Preparing for adulthood with three smiLE Therapy modules

Karin Schamroth, a Specialist Speech & Language Therapist (SLT) in Deafness and **Sarah Caffrey**, a Qualified Teacher of Visual Impairment, provide a summary of Hadiqa's journey as a deaf and visually impaired young woman to self-advocacy

This is Hadiqa's story. Of how she has learned to gain confidence and self-advocate at the age of 16, with the support of her Qualified Teacher of Visual Impairment (QTVI) Sarah, Specialist Speech & Language Therapist in Deafness (SLT) Karin, and her family.

Hadiqa has a combined visual impairment and deafness, which she has adapted extremely well to. Both her vision and hearing are affected at a severe level, but she uses her residual vision and hearing (she has a cochlear implant) to its fullest potential. On a daily basis she is using excellent skills in memory and contextual awareness to respond to situations where she is often missing much of the

information due to her sensory challenges. In familiar settings and with people she knows well, Hadiqa can ask for clarity when something has not made sense or she suspects she has missed some information.

Being deafblind is recognised as a unique disability in its own right. It's not about the amount of sight and hearing you have, it's about the combined impact of having more than one sensory impairment. This affects how you communicate, socialise, access information, and get around.⁽¹⁾

When Hadiqa has to deal with unforeseen situations or people who do not know her, she can face many

additional hurdles to overcome with her dual sensory impairment, compared with someone who is either VI or deaf. She can also experience anxiety in wondering 'will she be understood' and 'will she understand the response' (linked to her deafness), and 'will she be able to find assistance' (linked to her VI). Practising these scenarios in a safe and supported environment, such as smiLE Therapy (Strategies and Measurable Interaction in Live English)⁽²⁾, has enabled Hadiqa to prepare for the real world and the challenges she will overcome as an independent adult.

smiLE Therapy teaches social and communication skills that children, young people and adults who face communication challenges need for successful and confident interaction in the community. Here, members of the public are likely to be unaware of the communication needs of the individual. smiLE Therapy encourages self-advocacy, independence and teaches the skills and strategies needed for adulthood in everyday interactions.

Hadiqa participated in three smiLE Therapy modules from the age of 12–16. Therapy always starts with a real communication task chosen to support her learning along her pathway to adulthood. The different modules are explained below. The task is filmed to determine what skills she already has, and what skills she still needs to learn. Then through individual or paired therapy, Hadiqa learned the skills needed, through visually and experientially explicit learning techniques, adapted for her best access. These included



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guided role play techniques and 'freeze framing' the role play to problem solve and allow time for the development of theory of mind. This is the ability to think about one's own mental state and those of others – to 'tune in' to others' perspectives. This 'freezing' of the role play enabled Hadiga to directly examine the effect on her communication partner when she forgot to include a skill or used a slightly inappropriate skill. Importantly, also to examine the positive effect on her communication partner when an appropriate resolution was found and she was able to put a new skill into practice effectively. Hadiga always enjoyed scoring her own performance in her before and after therapy videos. She was able to enlarge the video image and hold the iPad in a position where she could use her right-sided peripheral vision. She used the specific Communication Skills Checklist (see next page) for each module to colour in the skills she already had pre-therapy, those she had learned, and to work out her before and after therapy percentage of skills scores. This way she could explicitly realise her own achievements and new skills gained.

1 Age 12. smiLE Therapy module: Requesting and refusing in a school office, including learning clarification strategies.

Hadiga learned to: knock on the office door, enter and stand in a good place, wait if the person was busy on the phone, greet with a friendly face, make her request politely, refuse politely if given the wrong item, and leavetake politely with a friendly face. This module included learning how to use clarification strategies within the weekly sessions if Hadiga did not understand the adult easily. This included learning to politely request that the adult speak louder, or slower, or not obstruct their lip patterns, as well as the meaning of any unknown vocabulary. smiLE Therapy actively supports students to take responsibility for their own learning and to take action if they themselves have not understood or if others have not understood them, no matter what their mode of communication is. For Hadiqa, this was the beginning of explicitly learning the language for self-advocacy.

Transferring skills to home

Parent groups are an integral part of the therapy, so that skills can be generalised to home and the community for maximum impact. Hadiga was able to transfer her skills and change her interaction patterns with the family, learning not to demand immediate preference, that had been testing and straining the family dynamic. Sameera, Hadiga's mother recalls: "The first time I saw her before and after videos from smiLE Therapy, I saw that she had learned to knock on the door; not to lean on furniture, but to stand well; to wait if someone was on the phone. At home she wasn't waiting, she always barged in and interrupted us talking. When she did the first smiLE Therapy module, she learned manners – like not to lean on furniture, to ask, 'excuse me' and ask nicely - no longer 'I want this/give me this' but 'please can I have this, thank you'. She learned to wait if someone was busy - she adapted her skills and we saw her using them at home. She started to knock on her brothers' bedroom doors and learned to wait if dad was on the phone. She then applied

this rule to all of us, insisting that we too learned to knock first on her door for permission to enter". Hadiqa's transferred skills had supported her self-advocacy and independence as a teenager.

Transferring skills to the community

Hadiqa, now aged 16, explained how she was able to generalise the skills learned when younger, to negotiate having an X-ray for hospital dental work during the Covid-19 pandemic, when her mother was not allowed to accompany her. She remembered to first explain she was deaf and VI and request information be explained on the process to come, before the necessary removal of her cochlear implants prior to X-ray. Later during dental treatment, when she was not able to understand the dentist (exacerbated by layers of masks), she explained politely that she needed him to speak slower and louder. He obliged and the client-dentist relationship was successfully repaired.

2 Age 14. smiLE Therapy module: Requesting assistance at a tube/train station

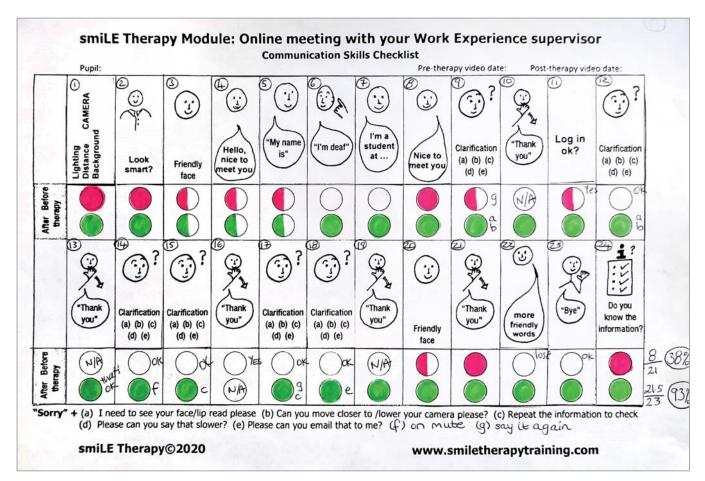
Sarah recalls the preparation for adulthood and independence involved in the module asking for help at a tube station. This communication task involved many additional factors linked to Hadiqa's VI and deafness. There was background noise, she had to ascertain who was safe to ask, and she had to learn to explain her needs and self-advocate in an easy to understand way. The public may not be familiar with terms such as 'visually impaired' or 'partially sighted' (particularly if their first language is not English), so using terms, such as "I cannot see and hear very well" can often be easier to get the message across. By practising as many of the 'what ifs' and planning for several possible alternative outcomes, Hadiqa can gain the confidence in herself to believe she will cope in similar real-life scenarios.

This module was created for Hadiga by Sarah and Karin, as it needed to address the specific needs of a deaf-visually impaired person when they travel on public transport. It included learning how to: locate the wide barriers for people who need assistance; ensure that her white cane was clearly visible; manage members of the public who came to offer help; request that a Transport for London (TFL) staff member was called; check their identification in order to stay safe; explain that she "cannot see or hear very well"; request assistance and give the name of the tube station she was travelling to; stay in a safe place while the TFL staff called ahead to the destination station; and hold the elbow of the staff member to be taken down the escalator to the platform and onto the front carriage of the train and know what was safe/unsafe to chat about as she was accompanied.

I was not feeling comfortable when carrying my cane and like saying deaf or visually impaired.

Hadiqa explains honestly her challenging journey through early teenage years, having to learn to accept her dual sensory impairment. "Well, at the beginning, I was not feeling comfortable when carrying my cane and like saying deaf or visually impaired – I don't know – I just had no

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idea what to say and then I learned lots of things. Right now I understand growing up being deaf and blind that it's important to explain 'I'm deaf and visually impaired' – that's OK for me. It's become easier for me now to say this. This is important, so that the other person knows how to help when I need help."

Transferring skills to travel independently to college

Through the summer holidays 2021, Hadiqa has started weekly one-to-one mobility training to support her independent travel from home to her new college and back. Sameera explained: "I absorbed lots of things that you taught Hadiqa on that tube station module. She's now got confidence like she knows everything. During recent mobility training, Hadiqa felt so comfortable and confident with her communication for her first journey practice to and from college".

3. Age 15. smiLE Therapy module: How to be successful in a Zoom meeting

Hadiqa found herself learning at home through the Covid-19 lockdown. Karin and her SLT team devised a module to prepare Hadiqa and her peers for face-to-face online communication.

The scenario was having an initial online meeting with a supervisor when starting a work experience placement, where details such as dress code and hours of work were explained. Hadiqa learned in a pair, skills that included how to: greet and have a 'larger than life' warmth, friendliness and enthusiasm, in order to overcome the online barrier; introduce herself; explain slowly and clearly

that she was deaf and VI; expect certain online 'conversation warmers' including 'did you manage to log on to the call ok?'; manage when things go wrong (such as not seeing the person's face clearly on the screen, mute button being activated accidentally or when there is too much information to retain); and finally to take leave with many thank yous and byes. One of the phrases Hadiqa suggested amending herself was from "Sorry, I think you're on mute!" to "Sorry, you may be on mute". She explained that she could not see the small mute symbol on the screen, so when the sound disappeared and the video still showed, she only wanted to suggest the possible cause.

Hadiqa's checklist showed that she had 38% of skills in place before starting the module (top row of circles), and she completed the module with 93% of skills learned (bottom row of circles). Nine months later she was retested on her skills through a further online meeting, and had maintained 93% of her skills.

Transferring skills to her online college interview

Hadiqa's interview for college at age 16 was held online due to the pandemic. She was able to generalise her new skills and so feel confident and well-prepared for the online format, despite understandable interview nerves. "It helped a lot with the college interview – 'hello, nice to meet you', 'thank you' ... I felt relaxed and comfortable about the Zoom call. I knew it would be ok to ask them to say it again, or louder or to say "sorry, you may be on mute!' When I later went in person to the college, I was

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able to use my skills to introduce myself, say 'Nice to meet you', and so on". Hadiqa was able to self-advocate about what support she would need at college. She was also able to calm her parents' nerves when they contemplated the physical risks of being in a college with over a thousand students.

Transferring skills for the future

Sameera and Shuja, Hadiqa's father, explain "We are very happy with the skills she's developed through smiLE Therapy, as she could really have struggled without this support. It built her confidence and manners and she was able to apply what she learned in the therapy to outside of school. It's been very helpful". Faisal and Hassan, her older brothers, say that the positive impact on her confidence has made her more willing to talk to other people, and they've noticed how others now understand her more easily.

Sarah reflects that as a QTVI professional, it has been a wonderful opportunity to be involved in Hadiqa's SmiLE Therapy and to know that the communication skills being developed will aid her self-advocacy for both her visual and hearing challenges both now and in the future.

Hadiqa has the final word

"For me, smiLE Therapy was the best way to help build my confidence and communication skills. Watching the before and after videos, I could enlarge the image on the iPad and see the difference in my own video. Which skills had stayed, and which things improved and what the difference was in the final video – to realise what we had just learned. What type of nice sentences to say. The difference between formal and informal talk, like talking to someone in an interview compared to having a conversation with other people, like at a train station. I really enjoyed learning different types of conversation. Breaking down sentences every week to learn more easily. Practising a lot in role play made me feel more confident that I could do this in real situations."

References

- 1 https://www.sense.org.uk/get-support/information-and-advice/conditions/what-is-deafblindness/
- 2 Schamroth K & Lawlor E (2015). *smiLE Therapy: Functional Communication & Social skills for deaf students and students with special needs*, Routledge Publishing, Oct 2015.

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