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COMMENTARY

Running head: Communication, human right, citizenship, politics

Communication as a human right: Citizenship, politics and the Role of the Speech- Language Pathologist

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Communication as a human right: Citizenship, politics, and the role of the speech-language pathologist

Abstract

According to Article 19 of the Universal Declaration on Human Rights "Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers." The purpose of this paper is to elucidate communication as a human right in the life of a young man called Declan who has Down syndrome. This commentary paper is co-written by Declan, his sister who is a speech-language pathologist (SLP) with an advocacy role, his SLP, and academics. Declan will discuss, in his own words, what makes communication hard, what helps communication, his experiences of speech-language pathology, and what he knows about human rights. He will also discuss his passion for politics, his right to be an active citizen, and participate in the political process. This paper will also focus on the role of speech-language pathology in supporting and partnering with people with communication disabilities to have their voices heard and exercise their human rights.

Key words: Article 19, Universal Declaration of Human Rights, United Nations, communication, citizenship, politics

The purpose of this paper is to elucidate communication as a human right in the life of a young man called Declan who has Down syndrome. This paper is an invited contribution to a special issue of the International Journal of Speech-Language Pathology to celebrate the 70th anniversary of the Universal Declaration of Human Rights, and particularly, Article 19 that advances the right to freedom of expression and is co-written by Declan, Declan's sister who is a speech-language pathologist (SLP) with an advocacy role, his SLP, and academics. Declan has a passion for advocacy, politics, and citizenship and is an active member of Down Syndrome Ireland (DSI), a national not-for-profit organisation in Ireland providing support, guidance, and services to people with Down syndrome, their families and the professional community connected by Down syndrome. Declan was an elected member of the organisation's first national advisory council on Down syndrome. In the first part of this paper Declan will discuss, in his own words, what makes communication hard, what helps communication, his experiences of speech-language pathology, and what he knows about human rights. Declan's role with regard to the writing of this paper was that of co-author and it was his choice to be a named author. A writing and editing contract was agreed in advance between Declan and the second author (see Appendix 1). This paper will then focus on the role of SLP in supporting Declan to achieve his life goals and exercise his right to communicate.

Declan's narrative

What makes communication hard?

Background noise has a big effect on me when people are talking to me. I feel the pressure to understand them. I feel pressure to talk to different people sometimes. There are two things. People talk to me too fast. People talk too fast on the phone and for me that is too much and I can't concentrate to have a good and decent conversation with them. I would like to say to people to calm down a little bit and just explain to me what they would like on the phone. So if I say, I will take a message, sometimes people say no it is ok, I have to go. I find that extra hard on me. When I can't understand a word that a person says on the phone I say to them – can you please spell the word? In the restaurant, I feel that if I order let's say from the menu and I read the menu and I know they are working quick and fast but I feel that I want to explain to them, to stress what I really want to order my own food and not for someone else to do it. It is a mixture in the shops – some of them are able to talk to me and we have a deep conversation and the other half of people they have to go really fast and I found that hard that they are not talking to me back. They have instincts about me and then it feels a bit weird.

What helps communication?

It is more comfortable in society that people are welcoming and support us as citizens. I particularly understand that some people in society that they don't have experience of people like me. It is more easier to have conversations with people who know me well

down through the years and they understand where I am coming from. When I make a smart comment or something they just laugh and I feel more comfortable and great like having a laugh with people that I know. I feel myself that I am comfortable talking to more easy going people. It is good for me, big time actually, if people talk to me slowly. I am particularly clear about that in my mind. People who ask questions like “how are you” “how are you doing” are great for starting conversations. I feel they have an interest in talking to me. It is about calm people who take it slow and explain things in conversation to me.

Declan’s experiences of speech-language pathology

I do two things. One is I write things down and second is I say things in easy and clear speech. I don’t go on a rant about something else. I am not in control of myself if I go on a rant. It keeps the pressure off if I take a deep breath and I say it again more slowly. It is decent advice from Mari [Declan’s SLP]. She told me how to cut down long words and pronounce it in that way. I breakdown words and underline syllables and then I clap it. Now, basically I write the word and underline it. Now I say to people to say it again please, nice and slow. Mari said it is important for me. I know she is right.

She had this really cool exercise – she had this tape recorder and she wanted me to listen to the tape recorder and then we said “oh that is interesting how you said that Declan”. Then I did repeat myself, and yes I said it more different that time. Those were the exercises she did with me. She told me that I have to go home and practise with your own family and pronounce all the syllables of the words. That is what my homework is. I had a conversation with May (my sister) and she said to me Declan your speech is so good, I am in shock with all

those long words you can say so well. It is why I am more comfortable to speak. Mari asked me what are my goals. This gave me real focus, discipline and control of myself. One goal for me is to get out there and to give a very strong statement, to give a message for everyone that everyone like me can speak out. Mari talked to Rena [Head of Discipline of Speech and Language Therapy, NUI Galway] and I got this job to be a guest lecturer in the University [NUI Galway]. This was real life and extra special to me because my sisters went to college there. I had to make a PowerPoint presentation about my life story. It is an honour in my life to do this. It is really important. I made a good and decent PowerPoint presentation all about my life living with Down syndrome. My speech is particularly clear when I am doing a lecture. The students do love it and ask me a lot of questions about my job and mainstream education. Mari does help me to listen to the questions. It is like the Xtra Factor – they put the questions on post-its and I pick a questions and particularly tell them my answer. People even speech-language pathologists need to listen to the message. The slogan that I say is they are professionals in the field to teach people like me to have really strong and particularly clear speech.

How Declan knows human rights

I took My Opinion My Vote on because politics always has been a big interest for me. This project inspired me and empowered people like me. I learnt that I have a lot of rights and responsibilities. I have the right to vote. I have a responsibility to know what I stand for. I have my right to have my own point of view. I found it a bit hard to understand and listen to politicians. I just think that for example in the Dáil [government assembly of Ireland] they are shouting and it is too hard to understand and it is like children in the yard. No I can't understand what they are saying. I particularly remember doing the My Opinion My Vote

workshops and we did brainstorming of ideas about what we could do in Ireland and in Europe. We got more aware with role play and working in groups. I was able to speak out in public speaking. I found out that human rights for people with disabilities can be on the world stage. I feel that people don't take us seriously as real citizens of Ireland. I say to those people don't write us off. We can do so many things in politics and my life. I met politicians in Europe and I travelled.

I was like a politician myself one time. I did the opening at the IALP [International Association of Logopedics and Phoniatrics] conference because the Minister for Health was busy. This was huge. My family came to see me. I think they were in shock about my speech and what I said. I have this memory now for all my life because I got a standing ovation. Rena said to me "how are you so confident up there Declan?" I told her and I particularly love this bit that I think about Barack Obama making a speech and then I am not nervous and I just want to do it.

Reflections on Declan's narrative in the context of communication as a human right

According to Article 19 of the Universal Declaration on Human Rights "everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers" (United Nations, 1997). The words 'human rights' are enshrined in vision statements (American Speech-Language-Hearing Association, 2017; International Communication Project, 2017). Nonetheless, the notion of communication as a human right remains aspirational and it is not clear how it translates into the everyday lives

of people with communication disability. Communication abilities can be viewed as a vehicle through which individuals can attain inclusion and independence (Roulstone & Lindsay, 2012), self-determination, self-advocacy, and self-efficacy (Lemke, Masiogale, & Inglebret, 2012). Indeed, there are claims that communication disability is more detrimental in relation to participation in society than physical disability in the 21st century because communication skills are so highly valued by employers (Ruben, 2000). However, communication as a human right has received less attention in the literature. Declan's powerful narrative illustrates the importance of communication in enabling him to fulfil his full potential in society; for example the importance of communication in his work, relationships with others, his passion to be involved in politics, and his wish to inform people about Down syndrome. Declan's narrative focuses on rights and abilities which challenges us to focus on strengths and a rights-perspective rather than on deficits and personal tragedy. This is in the context of evidence to suggest that people with intellectual disability are one of the most socially excluded groups (Ali, Hassiotis, Strydom, & King, 2012) and are at risk in relation to having fewer meaningful relationships (Overmars-Marx, Thomese, Verdonschot, & Meininger, 2014).

The International Classification of Functioning, Disability and Health

One of the frameworks underpinning speech-language pathology practice is the International Classification of Functioning, Disability and Health (ICF) (World Health Organisation, 2001). The ICF has relevance from a human rights perspective because it takes account of both the impairment and everyday activities and participation (Threats & Worrall, 2004). According to the social model of disability, societal barriers restrict activities and participation for disabled people and disability is a form of social oppression

(Finkelstein, 2004). Others argue that the impairment also plays a role in restricting activities and participation (Shakespeare, 2006; Thomas, 2004). Declan's narrative highlighted that he viewed some of his communication challenges are related to his own impairment and others are related to other factors; for example background noise, attitudes and behaviour of others. His story also validates the view of O'Halloran and Larkins (2008, p. 25) that communication participation is a subjective experience and

only people themselves can say if they feel that they can express who they truly are in social interactions, how much they enjoy and feel included in a social situation, how much they feel listened to...how much they are accepted and valued where they live.

Declan's narrative illustrates ways in which he feels accepted and valued by his family, his SLP, the university (lecturers and students), the wider speech-language pathology community.

Citizenship and politics

The ethos of the social model and a human rights perspective is that all people should be viewed as equal citizens and society must ensure that there is an enabling environment where everyone has equal opportunities for participation (Browne & Millar, 2016; Dakroury & Hoffman, 2010; Oliver, 2004). For example, according to Article 29 of the Convention on the Rights of Persons with Disabilities (United Nations, 2006) citizens with disabilities have the same political rights and opportunities as non-disabled citizens (Keeley, Redley, Holland, & Clare, 2008). However, people with intellectual disability may be excluded from the political process (Keeley et al., 2008; Kjellberg & Hemmingsson, 2013)

and this may be at least partly related to the inaccessibility of language used in public and political publications.

Through Declan's interest in politics he became involved in the European Union project My Opinion My Vote (European Down Syndrome Association, 2017). The aim of this project was to empower people with intellectual disabilities through active citizenship and participation in the political process. The adult education program promotes a total communication approach and adopts principles of social constructivism such as scaffolding, reciprocal teaching, and situated learning. Declan completed modules on a range of topics such as principles of politics, voting, and petitions and referendums. While completing this program Declan documented specific goals in his reflective logs in relation to effectively communicating his point of view on a range of political topics and made the decision to begin attending speech-language pathology again at the age of 23 years. He had been discharged from speech-language pathology services at the age of 17 years and at that time public speech-language therapy services for adults with intellectual disabilities were very limited. Declan's family accessed a private service.

The role of speech-language pathology in the context of communication as a human right

When he re-commenced speech-language pathology Declan's life wishes were to go into politics, to travel around the world, to get a decent job, and to educate the public about Down syndrome. A collaborative ethos underpinned intervention. Declan and his SLP maintained a working dialogue in relation to his aspirations. Therapy goals were designed to support Declan to achieve his life wishes (O'Halloran & Larkins, 2008). The development of personal autonomy is a characteristic feature of health and social care policies and

underpinned the intervention. There is an important difference between *de jure* and *de facto* autonomy (Ashley, 2012). The former refers to the moral and legal right to self-government and the latter relates to both the *skills* and *opportunities* necessary to exercise that right. In the initial phase of intervention there was a focus on supporting Declan to develop communication *skills* necessary to exercise his right to personal autonomy. The SLP assessment, which included cognisance of Declan's views and life wishes, indicated that intervention was required in two key areas. First, Declan presented with motor speech difficulties that affected intelligibility. It would be important that Declan's speech was intelligible to enable him to fulfil his wishes to into politics and public speaking about Down syndrome. Intervention focused on improving intelligibility through direct work on speech clarity; for example education in relation to the speech production process, discussion of oral placement and awareness of the nature of speech sounds, listening tasks, production and practice of specific speech sounds in all contexts, awareness of posture, and use of breath support and relaxation techniques. Working memory activities, production of speech sound sequences and relevant core multisyllabic words comprised core activities. Second, Declan presented with language comprehension difficulties in conversational contexts and he was not always aware of listener's needs. These deficits may impact on his ability to engage with others in the workplace. Intervention focused on repair strategies that could be used when communication breakdown occurred; for example he became aware of signs when his partner did not understand him, used text to support shared understanding, and learned to rephrase what he had said when his partner did not understand. Progress was monitored through observing Declan's ability to use strategies during sessions and through discussions and feedback from Declan's family (with his permission). Declan's family were

encouraged to provide direct feedback on communication skills and he became a more confident communicator as he reported in his narrative.

After two years of intervention Declan's desire to educate people about Down syndrome became a priority. Declan's SLP sourced *opportunities* for Declan to realise this wish and contacted the local university, which provided a program to educate SLPs. Declan was invited as a guest lecturer. Therapy sessions then focused on exploring the core content that Declan wished to present, ways in which the learning outcomes could be achieved, the classroom environment, and strategies that could be used to enhance intelligibility. The SLP co-presented on the therapeutic journey from her perspective and worked with Declan to reflect on additional strategies to enhance communication effectiveness. For example, one of the strategies involved changing the students' behaviour whereby they were invited to write their questions on post-it notes and place them on a flip chart. This strategy provided Declan with time to process and understand questions before answering them. This lecture has been positively evaluated as a meaningful and memorable experience by students who hear messages about rights directly from Declan. He teaches us to focus on possibilities rather than deficits and challenges future SLPs to view communication as a human right. Our experience resonates with that of others who report the benefits for both people with communication disabilities when they take on roles as teachers and for students (Beecham, 2005; Stevenson, 2010).

In conclusion, "communication represents an essential and very important human need as well as a basic human right" (Fulya Sen, 2015, p. 2813). It is important that SLPs design services in ways that "transform human rights from high-sounding principles that are

remote from everyday life, into practical principles that guide the everyday work of the service” (Laird, 2010, p. 6).

Appendix 1: Writing Contact

Declan and Grainne agreed a writing and editing contract in advance.

1. These are Declan’s ideas and words.
2. It is Gráinne’s role to support Declan to organise his writing and his ideas.
3. It is ok for Gráinne to correct spellings.
4. It is not ok for Gráinne to change sentences.
5. It is ok for Gráinne to remind Declan of the topic.
6. Declan will make the final decision about what is in his article.

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