes and added led lights to its crown and in a way Froggy learned to be good company and fight boredom.

Another speaking client, J, likes to play checkers and talk a bit with Froggy. As she also makes poetry we entered some and had Froggy quote it. This of course she appreciated and may count as use by a client in a centre during an activity. It is *not* use during an activity to assist in conversation by a client who clearly needs AAC to do that kind of thing. So sometimes stored text has to be adapted to the activity, other times to the client, to its audience or to other aspects of its context of use.

Doubts

Our doubts about the practical value of stored text in speaking software for institutes as well as for individual clients were confirmed. The verdict is not final because when considered from a purely technological point of view stored text appears effective in and out of conversations. WriteEasy may be useful for some reading people who want to have prepared conversations with synthetic speech and who share that desire with caregivers, friends or family. As yet, they are hard to find and service. The advice offered by another volunteer to "just help them have a good time" or, better, "try have fun" seems more reasonable than "let us fight the rate problem". But then, we can only do our part.

Froggy logs keystrokes

 Due to budget cuts, volunteers were allowed to visit clients at home. Froggy accompanied me to visit our poet, C, who wanted to learn play chess. He has cerebral palsy since his birth, speaks, learned to read at a young age from his mother, is wheelchair dependent and had not attended for a while due to stress with lack of sleep. He learned very little in his special school as he spent most of his time gaming related to lack of motivation. Also, he wants to work for money and we agreed I would come back in a week and pay him to help test Foggy.

 Next week we talked a bit and played chess assisted by Froggy. We use simple exercises from a chess course by Gude, like to put eight white pawns and two black rooks on the board and try to prevent pawns to promote into a queen. To document effectivity of Froggy we logged keystrokes typing with two fingers and text spoken in conversation, see Table 1. This time, communication was hardly multimodal and I never spoke except through Froggy. Therefor this illustrates effective use of WriteEasy in conversation.

1314 spoken length, 246 words selected,   779 chars chosen, Space included,   211 Spaces

 155 Macros, 26 of those word macros the other 129 character macros
 806 Total macro length, 211 length of wordmacros, 0 Length stored phrases in menus

 257 Length of predicted words and phrases
 111 Spoken by repeated space(s)

  26 Total hands-on time in minutes   50 Characters per minute

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Table 1. Edited logfile of use with a keyboard and two finger typing while playing chess with C.

 Table 1 does *not* document use of stored text in III of our Diagram because Froggy is not a client and neither is C, nor me. Also, this time no stored text was selected from the menus. I found too hard to attend to the play *and* attend to Froggy *and* use a single switch. So this time, we stuck to the keyboard.

Froggy logs a single switch

 At our next meeting we started with an open conversation, me using a single switch and C talking. This felt a bit awkward and not always convincing too, but it worked. Little stored text was used, probably because we did not agree on a subject before we started talking. Had we done that, even more impressive figures would have been possible.

1129 spoken length, 184 words/phrases selected,   527 chars chosen, Space included

 44 LMB Left Mouse Button, 1189 RMB Right Mouse Button,
 45 Sustained Dashes, 104 length Sustained Dashes
 73 Keystrokes,   36 Backspaces,   141 Spaces

 120 Macros, 14 of those word macros the other 106 character macros
 644 Total macro length, 134 length of wordmacros
 299 Length of predicted words and phrases, 96 Length stored phrases in menus
 167 Spoken by repeated space(s)

 26 Total hands-on time in minutes, 43 Characters per minute, 1.1 Clicks per character

 Pauses: 140/280 milliseconds.

Table 2. Edited logfile of use with a single switch, some codes entered with keystrokes [and] and Alternative Code in open conversation. We may calculate 1189+44+73-45 = 1261 clicks to select 527 characters and speak 1129 characters in 26 minutes.

 We intend to continue researching with C, who is a *speaking* man with cp who wants to learn Alternative Code and showcase Froggy himself.

Summing it up

Speaking software with stored text was playfully tested with a speaking frog. Embodiment helped to showcase and do patient related work in a day activity centre, where we needed much time to align with staff and with individual clients. Froggy helped having fun when playing board games and when reciting poetry written by two clients. Therefore, Froggy helped to explore practical value of stored text in day care and in the process addressed some unmet needs too. Little use by intended clients in conversations was documented and we still try to learn from that. As to what next, all suggestions are welcome.

Author Joris Verrips, MD, researches speaking software accessed by switches and re-use of stored text. Mail at j.verrips@planet.nl. This www.depratendecomputer.nl/froggy.pdf has much more detail than www.depratendecomputer.nl/shortfroggy.pdf.

Bias Due to methodological problems, researcher bias and change of plan being most important, no hypothesis testing is possible.

Criticism As we almost failed, to include some criticism seems reasonable.
First and most importantly, I did not start with needs of care givers, individual clients or the care organisation as a whole. None of this would have worked. Also, needs tend to change over time. When a non-speaking client moves or signs, typically a care giver approaches him or her and finds out, based on experience and on yes-or-no questions, what needs to address and how. Often background knowledge plays an important role and a grunt or a nod may establish consent. One changes the position of a wheel chair dependent lady before assisting her to drink or helps take off a coat in the morning. These communications are multi-modal, fulfil socially valued purposes and can not be redesigned at will. Still, if you do not address somebodies need one may ask what is your plan.
Second, clients had a say, but did not have control, they neither owned this technology nor paid for it. So trying things out could not easily align with their personal goals. At one time, C told me "if you want to know how it feels, just spend one day in a wheelchair and try to move from a to b with public transport. And come back later".
Third, I just wondered about practical value of stored text, did not have a clear hypothesis let alone an inkling about what clients need most. Some would answer "a day at the beach" or "better transport". Some comments made us wonder if the rate problem is a clinical entity at all and this is important because of its role in the design.
Fourth, different designs than WriteEasy are possible, and might be tried out. Instead of access by a single switch and stored text as I implemented myself, one may opt for gestures, eye-gaze and icons, select narratives created by "cognitive computing", use linked grids accessed by touch only, discuss video and pictures with low-tech, use low tech diaries for better quality of care or use one of many commercially available communication aids that remember used phrases.
Fifth, our research base is incomplete to put it mildly. Dressing up is typically understudied in AAC though very present in real life.
Finally, if volunteering in some centre and with some clients for some purpose *had* failed, other approaches need not. Inversely, what worked in Buitenveldert, Amsterdam, by a self-appointed researcher volunteering with optimism, need not work elsewhere when experienced professionals try realism instead. These experiences need not be reproducible at all and if I got along with caregivers, was allowed to assist with meals and with art work, and did not have to bother about management's priorities, others may be less lucky.

Little of the criticism above will shock an informed audience. Joan Murphy for one documented little functional use of many communication aids and that much service and much exercise is needed is clear from the literature on AAC. Authors such as Mick Joyce and Annalu Waller have stated quite convincingly that better aids need involvement and ownership of the intended clients. Janice Light once quoted studies of siblings who suggested aids designed for specific functions, like to spend time at the beach or to visit a zoo. Todman, File, Alm, Higginbotham, McGregor and others saw great possibilities of stored text, but little actual use. Work by Patterson suggests use of social media may be of greater interest to dysarthric adults than support of conversation, but needs follow up. And to involve care givers, institutions and next of kin in AAC seems also problematic elsewhere.

More details WriteEasy is described in www.depratendecomputer.nl/writeeasyagain.pdf including directed graphs of linked menus of stored text, partial design rationale, discussion of background and

references, It is a set of solutions intended for rather various problems and can be downloaded from www.depratendecomputer.nl/onlywriteeasysetup.exe. WriteEasy allows to personalise stored text, to select with a single switch, learning text prediction and abbreviation expansion most of it highly customizable. Default stored text is available for Dutch and English and can easily be adapted. RcScan implements variants of row column scanning, Alternative Code, text prediction and abbreviation expansion, an overview is www.depratendecomputer.nl/manual.pdf and it can be downloaded from www.depratendecomputer.nl/setupnewrcscan.exe.

Ethics We did not consult with the ethical committee as Froggy, of course, agreed his picture would be used, as clients could refuse to take part and as we do not have one either.