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Chapter

"One Day, Will This be also My Land Where I Belong?": A Narrative Participative Study with a Young Woman's Experiences of Reading and Writing Development, Having Severe Speech and Physical Impairment

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Abstract

The backdrop to this project is earlier studies showing a plateau in children's, with severe speech and physical impairment (SSPI), literacy learning at beginner's phases. The study has a transformative, participatory, and inclusive research approach. Research questions focus on what contributed the most to continued lifelong literacy development, according to existing research, and a young woman's narrative. Her chosen significant experiences and processes were investigated through a narrative inquiry in an e-mail dialog. A contextual case-based analysis was made by the first author with member checking with the participant/co-author. Findings are the importance of lifelong identity building, functional assistive technology at school and home, communicative relationships, creative expressions and long-term hopes, goals, and dreams. Conclusions for literacy learning struggles and possibilities of inclusive educational adaptations are discussed and at last, there are recommendations for future research.

Keywords: severe speech and physical impairment (SSPI), augmentative and alternative communication (AAC), literacy, reading, writing, participative, inclusive, transformative, capability approach

1. Introduction

Having severe speech and physical impairment (henceforth SSPI) involves you need reading and writing skills more than so-called able-bodied because by means of an alphabetic code communication and learning possibilities open. Furthermore, at present, the digital world offers any literate person new possibilities [1], especially with augmentative and alternative communication (AAC henceforth) via high-tech devices [2]. Through personal empowerment and self-advocacy, you can become an active member of society, and via inter- and intrapersonal communication, intellectual, emotional, social, and vocational development becomes reality [3]. "Providing effective instruction in literacy skills is truly the single most important step in empowering individuals with AAC needs to meet their personal goals and attain their full potential" according to a source in [4]. This quotation stands for nowadays even more than when it was written 30 years ago.

Nevertheless, few students challenged with SSPI learn to read at all; even fewer progress beyond beginner skills according to a longitudinal study with children 6, 9, and 12 years old [5]. Children's positive literacy development stopped after the first 3 years, and a decrease in IQ points was also found at 12.

1.1 Preschool

The child's first learning community outside the family is the preschool learning environment. Children's emergent and early phases of literacy learning need to be well-supported from the very start. Research shows nevertheless that already preschoolers (with SSPI) have fallen behind [6]. Struggling literacy learners (with SSPI) confront different environmental and intrinsic obstacles in the process of learning to read and write [5, 7–9].

1.2 Low expectations

Several studies show educators', augmentative and alternative communication-AAC experts' and parents' lack of confidence in literacy success for these students, which can lead to a small proportion of classroom time dedicated to literacy activities [5, 9–14]. How do teachers support children to build expectations of literacy learning in environments that do not believe in nor value their achievements in reading and writing? The negative spiral, which is initiated by ability factors and sustained by avoiding tasks [15], can eventually lead to a self-fulfilling prophecy [16]. No struggling reader makes progress while waiting for readiness factors to appear [15].

1.3 Intersecting ability

About intersectionality and student outcomes Grant and Zwier [17] found that the intersection of ability is understudied. Students intertwining identity axes are basic features for the increase of equity in learning environments. Few studies including children with disabilities are presented in two developmental journals since 1996 [18]. One found reason is that children having a disability seldom are included in studies concerning other issues than the disability, for example literacy. If the argument of the researchers was a 'normal' population, were children scoring IQ over 130 then consequently also excluded? In the USA 15% have a disability, why studies with a realistic population view include everyone [ibid].

Norton and De Costa [19] emphasize the learner's experiences in an unequal social world. Therefore, they ask us, researchers to take into account the following interrelated three decisive questions:

- Which are under-researched social categories?

- To enhance the understanding of the mutual relations learner-teacher-social context, what research is adequate?

- Which research populations need deeper analysis?

This current project aims at taking on those three challenges, with a marginalized group in the field of both disability and learning, namely young people having severe speech and physical impairment, who are engaged in a narrative dialogical inquiry about own experiences of continuing development of their reading and writing. Romero [20] guides us in creating these decentering interactions and practices in pedagogical spaces. In her study with focus groups, she used self-reflexivity in dialogic and multiperspectival ways, in search of potentially productive spaces in the forgotten, overlooked, and absent forms of expression. She also emphasizes using intersectionality-like thinking [21] to open these complex interrelated meanings of multiple forms of diversified expression. The last advice in relation to this, is to continue interrogating identity and language relationships in the classroom, as students tend to avoid decentering and looking at the margins.

2. Aim and methods

A literature review, focused on the findings on children's (with SSPI) struggling development of reading and writing, was combined with a narrative participative inquiry via an e-mail dialog. A contextual case-based analysis was made by the first author with a member checking the narrative's interpretation with the participant/co-author.

Another aim was moving subjects from the margins to the center, listening to the learners' own experiences of learning to read and write, in this case listening to "voices of the students with SSPI" ([13], p. 41). Grounded in this citation from an earlier case study's participant Emil: "I think it's a very good idea of yours to want to know more about how I read and write." ([14], p. 25).

A decisive point of concern since earlier experiences [14] was that the participant's investment of time and energy was counted to be more rewarding than exhausting. Therefore, the method of writing via e-mail was seen to best meet the individual accommodations and continuous readjustments. An important analytical bias to have in mind is 'the privileging of orality' in communication studies ([22], p. 54).

3. Findings in the literature and narrative

3.1 Time on task

A study shows only 10% of the students challenged with SSPI chose a literacy activity during the school day [23]. In two other groups of children (those with intellectual disabilities and those without any disability), 50 and 72% of children respectively chose literacy activities daily. Concerning reading on your own every day the figures for the groups were 3, 40, and 39% respectively (ibid). The need for larger quantity of instruction and learning possibilities is evident. "At a minimum, students who use AAC may benefit from the same proportion of activities in each of the literacy categories" ([24], p. 32).

Attitudes towards the learner are significant for both the quantity and quality of the literacy team's instruction. A survey of special education teachers' opinions related to literacy instruction for children with severe disabilities using AAC, concluded the need for preservice and in-service training to develop teachers' attitudes towards seeing potential capabilities and raise expectations [12]. Another study addressed the speech and language therapist's perceived preparedness and attitudes and presented generally negative opinions about teaching literacy skills to augmented speakers [10].

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3.2 Content-curricula

Studies indicate that all efficient literacy education needs an integrated balanced approach with combinations of more authentic and skills-based literacy activities, for our challenged group as for everyone else [24–27]. As for nondisabled children, important predictors of literacy development are shown to be phonological skills and working memory [9, 28].

A 6-weeks intervention study with an integrated approach of word identification and AAC instruction selected three participants out of the eight who met the criteria for the study [29]. When communicating with his/her speech generating device - SGD henceforth, the person is at the same time practicing reading frequent words. This makes the print processing speed increase. The participants worked with 75 digital lessons of the program "Literacy through Unity Study". All made progress with the identification and generation of words and developmental spelling, as well as expressive communication.

3.3 Transparent orthographies

Our context of Swedish-"speaking" learners using AAC, leads us to explore possible similarities and differences to learn from the studies with predominantly English-speaking literacy learners. To support the transference of knowledge, Erickson and Sachse [30] describe the literacy learning process of Seymour [31] as a base for comparisons, and its implications for German and English learners. This theoretical framework consists of four phases:

0: letter-sound knowledge.

1: foundation literacy.

2: orthographic literacy.

3: morphographic literacy.

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Phases 0 and 1 can be easier for literacy learners in more transparent languages. Phase 2 could be more natural to deep orthography languages (like English) because you already employ a lexical-logographic reading strategy instead of alphabetic coding. English studies focusing on the last two phases were however not identified in this project. There were German studies on writing alone that show morpheme-based instructional approaches had a positive impact [Walter, Schliebe and Barzen, 2007 source in 30], and combined with reading [Kargl, Purgstaller, Weiss and Fink, 2008 source in 30].

3.4 Internal speech

To process phonologically when reading, nonvocal people use internal/silent speech. On the way to learn to use your internal speech, the first step is to make the students aware of their inner voice through encouraging them to "say it in your head", and, for example, singing songs with subvocal letter naming [32]. The second step when awareness is present, is reading meaningful texts to practice using inner speech. Here practicing "subvocalizing" with the three steps of the nonverbal reading approach – NRA – could be another way [33]. In an intervention study teaching students to use their internal speech, four students learned to use a three-step decoding strategy [34]. Any possible vocalization was encouraged for checking active participation. If vocalization was impossible personally chosen motor indicators could substitute the voice. These also had the role of reminding the student of the different steps in the decoding process. Six months after intervention all four participants had been observed using the strategy independently when encountering unfamiliar words in texts. Another study that shows the importance of developing internal speech, showed different results on a visual rhyming task for children with CCN and children with typical development [35]. Results on the other eight tasks (which included verbal support on phonological awareness) did not differ between groups though.

3.5 Computer-assisted literacy learning

With the accessibility to computers, assistive technology, and the digital revolution of the last decades, the possibilities for literacy learning are expanding. Synthetic speech is a support in literacy learning for the students with SSPI [6, 35]. The study as described above [29], successfully used computer-assisted instruction – CAI. In another study, the nonverbal reading approach – NRA was combined with CAI [36]. All three participants made progress in word identification. Working with individually designed PowerPoint (PPT) slides, students were able to repeat word exercises independently and teachers could use their instructional time more effectively. NRA can be used both for shorter individual words and dividing longer words into parts and decoding them, and PPT is available and easy to handle. The study showed that the reliability of technology is an important issue though. Another visual issue, in combination with computers, is the result of a case study on spelling [37]: Their participant preferred visual print feedback, which might indicate a stronger visual learning focus in general.

With the last decade's growth of internet's social media and speech generating devices-SGDs, through the implementation of high-technology AAC systems literacy and communication have become a focus. Myers suggests that literacy and "technology skills" ([26], p. 274) should be integrated. Her four participating students could all work independently on the computer with more targets after intervention. For example, the students wrote a newsletter to their parents about the topic of the week. "By using the capabilities of AAC devices, the literacy skills of both the user and the people with whom he or she communicates can be effectively and functionally developed." ([38], p. 171).

3.6 Formative assessment

Every student needs to receive instruction in relation to his or her current abilities [39]. Teachers need to know their students' individual proximal zone of development in their literacy learning, to be able to help them. Unless the surrounding classroom environment also is assessed and changed, the education and students´ formative assessments cannot be successful. Malmqvist puts it in these words:” The pupils’ results must obviously be related to given educational conditions as well as their individual pre-requisites.” ([40], p. 47). The study found difficulties in getting students to participate in tests. The teachers argued that the test situation could be a negative experience for the students or that the student “was not able to participate” [ibid, p. 15]. We are here reminded of the documented low expectations (see above Section 1.2). It is important to offer” repeated authentic literacy learning opportunities for all students, “as learning takes a different amount of time for everyone ([24], p. 33). Maximizing time dedicated to learning and intensive individualized instructions in areas of critical skills are necessary, the same authors continue.

Altogether, a profile of the student’s educational literacy capabilities, emerges. The teacher can then balance instruction and direct quantity and quality of the teaching. Ferreira [7] seeks the area of greatest instructional need. This area receives the instructional emphasis and is addressed by the most highly qualified personnel available at the school. The educational implications for learning, show instruction with others is important [40], as in all three studies pupils were educated by their school assistant (para-professional aid) outside the classroom. Finally, also Erickson and Sachse emphasize the need to address the complexity of literacy learning as for example relationships in the classroom and the trust in children’s skills [30].

3.7 Learners’ own voices

Most of the existing studies lack the learners’ own voices. Only Myers [26] and Swinehart-Jones & Heller [34] asked for the participating children’s own reflections: Myers’ participants in an intervention study with an integrated approach to literacy, communication, and language, changed opinions after 4 weeks when re-answering the same questions. After intervention they said that: they did not like their parents to answer in their place, they liked reading books on their own and they liked creating stories and seeing them in print. Changes in the students’ own perceptions of themselves as readers and writers were shown after only 4 weeks. The peers’ role modeling was also reported as an important factor.

In a study about Nonverbal Reading Approach-NRA both students and teachers agreed on the following evaluation ([34], p. 141):

> *“Students with severe speech and physical disabilities can learn to read.”*
>
> *“The NRA is easy to use.”*
>
> *“Internal speech helps decoding.”*
>
> *One participant wrote: “Finally, someone knows a way to teach me to read.”*

3.8 Narrative about my literacy learning, by Louisa, 20, with SSPI

Here are the findings about what Louisa experienced as the most important contributing aspects to her reading and writing development. These are intertwined in the narrative and therefore, presented in chronological order. The narrative’s found themes were lifelong identity building, functional assistive technology at school and home, communicative relations, creative expressions and long-term hopes, goals, and dreams.

"During my entire childhood, I always attended the closest local preschool in my living area, and later the nearest elementary school, as my playmates and neighbours of the same age attended. My parents chose this, opposite the advice from health service providers at the hospital. I started preschool at 10 months in an integrated class with children up to 5 years of age. After one term I got my own (pre)school aid who supported my needs, and the older children also took good care of us younger ones. My parents have told me that when they came in the afternoon, they often found me on the sofa reading a book with the 5-year-olds. At this preschool the teachers also used signing as a child with Down's syndrome was in the class before I started. During my childhood, I did not look upon myself as disabled. I always played with my peers, using walkers both inside and outside. My school aid also supported me in the play. There and then my self-identity started to be created. An identity that was not disabled.

My first augmentative and alternative communication (AAC) tool was home-made pictures organized in thematic topics. Soon I got a picture communication symbols- PCS-board from my speech and language therapist (SLP). This picture and symbol based AAC tool was very limiting and frustrating for me. I eye pointed or used a head laser pointer. The communication board was 5 paged with around 200 PCS-pictures, with the alphabet and numbers on the first, then pronouns, verbs, adjectives, and nouns. My mother tongue or first language was also "Louisian" which meant lots of nonverbal expressions, such as movements of eyebrows, mouth and lips, eye gazing, over all face mimic and muscle tone and voluntary movements in all my body. I started to learn to read and write, but I did not realize then that it would be the key to my whole life. In the rear mirror, I now understand that some important persons in my life predicted or at least hoped for this early on. When I started learning initial sounds of words, it helped a lot to avoid misunderstandings and speed up communication.

At 5 years of age, my therapists wanted me to start learning Bliss. My parents then asked who would teach me, and the answer was them. Due to their being unqualified at that language and as I was already gripping many sounds and letters, they chose to wait and start Bliss later if the alphabetic reading and writing would fail. Bliss is picture based and not like Swedish phonological. I also got a head mouse as steering assistive technology (AT), which still is my best friend, and a special sounding qwerty. Now I could explore the letters and sounds better on my own. Before I used a large single button to push "enter" at the computer, and someone else steered the mouse to where I eye gazed. I played lots of learning games this way but now I could play by myself! When I started to learn to write on the computer and eye gaze at the alphabet board, communication became so much smoother. Especially, easier for the communication partner, and less frustrating for me.

During my six preschool years, I had many different school aids. Some were good and some were less professional. Even then it was important for me that they kept in the background and only interpreted whenever I said something. Some aids did not understand this interpretive role, and instead took too much attention and space. I remember one incident at a school assembly in the hall. We met once a month the whole school and I loved to sing together. I was seated with help on the floor with my class, the aid supporting me from behind. That day I got so irritated when my aid also sang along, because I felt the assistant was not there "in person." I did not want an extra person behind me. Therefore, I told the aid to stop singing. She got angry with me and said that everyone could sing along at the assembly. All the teachers agreed too. When my grandmother came to pick me up that afternoon the aid told her about what happened and my behaviour. My grandmother agreed as well and confirmed their point of view. Nobody asked me about my perspective or my feelings and experiences. Nobody bothered to understand why I said as I said. Looking back, I see this was an important experience for my development with assistance. Still, until this day, it hurts to think that nobody confirmed or was able to see it from my perspective. I will probably never forget this experience. It felt like abuse. Today, I lecture at teacher programs in inclusive education, to contribute to better comprehension and self-critical reflection. Teachers need to learn to listen better, even to children without oral speech. My goal is to contribute to developing tools to reinforce and empower young children's identity development during the pre- and elementary school years.

When I was a child, I never saw my limits. I felt just like any ordinary kid! My personal assistant (PA) or school aid, and different supporting equipment were all just parts of myself and my body. Now in retrospect, I understand how important it was for me to think like that, for my future self-image and identity building. I believe it was my mother who gave me that view of myself and always kept supporting me keeping that confidence. Accepting me made me a whole Louisa, a whole human being. My person is whole and includes all equipment and assistants. A person with strong identity and integrity, might be the most important of all.

Starting elementary school at seven was a smooth transition as I was in an integrated pre-and elementary school with kids aged 4–10 in the same group. We all knew each other and the teachers very well already in the past 2 years. Every day I chose a book (easy to read for beginners) from the classroom library to take home and read. On the computer, I used a program called Clicker to write and listen to my texts. I loved to create stories and make pictures in the program Paint. The impossibility to draw and paint was the reason I did not change to eye tracking when it was introduced to me later.

One of the most important things was, when I received my first speech computer at eight. A couple of years before we had found it at a national disability fair. When I finally got hold of it, to my huge disappointment it could just whisper... Many months passed until it was fixed, so we did not get a good start. Even when it came back mended, I did not use it very much, as I had the best assistance team of my life. I spoke with the alphabet board we both knew by heart, so it was faster than using the computer. My PA always used "I" when interpreting me, so they were my voice. A functioning personal assistant being my voice, my hands, and my feet.

Transition to another nearby school was inevitable at ten. We were fighting a lot for my rights, but the reception and inclusivity were not working. Finally, I ended up restudying year four instead of moving to a special unit for motor disabled in the nearest town. The new teacher and class were great, and we had 3 years together. Here, I finally learnt to read more fluently and could watch tv with subtexts. Words with consonant combinations were and still are a struggle. I also learnt to write in my other first language Spanish (because my father is Spanish speaking) and English. It was still more difficult because I could not receive the same word prediction programs as in Swedish, due to economical restrictions in the health habilitation services. Finally, my school bought them to me. So, when going abroad or just talking with people in these languages I had to bring my school computer instead of or combined with the smaller speech generating device-SGD for only Swedish.

Later junior high school proved to be a challenge, nevertheless, they made some adaptions for example with a home classroom. Additionally, for the first time I did not have a paraprofessional aid, but a qualified resource teacher. She helped me a lot in preparing new vocabulary word banks on my school computer for each subject, in collaboration with the different teachers. I started using text-to-speech synthesis- TTS for reading longer texts. I also got personal assistance during schooldays for the first time. The last year though, I was harassed and exposed to many evil stares every day. I felt like their eyes wanted to kill me. The school principal talked to them, and they explained it was a misunderstanding, so nothing changed. I was crying myself to sleep every night, had difficulties sleeping at all, and even was offered sleeping meds by my doctor. I thought about never going to school again, not even continuing the next year at a senior high school. My mother tried to comfort me and pepped me to go back every morning, saying "each day you show up at school you win, and you show them they cannot break you." Two other things which helped me through these worst months were my favourite artist Pernilla Andersson inviting me to her Christmas concert, and then also talking to Allan Linnér – the radio psychologist on Swedish national public broadcasting. We used to listen every week to his conversations, so it felt natural to turn to him. I wrote to the program and got the chance to speak with him about my situation for 2 hours. He told me it was the first time he talked to someone using TTS, so he felt very nervous! The program itself was 30 minutes [41]. He helped me a lot and I got more than 700 empowering commentaries and mails afterward. We also had a follow-up program when I had changed to a new senior high school [42].

Senior high school was like heaven. My teacher from junior high school continued to work with me, and the PA too. I chose to study esthetical program with gaming graphics. I wanted to create more inclusive computer games with disability issues. I still love creating pictures on my computer. Three things helped me with regaining my self-confidence these years. Firstly, I got a new PA who was very professional and made me trust myself again and hold my ground. So, I started to form and make the PA exactly my own way. Thanks to my writing ability I lead my personal assistance all by myself. Secondly, I got my first job during summer preparing a material for developing the competence of PAs at my cooperative. I had already started to question, how my PAs were treating me and how the environment treated us. Thirdly, as it is difficult for me to study abroad, we have had exchange students in our home from different countries. I was skeptical at first but changed my mind. It was one of the best things ever! My host sister was completely natural towards me and did never turn to my PA. When we sat together on the bus to school and chatted the entire bus stared and wondered how on earth she could sit there next to me day after day… It was fun to shock everyone! Can you talk to that girl in the wheelchair? Now we keep in contact and have been visiting each other's families several times. Due to being at high risk for Covid-19, not lately though. These three things helped me develop my identity as human being and personal assistance user. If the PA follows my instructions and keeps quiet in the background, he/she is often seen as rude by the surrounding people. But according to me the PA only is doing the job correctly and professionally. I do not want a commentator in my life. The PA knows not to be personal at work. This is seldom understood and even more difficult to develop nowadays as fewer are interested in working as a PA.

Writing poems have been a way for me to handle life and get the power to continue living, even when life is not treating me humanly. Like when a PA quits and I must find a new, and I get again dependent on my family for some weeks. It is hard to be over 20 and still need your family totally to survive. At the same time, we must accept facts and reality. This poem was written to manage frustration:

As an active volcano

Everything can happen in a minute.

Everything can change in a second.

It is like living on top of an active volcano.

Having an outburst.

Whenever.

No safety.

No trust.

No calm.

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I rewrite many times, reading and listening to the written through TTS. I also use spelling correction and before I publish let someone read and correct the text. Another of my poems is published in a Spanish writer's book [43].

Creative expressions such as lyrics and music play important roles in my life. When I was a child, I sang in the church children's choir with my best friends. I have always sung in my own way. I find lyrics fitting into my life. Just like "Let it go" by Pernilla Andersson [44]. It came truly as a gift the day my employer's office had told me I was unrealistic in my searches for a job and some private smaller problems: "Let them go, let them fall. You don't have to save them all." Even if it is difficult, you must accept this, to survive as a human being, I think. I have also played the drums since I was 12. I had always been making rhythms with my feet on different chairs on wheels. Practicing conductive education for all my life included singing and rhythmical intention. It helps my brain to coordinate and automatize movements easier. That is why rhythms are so natural to me, I guess. Now, 2022 when performing, I still find stages not adapted to wheelchairs, so I also find it important to fight for future generations rights to perform and play music.

Some years ago, I took part in an art project about 'challenging the urban norm.' I made photos with my pony, rabbits, and cats in the forest to show it is possible to have relations with animals and nature even using wheelchairs and personal assistance. The photos were in exhibitions around my region Västra Götaland and I also produced a photo book for children as my final high school work [45]. My intention was to show children photos of a person and her pets, and later discover the wheelchairs hidden under a patch you can fold up. When I was a child there were no picture books representing children with mobility devices. I think it is important both to children having a similar impairment and for more typically developed to get used to seeing different disabilities early in life. Picture books and tv-programs are good ways to contribute to a more open and inclusive world in equity. The UR, Swedish education public service, made a tv-film about my life using text when I was 15. It is called "The word is mine – Louisa [46]." In the future I would like to write more books. Taking part in this literacy project was an important step. I have been involved before in a Swedish anthology about "positive special education" where parts of my life story can be found [47]. Few have expectations of me, but I have my own high expectations. We need to be a counter force to the dehumanization of persons with severe disabilities needing support from personal assistance all their lives. I wish to show children they are not alone and that their value and needs are equal all others.

Recently, I got a new speech generating device – SGD, a "Grid pad" with all three languages in one. The only thing to improve now is that the voices change, so when I speak, I have different voices depending on the language. In Swedish I chose the voice called Anna, in Spanish Inés and in English Kate. Over a decade ago there were only two options – one female and one male, so things do improve. I am not sure if there are several voices of children to choose between though. In the future, I hope to sound the same regardless language, and to be able to express feelings with sounding for example happy, caring, sad, angry, firm, or insecure. Another thing is that I want my SGD to save words I use, now my PA must help to prepare new words in word banks, and it is not easy for them. Many has learnt Swedish as a new language.

I also hope there will be more recognition in society for us using other forms than oral speech as communication. When I speak it takes longer as I write what to say. Meanwhile many get unsecure at best, or just walk away not waiting for my answer at worst, depending on their silence tolerance. They might also turn to my PA, who then direct them back to me. Then they can get scared and walk away. Many suppose I cannot think, and then I want to show off and feel tense, and it takes even more time to write. Consequently, I love keeping conversations and relations on internet, where Facebook and messenger are the most accessible for me. I feel like anybody else; it is easier to chat there than face to face. I can relax and the friend does not have to wait for my answer. No PA risks interfering in our conversation either and it feels wonderful. Nobody else knows, it is only between me and my friend. There I can have my true private life. Thanks to my two other languages Spanish and English I can follow disability activists and organizations worldwide. I really feel like a part of a huge community where everyone understands each other!

My younger sister has always understood me best and fastest. We do not have to use the alphabet to understand each other. She is my everyday salvation and gives me strength to continue living in a world that does not see you as a human being. When she hugs me fare well in the morning, my day begins with a warmth and calm in my whole body. She reminds me of the fact that I also am a person, an ordinary person. I am allowed to be just her human sister! Therefore, my biggest dream is to become a mother one day. To be seen only as someone’s loved mum, without focusing on a PA or equipment. Just being the person I am.

Participating in different projects about personal assistance, communication, literacy [47], and sexuality, have given me new experiences. Therefore, I also counsel teams with PA working with children. The question I pose to myself is to which extent we should let the child keep his/her dreams and confidence, even if I now know how society will look upon him/her and crush the individual. Is it better to let the child know his/her place in society right away? Do you tell a child with more typical development his/her dreams are unrealistic?

At last, for some years I participate in peer support meetings with my assistant cooperative STIL, a cornerstone in the independent living (IL) movement. In peer support meetings our PA wait outside the door, and we can discuss themes together exclusively for users of personal assistance. We have a leader among us who also have a PA, and we can ventilate our struggles and discriminating experiences on a regular basis. We live in a similar world and can understand each other better. We need to get together in our own world regularly to be able to continue listening to ourselves and stand our grounds, in a society who does the opposite. Then, inspired by singer/songwriter Sofia Jannok’s lyrics ‘This is my land’ [48] I ask: One day, will this be also my land where I belong?”

4. Conclusions

There is consistent evidence for the need for environments throughout childhood and beyond that inspire the learner’s further practice his or her literacy skills, on the complex journey towards becoming a member in a greater (reading and writing) community. This evidence was found both in Louisa's narrative about her years of literacy development in preschool, elementary school, senior high school, and beyond, and in the literature (see further 'local understanding' and 'literate citizenship' [3]). The learning communities of preschool and school have these potential possibilities with long-term relationships between the child and his/her peers, teachers, and aids [49]. In summarizing, the importance of lifelong identity building, functional assistive technology at school and home, communicative relationships, creative expressions and long-term hopes, goals, and dreams, stand out in Louisa's narrative, as well as in the more participative studies [26, 34].

As preschool, at least in Sweden, is attended by most children, the emergent and early phases of literacy learning can be seen as general interventions. The flexibility of meeting the learners' individual needs might be more natural in age-integrated groups, which is emphasized by Louisa. She also describes the possibility of attending an extra year in the beginning of schooling. The Swedish Compulsory School legislation [50] gives students the right to two additional years of schooling, recognizing different learning trajectories within the compulsory school. Families of children with SSPI should be informed of this right, to achieve basic learning to read and write on an independent basis with the elementary school teachers' profound knowledge.

The learner's motivation for individual interventions can rise with perceived needs of, for example, spelling consonant clusters and achieving better reading fluency. An area of concern in both writing and reading Swedish, showed to be frequent multiple consonant combinations and clusters according to Louisa. Experiences from other participants suggest that in Swedish it is also critical to learn to analyze and divide long words into their prefix, suffix, and the root of the word [49]. These needs can be discovered through using whatever literacy skills the learner has reached in meaningful communication. The balancing act between acquiring skills and their improvement is a delicate question. The teachers' sensitivity towards and trust in their learners are important tools as Erickson and Sachse emphasize [30].

Providing digital equity and reliability of technology are two important issues easier met at school than at home. Important is to balance between individual computer-assisted instruction and more community-oriented instruction. Digital social media can break isolation and alienation, as Louisa gives examples of. Combining literacy and general curricula, learning and communication with high-tech SGDs (speech generating devices) and the internet is highlighted by many references. This might lead to taking responsibility in advocacy issues for yourself or/and in the disability movement as Louisa emphasizes.

To what extent are the results from the dominant research with English-augmented speakers transferable to literacy learning in more transparent languages? The assumptions are that using several strategies for decoding is more demanding for persons using English. Encoding and decoding develop in reciprocity in more transparent languages. Writing and reading are consequently inseparable. The first phases of literacy learning could be easier for students with more transparent languages, as discussed in [30]. Learning to "read" logographically is not a successful tool in a transparent language, sight word reading is seen as a tool of an emergent literacy phase. To impede the plateau in the literacy development at 9 years of age, their perseverance needs to be supported in different ways for example practicing internal speech, where NRA might be helpful as the learners evaluated [34] and could be used in other languages in adapted ways. If a transparent language is easier to read and write in the beginning, the corollary may be that the transition to morphological and orthographic phases gets more complicated.

Finally, documentation of success, even when seemingly very small and slow, gives the learners motivation and self-confidence, and fosters success [39]. There is no need to fear assessments, especially formative ones. With the mentioned results of speech and language pathologists-SLPs' and teachers' attitudes towards literacy learning, they might be the only ones fearing a documentation of assessment of literacy development (or lack of the same). In inclusive education, the literacy learning community strives for equity and affiliation with each other. Through celebrating differences as valuable, the community can develop a unity in diversity.

5. Future recommendations

At last future needs are discerned for investigating children with SSPI's literacy learning struggles, and possibilities of inclusive educational adaptations. Research from an educational view was scarce, why documenting the classroom's intertwined teaching, learning and interaction for and by these students and evaluating the results are urgent. A future study could be about the role of peers in reciprocal cooperative literacy learning in inclusive communities of learners with and without disabilities. For example, silence in the classroom is probably one important prerequisite for developing inner speech and silence tolerance. These questions need to be further explored together with reading and writing students with SSPI, their peers and teachers. The need for educational research was concluded by Malmqvist [40] two decades ago. Neither these nor other struggling readers learn through waiting for readiness factors to appear [15]. Research in the field of literacy learning after the beginning phases was even harder to find. Studies of inclusive literacy learning are few also in the transitional and emergent phases. Case and intervention studies of English-speaking students show an optimistic future. Comparative studies with even more transparent languages such as Finnish and Spanish are also important.

There is a need for more participatory and transformative studies in this area. Very few studies included perceived environment and personal experiences of literacy learners with SSPI. Encouraging the expression of and listening carefully to participants' (with severe disabilities) own experiences in the areas of learning to use internal speech in reading and synthetic speech in writing, would be helpful. In the future their voices need to be at the center of the research process using current information, communication, and assistive technology, and focusing on the third of Sen's human diversity areas – the ability to convert resources into valued functionings [51].

bell hooks [52] emphasizes the healing power of theory in addressing pain and ground a resistance struggle. She also points at the children's important ability to theorize without cultural biases, as "they do not see why we might not do things differently" [Eagleton in 52, p. 28]. In this case, a mass-based disability resistance struggle [52], includes for example researchers listening to children with severe disabilities even when very young and using AAC, integrating alphabetical print with digital equality [1, 53]. This is important because "Disabled people do have both knowledge and ways of knowing that are not available to the able-bodied" ([54], p. 348). To facilitate participation and give each participant optimal prerequisites, digital means can be explored such as on-line focus groups, writing "easy-to-read," adapted questionnaires, handling personal secretarial support, and combining verbal answers and pictures/photos.

Obviously, the informational base for evaluative judgments is important [55]. Depending on which approach is chosen, different information and evaluations are given. Sen deliberately refrains from setting out a list of core capabilities, as the capabilities a person values are context-bound and changeable over time. Dignity and self-reliance, however, are personal characteristics of great importance in converting capabilities into valuable functionings, according to Sen [51]. Let us remember to emphasize the emphasis on literacy functionings because they are also instrumental in expanding other capabilities [55], especially when you do not use oral speech. Do multilingual augmented young speakers in different countries, contrary to Louisa, get support from the start nowadays [56]? Where are the conscious, intersectional, and more collaborative inclusive approaches towards in our case literacy learning, related to ability, gender, age, and language issues?

New questions have also risen about how and why power is clustered around some disability categories and not others, a question to study further and analyze both intersectionally and intrasectionally [19]. In a geopolitical space as Sweden with few millions of Swedish language speakers, which are the possibilities for organizations to support their populations in literacy learning? The heterogeneity within the small group of students with SSPI can further complicate research, and this in combination with the small population might make studies far from number one in funding. However, the increased quality of life once you acquire functional literacy skills is considerably higher. Students with SSPI will not learn to read and write unless thorough early interventions and ongoing continuous modifications of instruction are made. Is it reasonable to expect a student to succeed in something he or she does not even work on daily? Should a so-called developed country in year 2022 have analphabets with what we call “typical” average intelligence? The results could also be of interest for persons with traumatic brain injuries, stroke, and aphasia. Nevertheless, a recent review about research with disabled young people transitioning from child to adult, revealed that studies with persons having physical disabilities were rare. Neither participatory longitudinal studies with young having disabilities of any kind nor intersectional approaches were many [57]. If students with SSPI are to reach the goal of whatever literacy skills they can, further participative and transformative studies of their lives and education are necessary.

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References

[1] Jaeger PT. Disability and the Internet. Confronting a Digital Divide. Colorado and London: Lynne Rienner Publishers; 2012

[2] Baxter S, Enderby P, Judge S, Evans P. Barriers and facilitators to use of high technology augmentative and alternative communication devices: A systematic review and qualitative synthesis. International Journal of Language and Communication Disorders. 2012;**47**(2):115-129

[3] Kliewer C, Biklen D. Enacting literacy: Local understanding, significant disability, and a new frame for educational opportunity. Teachers College Record. 2007;**109**(12):2579-2600

[4] Light J, McNaughton D. Addressing the literacy demands of the curriculum for conventional and more advanced readers and writers who require AAC. In: Soto G, Zangari C, editors. Practically Speaking. Language, Literacy, & Academic Development for Students with AAC needs. Baltimore, MD: Paul H. Brookes; 2009. pp. 217-245

[5] Dahlgren Sandberg A. Reading and spelling abilities in children with severe speech impairments and cerebral palsy at 6, 9 and 12 years of age in relation to cognitive development: A longitudinal study. Developmental Medicine and Child Neurology. 2006;**48**:629-634

[6] Peeters M, Verhoeven L, de Moor J, van Balkom H. Importance of speech production for phonological awareness and word decoding: The case of children with cerebral palsy. Research in Developmental Disabilities. 2009;**30**:712-726

[7] Ferreira J. Sounds of Silence—Phonological Awareness and Written Language in Children with and Without Speech. Linköping, Sweden: The Swedish Institute for Disability Research. Linköping's university; 2007

[8] Ferreira J, Rönnberg J, Gustafson S, Wengelin Å. Reading, why not? Literacy skills in children with motor and speech impairments. Communication Disorders Quarterly. 2007;**28**(4):236-251. DOI: 10.1177%2F1525740107311814

[9] Larsson M. Reading, Spelling and Silent Speech: Exploring literacy in Children with Severe Speech and Physical Impairment. Göteborgs universitet. Sweden: Institutionen för psykologi; 2008

[10] Fallon KA, Katz LA. Augmentative and alternative communication and literacy teams: Facing the challenges, forging ahead. Seminars in Speech and Language. 2008;**29**:112-119

[11] Pufpaff LA. Barriers to participation in kindergarten literacy instruction for a student with augmentative and alternative communication needs. Psychology in the Schools. 2008;**45**(7):582-599. DOI: 10.1002%2Fpits.20311

[12] Ruppar AL, Dymond SK, Gaffney JS. Teachers' perspectives on literacy instruction for students with severe disabilities who use augmentative and alternative communication. Research & Practice for Persons with Severe Disabilities. 2011;**36**(3-4):100-111

[13] Zascavage VT, Keefe CH. Students with severe speech and physical impairments: Reflection of models of social construct in educational decisions for literacy instruction. Journal of Disability Policy Studies. 2007;**18**(1):33-42

[14] Atterström A. "Jag ska bli författare när jag blir stor"- elever utan tal utvecklar sin skriftspråklighet./'I will Become a Writer When I Grow Up'- Students Without Oral Speech Develop Their Reading and Writing. Jönköping University: Master Thesis. 2010

[15] Myrberg M. Läs- och skrivsvårigheter. In: Skolverket, editor. Att läsa och skriva—forskning och beprövad erfarenhet. [Difficulties in reading and writing. In National Agency of Education (Ed). To read and write—research and approved experience.]. Stockholm: Liber; 2007

[16] Light J, McNaughton S. Literacy and augmentative and alternative communication (AAC): The expectations and priorities of parents and teachers. Topics in Language Disorders. 1993;**13**:33-46

[17] Grant CA, Zwier E. Intersectionality and student outcomes: Sharpening the struggle against racism, sexism, classism, ableism, heterosexism, nationalism and linguistic, religious, and geographical discrimination in teaching and learning. Multicultural Perspectives. 2011;**13**(4):181-188

[18] Feldman M, Battin S, Shaw O, Luckasson R. Inclusion of children with disabilities in mainstream development research. Disability & Society. 2013;**28**(7):997-1011

[19] Norton B, De Costa P. Thinking allowed. Research tasks on identity in language learning and teaching. Language Teacher. 2018;**51**(1):90-112

[20] Romero Y. Developing an intersectional framework: Engaging the decenter in language studies. Critical Inquiry in Language Studies. 2017;**14**(4):320-346

[21] Hancock A-M. Intersectionality: An Intellectual History. Cambridge: Cambridge University Press; 2016

[22] Bagga-Gupta S. Going beyond oral-written-signed-irl-virtual divides. Theorizing languaging from mind-as-action perspectives. Writing and Pedagogy. 2017;**9**(1):49-75

[23] Dahlgren Sandberg A. Reading and spelling among nonvocal children with cerebral palsy: Influence of home and school literacy environment. Reading and Writing: An Interdisciplinary Journal. 1998;**10**:23-50

[24] Sturm J, Spadorcia S, Cunningham J, Calf K, Staples A, Erickson K, et al. What happens to reading between first and third grade? Implications for students who use AAC. Augmentative and Alternative Communication. 2006;**22**(1):21-36

[25] Light J, McNaughton D, Weyer M, Karg L. Evidence-based literacy instruction for individuals who require augmentative and alternative communication: A case study of a student with multiple disabilities. Seminars in Speech & Language. 2008;**29**(2):120-132. DOI: 10.1055%2Fs-2008-1079126

[26] Myers C. "Please listen, it's my turn": Instructional approaches, curricula and contexts for supporting communication and increasing access to inclusion. Journal of Intellectual & Developmental Disability. 2007;**32**(4):263-278

[27] Swärd A-K. Att säkerställa Skriftspråklighet Genom Medveten Arrangering. Wittingmetodens Tillämpning i Några Olika Lärandemiljöer. [Ensuring literacy through Didactic Arranging. The Witting Method set in Context.]. Stockholm: Specialpedagogiska institutionen. Stockholms universitet; 2008

[28] Gómez Taibo ML, Vieiro Iglesias P, Sotillo Mendéz M, González Raposo MS. A descriptive study on working memory, phonological awareness and literacy performance of people who use AAC. International Journal of Special Education. 2009;**24**(3):1-20

[29] Hanser G, Erickson K. Integrated word identification and communication instruction for students with complex communication needs: preliminary results. Focus on Autism and Other Developmental Disabilities. 2007;**22**(4):268-278

[30] Erickson K, Sachse S. Reading acquisition, AAC and the transferability of english research to languages with more consistent or transparent orthographies. Augmentative and Alternative Communication. 2010;**26**(3):177-190

[31] Seymour PHK. Early reading development in European orthographies. In: Snowling MJ, Hulme C, editors. The Science of Reading: A Handbook. Malden, MA: Blackwell; 2005. pp. 296-315

[32] Erickson K, Koppenhaver D, Cunningham J. Balanced reading intervention and assessment in augmentative communication. In: McCauley R, Fey M, editors. Treatment of Language Disorders in Children. Baltimore, MD: Paul H. Brookes; 2006. pp. 309-345

[33] Heller KW, Coleman-Martin M. Strategies for promoting literacy for students who have physical disabilities. Communication Disorders Quarterly. 2007;**28**(2):69-72. DOI: 10.1177%2F15257401070280020701

[34] Swinehart-Jones D, Heller KW. Teaching students with severe speech and physical impairments a decoding strategy using internal speech and motoric indicators. The Journal of Special Education. 2009;**43**(3):131-144

[35] Larsson M, Dahlgren Sandberg A, Smith M. Reading and spelling in children with severe speech and physical impairments. Journal of Developmental and Physical Disabilities. 2009;**21**(5):369-392. DOI: 10.1007%2Fs10882-009-9149-5

[36] Coleman-Martin MB, Heller KW, Cihak DF, Irvine KL. Using computer-assisted instruction and the nonverbal reading approach to teach word identification. Focus on Autism and Other Developmental Disabilities. 2005;**20**(2):80-90. DOI: 10.1177%2F10883576050200020401

[37] Raghavendra P, Oaten R. Effects of speech and print feedback on spelling performance of a child with cerebral palsy using a speech generating device. Disability and Rehabilitation: Assistive Technology. 2007;**2**(5):299-308. DOI: 10.1080%2F17483100701256388

[38] Wilkins J, Ratajczak A. Developing students´ literacy skills using high-tech speech-generating augmentative and alternative communication devices. Intervention in School and Clinic. 2009;**44**(3):167-172

[39] Ahlgrim-Delzell L. Educational assessment issues. In: Soto G, Zangari C, editors. Practically Speaking. Language, Literacy, & Academic Development for Students with AAC Needs. Baltimore, MD: Paul H. Brookes; 2009. pp. 3-26

[40] Malmqvist J. Lärande med rörelsehinder. Studier av förutsättningar och möjligheter för kunskapsutveckling i skolan. [Learning with a mobility Disability. Studies of Conditions and Possibilities for Learning at School.] (Specialpedagogiska rapporter, 19).

Göteborgs universitet, Sweden: Institutionen för pedagogik och didaktik; 2001

[41] Atterström L. I am not Stupid' Radio Psychologist. Swedish Public Radio: SR; 2015. Available from: https://sverigesradio.se/avsnitt/538752 and (2016) A follow up. Radio psychologist, Swedish Public Radio: SR P1 https://sverigesradio.se/avsnitt/658190

[42] Linnér A. "Jag är inte dum i huvudet"/ "I am not Stupid" in Vi slog följe en stund, möten och minnen från terapirum och radio/We Accompanied Each Other for a Moment, Encounters and Memories from the Therapy Room and Radio. Stockholm: Natur & Kultur; 2019. pp. 162-167

[43] Atterström L. In: Rendibú RE, editor. El hilo más fino. 2018

[44] Andersson, P (2018). 'Låt det gå (Långfinger upp)'/'Let it go'. Available from: https://open.spotify.com/album/6vDj2WmvoRQJs3EvrzyfPg?uid=2c6e4f804f0f016476db&uri=spotify%3Atrack%3A1sUXXgBM8byzqDXcOV7ARK

[45] Atterström L. Kom ut!/Come out! (Unpublished Photobook). 2018. p. 20

[46] UR (2017) Ordet är mitt-Louisa/The word is mine-Louisa. Available from: https://urskola.se/Produkter/193590-Ordet-ar-mitt-Louisa

[47] Atterström A, Atterström L. Jag hör inte hemma i någon annan värld/I don't belong to another world. In: Swärd A-K, Reichenberg M, Fischbein S, editors. Positiv Specialpedagogik: Teorier och Tillämpningar/Positive Special Education: Theories and Applications. Studentlitteratur: Lund; 2020

[48] Jannok S. 'This is My Land'. 2016. Available from: https://open.spotify.com/artist/61GJGvVkImL0wkfUQ5XuR8/discography/all?pageUri=spotify:album:69wOjfSUPqUFoNvhufYCkk

[49] Atterström A, Malmqvist J, Swärd A-K, Anderberg E. Experiences about reading and writing development narrated by students with severe speech and physical impairment. International Journal of Disability, Development and Education. 2021:1-19. DOI: 10.1080/1034912X.2021.1940880

[50] Svensk författningssamling (2011). Skollagen/School Law. Available from: http://www.riksdagen.se/sv/Dokument-Lagar/Lagar/Svenskforfattningssamling/Skollag-2010800_sfs-2010-800/?bet=2010:800#K7

[51] Sen AK. Inequality Re-examined. Oxford: Clarendon Press; 1992

[52] Hooks b. Theory as liberatory practice. In: Kolmar WK, Bartowski F, editors. (2010) Feminist Theory. Higher Education: A Reader. Mc Graw Hill; 1999

[53] Curran T, Runswick-Cole K. Disabled children's childhood studies: A distinct approach? Disability & Society. 2014;**29**(10):1617-1630. DOI: 10.1080/09687599.2014.966187

[54] Wendell S. Toward a feminist theory of disability. In: Davis LJ, editor. (2010), The Disability Studies Reader. New York: Routledge; 1997. pp. 336-352

[55] Sen AK. Development as Freedom. Oxford: Oxford University Press; 1999

[56] Tönsing KM, van Niekerk K, Schlunz G, Wilken I. Multilingualism and augmentative and alternative communication in South Africa—Exploring the views of persons with complex communication needs. African Journal of Disability. 2019;**8**(0):a507. DOI: 10.4102/ajod.v8i0.507

[57] Tideman M, Lövgren V, Malmqvist J. Övergången från ung till vuxen för personer med funktionsnedsättning—en kartläggning av det vetenskapliga kunskapsläget/The Transition from Young to Adult for Persons with Disabilities—A Review of the Scientific Status. Stockholm: Forte; 2020

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