Health literacy through the lens of RCSLT's Five Good Communication Standards

Sheridan Forster

KEYWORDS
HEALTH LITERACY
FIVE GOOD COMMUNICATION STANDARDS

Sheridan Forster

In 2013, the Royal College of Speech and Language Therapists in the United Kingdom released the Five Good Communication Standards. In this paper, I will introduce the Standards, outline how they may play an influential role in the journal's theme, "Empowering Health Literacy", and describe how I have used them in speech pathology clinical practice in Australia through an authorised case description.

The Five Good Communication Standards: what are they?

The *Five Good Communication Standards: Reasonable Adjustments to Communication That Individuals With Learning Disability and/or Autism Should Expect in Specialist Hospital and Residential Settings* (Royal College of Speech and Language Therapists [RCSLT], 2013) is a document developed by the U.K. RCSLT in response to revelations of abuse and neglect of adults with intellectual disability (called learning disability in the United Kingdom) and autistic adults in hospitals (often "assessment" hospitals for people with learning disability) and residential services. Investigations occurred, with the Department of Health (2012) releasing a report, *Transforming Care: A National Response to Winterbourne View Hospital*. The report listed quality outcomes that should be able to be expected for people with intellectual disability, autism, and behaviours that challenge. The outcomes included being involved in decisions about care, making choices, and being treated with compassion, dignity, and respect. Drawing from these outcomes and from a working party across the United Kingdom, the Five Good Communication Standards (the Standards) were written and shared with members.

Since their release in 2013, the Standards have been shared, incorporated into several other professional documents endorsing their importance, been used as service evaluation and education tools, been the basis of several videos including people with intellectual disability outlining their personal meanings, and received some early research attention (Bradshaw, 2019). They have been shared in Easy Read formats, and several documents have been produced to show how the Standards may be translated to practice actions. The Standards have been an important partner to RCSLT's inclusive communication model (Money et al., 2016) that focuses on speech pathology practices that enable all communicators to be included at an individual, immediate environment, and community level, across all disability types. Wording of the Standards has changed a little over the years, and I have chosen to share the wording given by Money (2015) in the RCSLT Bulletin (Figure 1).

The Five Good Communication Standards

Standard 1: *There is a detailed description of how best to communicate with individuals* – meaning everyone understands and values individuals' speech, language and communication needs and knows "how to be with them".

Standard 2: *Services demonstrate how they support individuals with communication needs to be involved with decisions about their care and their services* – using innovative and creative solutions to including and involving individuals with SLCN (speech, language, and communication needs).

Standard 3: *Staff value and use competently the best approaches to communication with each individual* – meaning staff know that how they are, what they think and how they say things matters.

Standard 4: *Services create opportunities, relationships and environments that make individuals want to communicate* – providing quality interaction that contributes to overall emotional and mental wellbeing through providing a sense of belonging, involvement and inclusion.

Standard 5: *Individuals are supported to understand and express their needs in relation to their health and wellbeing* – reducing health inequalities, diagnostic overshadowing and increasing capacity around health treatments.

(Reproduced with permission from D. Money, 2015).

Figure 1. Five Good Communication Standards (Money, 2015)

In Australia, some speech pathologists have been aware of the Standards, and there has been some mention of the Standards in Speech Pathology Australia reports. However, they are generally little known or used. It is my suggestion that recognition of the Standards has potential to influence speech pathology practice in the areas of assessment, recommendations, goal setting, and practice guidelines and in the underlying ethics of our work (Forster, 2022). In particular, they may be a tool for framing and evaluating speech pathology supports under the NDIS.

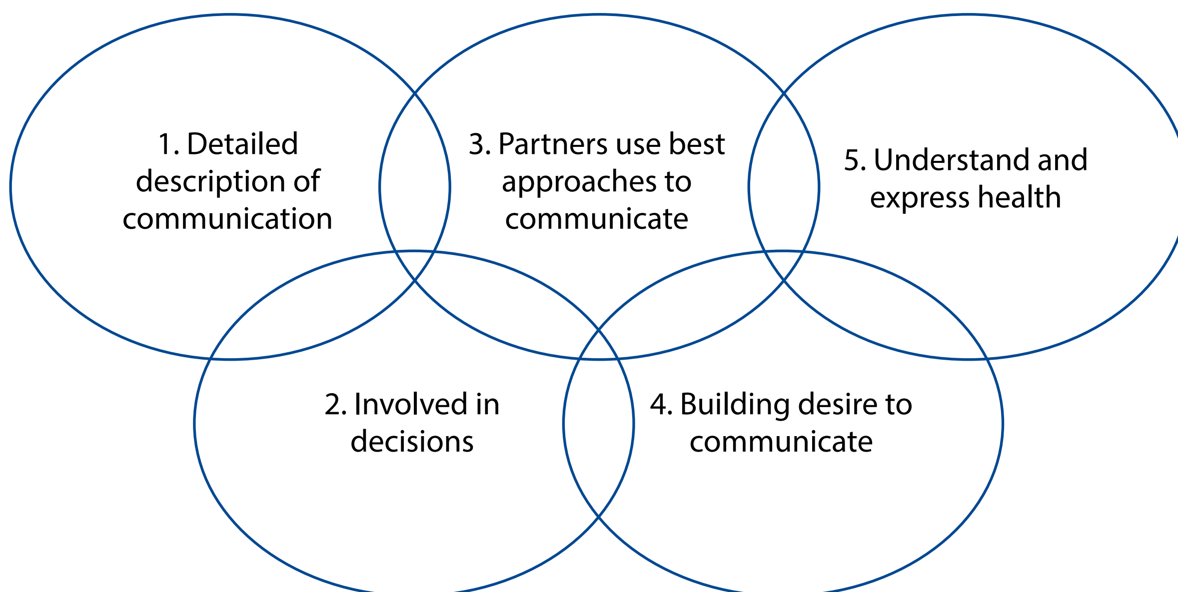

Figure 2.: Five Good Communication Standards interrelated

While RCSLT has illustrated the Standards as a list, my experience of their use conceptualises them as interrelated concepts, reliant on each other in order to be carried out in practice (Figure 2).

The Standards in clinical practice

A short example in the area of health literacy can illustrate the essential interdependency of each standard. In considering health literacy specifically, on a most surface level, readers may only think of Standard 5 for understanding and expressing oneself about health.

Standard 5 was the starting point of a recent case study presented at the AGOSCI 2022 conference. On writing my abstract in early 2021 (the conference was then rescheduled to 2022), I planned to share the individualised videos that had been created for an autistic man I will refer to as H, with possible intellectual disability, health issues, and very complex communication needs. The ongoing process of intervention with H and his team, however, unveiled how his health literacy improved through actions far beyond provision of a modified accessibly document. Over the 18 months, is health literacy improved through attention to all the Standards. Below, I outline how each standard was considered.

1. **Detailed description of communication**
   This standard has typically focused on static documents like *All About Me* books. However, the present team went beyond these and undertook a constant process of video reviews, and written and spoken conversations to gain a deep understanding of H's expressive communication. Meanings of words, phrases, artwork, objects, and body language were reflected on in the context in which they were heard. Commitment was made to acknowledge, respond, and problem-solve to help H build his trust in the responsivity of his team. The subsequent trust, through refined interpreting and responding, enabled deeper reading of his signals of health and abilities to name emotional and health issues in a growing way.
2. **Involved in decisions**
   H's mother's involvement in the Royal Commission Into Violence, Abuse, Neglect and Exploitation of People With Disability spurred her forward, ensuring a deeper level of involving H in decisions in his own life. Simultaneously, his autistic art mentor provided a constant voice to "have we told him/asked him". A deeper understanding was gained of the process of informing that required specific skills and a monitoring of his responses, which could take several days to be expressed and still require interpretation. A profound shift from past practices of providing him with little to no information until the last moments of health interactions (based on a fear of provoking behaviours of distress and assumptions of him not understanding) was replaced with a systematic approach of informing in multiple ways.
3. **Partners use the best approaches to communication**
   Without all communication partners attending to how they communicated, H would not have made the steps in his health communication that he did. With support from Phoebe Caldwell (Caldwell, 2010; Caldwell & Gurney, 2016) sharing responsive communication (intensive interaction with attention to sensory processing differences), the autistic art mentor, and me, as team speech pathologist, the team constantly analysed and refined the methods that they needed to use to communicate with H. The team frequently used "passive conversation" in which two staff members would have a planned conversation within the hearing of H—a technique that was essential when direct questions or conversations appeared overwhelming for H. The low-arousal forms of communication included videos made for him to watch in his own time and pictures left for him to reflect on (with his drawing on them often indicating an affirmation). When direct conversation was possible, the team refined their knowledge of conversational moves that could deepen and continue the conversation (e.g., repeating his words with a question intonation, asking either closed or open questions of H's plans in visiting a place, asking questions inviting a gestural response rather than verbal such as a hand up). The expanded conversation abilities enabled conversations of health to be deepened beyond single comments requiring interpretation to understand the meaning of words. For example, a comment by him about a "sore leg" was able

to be deepened to suggest that he was not referring to a sore leg now but a previous traumatic experience that he continued to process.

4. **Building the desire to communicate**
   One of the most profound shifts across the team that enabled H's health communication was the perception of him as someone who does want to communicate but struggles to do so. Prior to the case study, expressions of distress by H were met by some staff with responses of "giving him his own space". Responsive communication, conversations about the need for coregulation of emotional/energy states, and a lot of video shared reflection contributed to his needs being more frequently listened to and met, increases in staff actively supporting H to use his adaptive self-regulation and be involved in mutual regulation, and debriefing with him after incidents of distress had occurred. Distress still occurs, but staff are much more aware of the underlying health and emotional patterns that may be contributing (also through systematic monitoring of health and behaviour in conjunction with his behaviour support practitioner). His team are more able to provide support instead of leaving him alone in a distressed state. Over the last 6 months, the number of team members with whom he will engage in multiturn conversations has increased, alongside the duration of interactions. Trust has paid off. Alongside this, a local Facebook group of 2.6k members and his growing art work (drawings and laces) have built links of understanding with his local community, where previously fear, judgement, and avoidance may have been a more prominent response to H who walked many kilometres daily, with a loud voice, and a frequent drive to take/buy Coke and art materials (side point … he is now successfully scanning shopping items more than ever and always has team members to sort purchases when needed).
5. **Understand and express health**
   A commitment has been made to inform H about his health and involve him in decisions. Words to describe potential emotional states (e.g., "fast brain" to describe high levels of anxiety), real words to describe physical states (e.g., "hard poo", "runny poo"), and labels for medical interventions (e.g., using a medication's name and why it is being offered rather than just handing over a pill) are all used to find a shared language. COVID-19 vaccinations were made successful with videos of Dolly Parton and Queen Elizabeth receiving their injections, edits of national information, descriptions by team members of their experiences, a planned video explaining what would be happening with the support of the COVID-19 disability team, and a team that observed and listened for his expressions of anxiety about impending injections. Vaccinations happened in cars where he was most comfortable, with team members, sharing the countdown for being still. Success begot success.

Conclusion

The Five Good Communication Standards can provide a scaffold for the complex approaches needed to work with very unique communicators. While the theme of this issue is "Empowering Health Literacy", I argue that the term "empowering" overly suggests what *we do* to give power to another person in a vulnerable state. Instead, the Standards and this case example illustrate that a focus that recognises and amplifies an individual's existing power is needed in being a health communicator. You must listen to the person, engage in a trusting relationship that gives reason for the person to listen to you or read your information, be in constant subtle reading of meanings, and admit when you've missed the meaning. In the case of H, he did not require empowerment—but he needed us to listen to the power he had, trust in his power to be involved, and build the relationships that made health communication a two-way (actually much more than two) process.

References

Bradshaw, J. (2019). *Evaluating the impact of communication passports*. NIHR School for Social Care research. https://www.sscr.nihr.ac.uk/wp-content/uploads/SSCR-research-findings_RF124.pdf?fbclid=IwAR2CaKf6zshayqkqVNfjx2Vbo4V-fqeTtdzQdaVz6bKjszBBU5pLPaN3UMk

Caldwell, P., Hoghton, M., & Mytton, P. (2010). *Autism and intensive interaction: using body language to reach children on the autistic spectrum*. Jessica Kingsley.

Caldwell, P., & Gurney, J. (2016). *Responsive communication: The films*. http://thecaldwellautismfoundation.org.uk/index.php/responsive-communication-the-films/

Department of Health (2012). *Transforming care: A national response to Winterbourne View Hospital: Department of Health review final report*. U.K. Government. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/213215/final-report.pdf

Forster, S. (2022, July 1). *Five good communication standards: 5 service applications; 100s of opportunities for interaction success?* [Keynote]. 11th National Deafblind Conference, Perth, Western Australia.

Money, D. (2015, October). Five good communication standards in practice: Two years on. *Bulletin*, 13–15.

Money, D., Hartley, K., McAnespie, L., Crocker, A., Mander, C., Elliot, A., Burnett, C.-A., Hazel, G., Bayliss, R., Beazley, S., & Tucker, S. (2016). *Inclusive communication and the role of speech and language therapy* (Royal College of Speech and Language Therapists Position Paper). RCSLT. https://www.rcslt.org/wp-content/uploads/2021/02/20162209_InclusiveComms_final.pdf

Royal College of Speech and Language Therapists. (2013). *Five good communication standards*. https://www.rcslt.org/wp-content/uploads/media/Project/RCSLT/good-comm-standards.pdf

Sheridan Forster is a speech pathologist, educator, researcher, and person with an acquired disability. She works in private practice and collaborates with multiple organisations and universities.

Correspondence to:
Sheridan Forster
74 Karingal Drive, Eltham North 3095, VIC, Australia
Email: sheri@sheridanforster.com.au