

Supporting students to self-advocate

Karin Schamroth, presenter at the 27th FEAPDA Congress, outlines how a deaf and visually impaired teenager journeyed to independence across seven years with smiLE Therapy

This is a version of the presentation Karin Schamroth gave at the FEAPDA Conference, Dublin, April 2024

I would like to tell you a story about Hadiqa. She is 18 years old. She is Deaf and Visually Impaired and so has highly specific individual needs. One day she went to her hospital appointment. She walked up to the reception desk to check in. The receptionist pointed and asked her to please go to the self check-in screen.



This is an impossible task for Hadiqa. She will not see the information display when it's her turn and will not hear her name being called in a noisy waiting area. In an ideal world, the receptionist might have noticed her white cane, or seen her cochlear implants, or been aware that this task could be a challenge for some people.

The world is not ideal, and for Hadiqa to thrive she needs to manage such short social interactions in her preferred way, understanding her own needs, and being confident to self-advocate. This doesn't happen by itself. As professionals, it is vital for us to teach these skills ^[1].

I have worked with deaf and hard of hearing (DHH) students across educational settings from mainstream schools to oral units to specialist deaf bilingual schools. I have seen how therapy and teaching has focused on the curriculum and the development of discrete skills like auditory training, speech, vocabulary, and syntax. Little attention is given to teaching pragmatics – that is, how we use language to support effective social interaction. This includes taking turns, topic maintenance, repairing misunderstandings, compromise and negotiation, as well as understanding jokes, and drawing inferences. To be effective, pragmatic skills involve the coordination of a wide range of cognitive, linguistic, and social skills, which are likely to be significantly impacted by a child's social and emotional life experiences ^[2,3,4].

Having poor pragmatic skills carries a high risk for DHH people on a wide range of outcomes. This is well researched – poorer mental health, physical health, poorer

employment outcomes, reduced participation in community activities, and likely social isolation ^[5,6]. Goberis and Yoshinaga-Itano have called pragmatics “the missing link” in language learning for DHH children ^[7,8].

smiLE Therapy, created in 2002, specifically teaches pragmatic skills to DHH students. 'smiLE' stands for Strategies and Measurable Interaction in Live English ^[9], meaning face-to-face live interaction. It gives deaf students a structured and meaningful way to learn essential communication and social skills for everyday use in the mainstream hearing world. Since 2009, smiLE Therapy has expanded to students who have communication needs due to developmental language disorders, Down's syndrome, learning difficulties, physical disability and multi-sensory impairment ^[10].

What has smiLE Therapy given Hadiqa?

It has developed her independence.

For example, to confidently make requests from people who don't know her, shop independently, travel independently, succeed in interviews, and negotiate hospital appointments independently.

It has taught her to self-advocate.

What does self-advocacy in a supermarket look like? Hadiqa needs staff assistance, for example, to find the milk aisle, find the semi-skimmed one litre carton, and to check the sell-by date. For her, self-advocacy includes explaining she needs help while keeping the lead position in the interaction. She has to consciously learn these skills in order to politely maintain agency.

What does self-advocacy in a noisy hospital reception look like? It means explaining why she needs someone to collect her for the appointment, and politely asserting herself if she has had to wait too long.

What does self-advocacy in an interview look like? It



means focusing on her ability, not her disability. When being interviewed for a school work placement, she's asked "How would you manage fights in the playground?". Self-advocacy for Hadiqa is to explain that she may not hear or see a fight. Instead, to say that she would prefer to use her talents to run breaktime clubs in Braille or in British Sign Language. So, she focuses on shaping the agenda.

It has taught her parents to give her practice.

It's given them confidence in knowing that their daughter has learned new skills to manage independently in a variety of situations. They have seen her videos. They see that she has learned the language to stay safe and not be guided onto transport by a seemingly helpful stranger in situations where she could be vulnerable. To know what topics are safe to talk about when London Transport staff guide her down the escalator onto the underground train, knowing not to give her personal details. This in turn has encouraged her parents to be brave and 'let go' a little, giving Hadiqa that important experience of managing by herself. Seeing her succeed then increases parental learning and confidence to let go a little bit more. For her parents, this has been an incremental learning process.

smiLE Therapy uses three key elements:

1. Progress has measurable outcomes

Student outcomes are not benchmarked against some external standards. They are co-created with the student, so that they can 'own' their success. They are specific to the student, specific to the interaction task, and specific to the context. Students evaluate their own skills on watching their before and after-therapy videos.

Below is an example from the module co-created with Hadiqa where she learned how to request assistance and self-advocate in a supermarket. Figure 1 on the following page shows the outcome measures for the start of the interaction, 'The Entering Skills'. The other two sections of the module being the shopping and then the

paying/leaving sections.

Across the top, you see that Hadiqa has identified 13 skills needed for the entering or start of her shopping. The first skill is to have her vision clear with no fringe covering her face! To explain clearly that she's Deaf and Visually Impaired and needs help with her shopping. To also take the initiative, say the first item on her list, and then direct with "I will follow you".

The top row of circles is for skills observed in the baseline (before-therapy) video, the bottom row, for skills in the after-therapy video. Students colour in their own circles – the whole circle if the skill is fully present, half a circle if half achieved, or left empty if not achieved. Hadiqa coloured 4.5 circles out of a total of 12 (three skills were not applicable (N/A) in the baseline video). Converted into percentages, she had 38% of skills needed before-therapy, and 100% of skills needed in the after-therapy video.

2. Parent training*

Training parents helps them to realise how important it is to provide practice opportunities out there in the community. They see their child has new skills, they become confident to 'let go' a little, see their child succeed, and so go on to provide them with more opportunities. So a positive spiral of learning, confidence, and opportunities is set in motion for both parent and child.

3. A real world task in an authentic setting

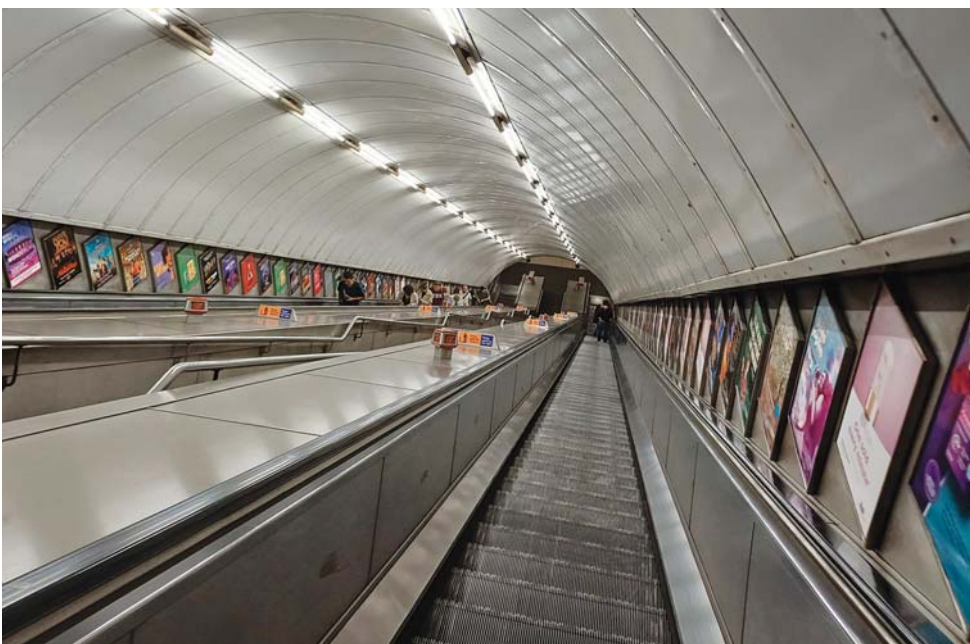
This is where smiLE Therapy starts, with a real task. This makes the therapy meaningful for students. It creates the context, incentive, and understanding for students as to why it might be useful for them to improve their skills.

What the team say:

Sarah Caffrey, Qualified Teacher for Visual Impairment.

"For me, smiLE Therapy has brought everything together – it's brought mobility, it's brought vision, hearing, speech, your confidence, being able to get out in your local community. You know all of those things. I think it's been a fantastic way to bring everything together. Learning isn't just about school; this learning is about real life. We've seen you growing from the first day you went and knocked on your school office door, and now you're able to go and buy yourself coffee and go buy yourself clothes in New Look and River Island and things like that, so it's been a really positive journey."

Sameera, Hadiqa's mum
"smiLE Therapy gave Hadiqa more confidence. The first time when me and Hadiqa's dad, we saw your module, I just wanted to cry because



she had confidence and then talked, and went by herself and everything. And now she's got more confidence. But that was the first time – otherwise we would just say OK, how will she do this? She can actually do all of these things. Before we didn't know she can do this, you know. Because when you see your child build up confidence, and do this, this and this... you can imagine.... That's the base, the first step. Without the first step, you can't reach the top."

smiLE Therapy module: Requesting assistance in a supermarket													
Date of before therapy film:				Date of after therapy film:				Student Name:					
Section 1: ENTERING SKILLS													
ENTERING SKILLS	1	2	3	4	5	6	7	8	9	10	11	12	13
	Vision not blocked Face clear to see	Walk to counter + Wait in queue	Hello	I need some help please	I am deaf	Point to ear + point to eyes	I am visually impaired	I need some help with my shopping please	I need a wheely basket please	Thank you	I'll take it, thanks	The first thing I need is ... <i>"blue milk"</i>	Initiate + I will follow you
Before Therapy	○	●	●	●	○	○	○	○	○	○	○	○	○
After Therapy	●	●	●	●	●	●	●	●	●	●	●	●	●
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Figure 1: The outcome measure for Section One: 'The Entering Skills' of the module 'Requesting assistance in a supermarket'.

The final word goes to Hadiqa herself

"Why is it important for me to be independent? Well, because I'm a teenager, and I want to be able to order Chai Latte in Starbucks, shop for presents for friends and family, and travel independently anywhere. It doesn't matter that I'm Deaf and Visually Impaired; I want to be able to do everything that I want to do. Now, about me shopping in Sainsbury's... At first I was anxious, because I wasn't sure what to say, how to ask for help, how to choose products, and how to pay. I started in a small quiet shop – The Body Shop, to learn all the skills I need and build up my confidence. I'm really proud of myself and I felt self-confident! Watching the before and after video helps me to realise which skills I already have or need to learn or need to improve. Role playing the task helps to

make me think and gives me ideas of what to say, language skills that I need to improve, or polite words to use, like lots and lots of please and thank you!"

* By using 'parents', we include carers, and for example older siblings, cousins, grandparents



Karin Schamroth is the smiLE Therapy Creator and a Specialist Speech and Language Therapist.

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