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Jane McCormack, Elise Baker & Kathryn Crowe

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ORIGINAL RESEARCH

The human right to communicate and our need to listen: Learning from people with a history of childhood communication disorder

JANE MCCORMACK¹ , ELISE BAKER²  & KATHRYN CROWE^{1,3} 

¹School of Teacher Education, Charles Sturt University, Albury and Sydney, Australia, ²Discipline of Speech Pathology, Faculty of Health Sciences, The University of Sydney, Lidcombe, Australia, and ³Rochester Institute for Technology, Rochester, NY, USA

Abstract

Purpose: In 2013, the Australian Government Senate formed a committee for inquiry and report into the prevalence of speech, language, and communication disorders and speech pathology services in Australia. Submissions were sought from individuals and organisations. In this paper, submissions made by individuals with a history of childhood communication disorder were examined to explore their life experiences and the impact on their lives when the right to communicate could not be enacted.

Method: There were 305 submissions to the Australian Government Senate Committee Inquiry, of which 288 were publically accessible. In this study, the submissions ($n = 17$) from children or adults with a history of communication disorder (including speech, language and stuttering), who provided personal accounts of their experiences, were analysed using an interpretative phenomenological approach.

Result: Four themes emerged relating to: personal identity, life with communication disorder, the importance of help, and how life would be different without a communication disorder.

Conclusions: This paper gives voice to children and adults with communication disorder. In listening to these voices, the impact of communication disorder on the right to communicate and on other human rights can be heard, and the need for a response is clear. However, the challenge is to determine how the voices of these individuals, and others like them, can be enabled to exert real influence on practice and policy so communication disorder will no longer be a barrier to attainment of their human rights.

Keywords: Article 19; Universal Declaration of Human Rights; United Nations; communication disorder; speech impairment; speech sound disorder; language impairment; developmental language disorder; fluency disorder; speech-language pathology; qualitative research; children

Introduction

Article 19 of the Universal Declaration of Human Rights (United Nations, 1948) states that “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 right can be conceived in two ways: (1) the right to communicate (e.g. to share ideas and information with others), and, implied by this, (2) the right *to be able* to communicate (e.g. to have a mode of communication). That is, according to the Universal Declaration of Human Rights, individuals have a right to voice opinions and have those opinions heard, but they also have a right to a *voice* and for that voice to be understood.

Yet 70 years after the Universal Declaration of Human Rights was written, the right to freedom of opinion and expression is not available to all. Challenges to Article 19 are most often recognised when the right to communicate is stifled through inequalities related to race, sex, religion, or status. That is, when the right of individuals to voice opinions is challenged due to discrimination. However, challenges to Article 19 are relevant to another group, those whose right to communicate is stifled due to communication disorder. Communication disorder refers to difficulties with producing or comprehending messages in oral and/or written form. Individuals (children and adults) with communication disorder are doubly disadvantaged; their lack of voice (i.e. an effective mode of communication), means their voice (i.e. what they want to communicate) goes unheard.

Their right to communicate is challenged by their impaired ability to communicate, and the impact can be broad and long-lasting.

People with communication disorder experience challenges across many life areas (McCormack, McLeod, McAllister, & Harrison, 2009). For example, large group studies of children with a communication disorder have reported poorer academic performance, reading difficulties, more bullying, poorer peer relationships, and higher rates of psychosocial difficulties compared to typically developing peers (Lewis et al., 2016; McCormack, Harrison, McLeod, & McAllister, 2011). When examined through the lens of human rights, these studies show the impact of communication disorder extends far beyond Article 19 to other Articles of the Universal Declaration of Human Rights, including the right to work (Article 23), the right to education (Article 26), and the right to participate in the cultural life of the community (Article 27).

The right to communicate was described by Lundy (2007), in her analysis of the United Nations Convention on the Rights of the Child, as having “transformative potential . . . since, when it is implemented effectively, other rights fall into place naturally” (p. 940). The impact of childhood communication disorder shows how other rights fall *out of place* when the right to communicate is challenged by the child’s lack of an effective communication mode. Thus, we begin to see the importance of supporting individuals with communication disorder; not just to provide them with a voice (i.e. enact the right to communicate), but so they may use that voice to participate in daily life (i.e. enact all their human rights).

Human rights and speech-language pathology

When we seek to address violations of human rights, we respond to a call to arms for the promotion and securing of those rights. The Preamble to the Universal Declaration of Human Rights states that “every individual and every organ of society. . . shall strive by teaching and education to promote respect for these rights and freedoms and. . .to secure their universal and effective recognition and observance”. With the 70th anniversary of the Universal Declaration of Human Rights, it is timely for health/education professionals who work with individuals with communication disorder to reflect on how well we undertake our role in promoting and securing the right to communicate for the individuals with whom we work.

Lundy (2007) suggested a framework that might aid this reflection. According to this framework, the degree to which all individuals have the right to communicate can be evaluated according to the degree to which they are provided with space, voice, audience, and influence. In a sense, this framework combines Article 19 with the Preamble, recognising

that the securing of any individual’s human rights is dependent on the action of other individuals. Thus, a person’s right to communicate is only partially secured when they have a voice (or means of communication). The right also requires that others provide an opportunity for the person to use that voice (space), *and* listen to what they say (audience), *and* respond in a way that demonstrates the person’s communication has been heard and given due weight (influence). So, when we consider how well we have secured the right to communicate for individuals with communication disorder, we need to consider not just whether we have supported them to be able to communicate, but whether we have listened and responded to what they had to say and encouraged/assisted others to do so too.

Space and voice: Having the opportunity to speak

As health/education professionals working with individuals with communication disorder we aim to provide opportunities for expression (space) and modes (voice) to express ideas and experiences as a core component of our daily clinical activities. As health/education researchers, we have examples of this too. In particular, qualitative studies offer space and voice for individuals with a history of childhood communication disorder to share their lived experiences, and their insights can be challenging and thought-provoking.

For instance, interviews with pre-school children with communication (speech) disorder have revealed differences in the nature of the problems they experience: for some, speaking intelligibly; for some, being heard/understood; and for others, the frustration of communication breaking down (McCormack, McLeod, McAllister, & Harrison, 2010). Interviews with school-aged children have revealed similar differences in their understanding of their difficulties and the purpose of intervention (Owen, Hayett, & Roulstone, 2004). Longitudinal case studies of children have illustrated the complex, and ongoing nature of difficulties (Brinton, Fujiki, & Robinson, 2005), as have single case studies of adolescents/adults with a history of childhood communication disorder (Carrigg, Baker, Parry, & Ballard, 2015; McCormack, McAllister, McLeod, & Harrison, 2012). From the individuals in these studies, we can begin to understand the persistent and pervasive impact of childhood communication disorder on academic attainment, social relationships, education and employment prospects. We can also see the impact on emotional and mental health. For instance, Carrigg et al. (2015) reported 22-year-old BJ’s reflection on his experience of living with communication disorder. He recounted: “I often felt left out because I wasn’t able to talk with other people, I wasn’t able to tell other people my thoughts or if I needed something. It was heartbreaking because I knew what I wanted to say, but I couldn’t

say it” (p. 46). The impact for BJ was so profound that by 18 years, he had attempted suicide on three different occasions.

In their pioneering text *Listening to Children and Young People with Speech, Language, and Communication Needs*, Roulstone and McLeod (2011) compiled other first-person accounts from children, teenagers and young adults who live with communication disorder. Their accounts provide vivid insight into their lived experience, and in doing so, demonstrate the challenge of enacting the right to communicate when an effective mode of communication (voice) is absent, and the subsequent impact of communication disorder on other human rights. When sought and shared, these individual voices cause us to reflect on what we do and how we could do it better (Roulstone & McLeod, 2011). However, for these voices to inform policy and practice, they need to be heard.

Audience and influence: Having people to listen

As health/education professionals working with individuals with communication disorder, listening to our clients is core to our daily clinical work. Qualitative researchers aim to do this too. However, it is useful to reflect on the extent to which our clinical interactions and research insights influence what we do, particularly in an advocacy role. Qualitative research is usually focussed on a small select sample, guided by the agenda of the researchers and accessed by a relatively small audience of other researchers and clinicians. In order for this research to be truly reflective of individual perspectives and responsive to their priorities, there is a need for individuals to determine the focus of the research and the content to be shared. There is also a need for the information to be shared with a broad audience, and a need for the information that is shared to be acted upon by that audience. As the Honourable John Bercow stated in the foreword to Roulstone and McLeod’s book, “the fundamental principle... is that children and young people with speech, language and communications needs have, potentially, within them many of the answers to the questions which others are posing about them. Despite this, they tend to be ignored...” (Bercow, 2011, p. xxvii).

Lundy offered her framework (space, voice, audience and influence) as a potential model for “informing understanding, developing policy and auditing existing practice” with regards to enacting the right to communicate (p. 941). While health/education professions in Australia have provided some space and voice for individuals with communication disorder, our provision of an audience and advocacy for their influence has perhaps been less apparent.

Context of this study: The Australian Government Senate Committee

In 2013, the Australian Government Senate formed a Community Affairs References Committee for inquiry and report into the prevalence of speech, language and communication disorders and speech-language pathology services in Australia (Commonwealth of Australia, 2014). Submissions were sought from individuals and organisations in 2014. The terms of reference for the inquiry related to: the prevalence of different types of communication and swallowing disorder, the incidence within specific demographic groups, the availability/adequacy of public and private speech-language pathology services, the social and economic cost of failing to provide intervention and the projected demand for speech-language pathology services. Those wishing to make a submission were encouraged to address one or all terms of reference, highlight their own perspective, and suggest how any identified problems could be addressed. Thus, the Australian Government Senate Committee provided a *space* for children and adults with a history of communication disorder to *voice* their lived experience to a wide *audience*. Accessing, and engaging with, these submissions then provides a valuable starting point for reflecting on how the voice of individuals can *influence* understanding, practice, and advocacy for policy change.

Aim

Having applied Lundy’s framework to current research and practice in speech-language pathology, we identified some gaps in the extent to which individuals with communication disorder have been provided with a space, voice, audience and influence in the past. In this paper we attempt to address those gaps. Specifically, the aim of this paper is to examine the voices of Australian children and adults with a history of communication disorder in childhood; to consider their lived experience, and the impact of their communication disorder on their right to communicate, and on other human rights. Through this paper, the value of first-person accounts in understanding communication disorder and the potential power of individuals’ voices in influencing clinical practice and policy, to better enact the right to communicate, is emphasised.

Method

***Participants*¹**

There were 305 submissions to the Australian Government Senate Committee, of which 288 were publically accessible (Parliament of Australia, 2014). For the purpose of this study, submissions were excluded if (1) the topic was not childhood communication disorder, (2) an account of living with communication disorder was not included,

and/or (3) the account was not given by the individual with communication disorder.

There were 245 submissions related to childhood communication disorder, but the majority of these ($n = 231$) were made by academics who research in the field of childhood communication disorder, speech-language pathologists, associations/organisations that support people with communication needs, family members, teachers/principals, and other health professionals. These submissions were excluded as the purpose of this study was to explore first-person accounts from individuals with communication disorder. Of the remaining 14 submissions, two described general experiences of people with communication disorder only, rather than presenting a first-person account. As such, they were removed from the analysis. The final sample consisted of 12 submissions that included 17 first-person accounts of communication disorder in childhood made by either children or adults (one submission included letters from six children).

The children/adults who wrote the accounts experienced a range of communication disorder: speech and/or language and/or literacy difficulties ($n = 10$), childhood apraxia of speech ($n = 1$), communication disorder associated with cleft lip/palate ($n = 1$), and stuttering ($n = 5$). The authors ranged in age from children in the early years of school, adolescents, young-middle aged adults and older adults. Some noted their communication disorder was resolved, while others continued to experience difficulties. The submissions ranged in length from two to three sentences (from the youngest children) to multiple pages.

Procedure

The submissions received by the Australian Government Senate Committee investigating the prevalence of speech, language, and communication disorders and speech-language pathology services in Australia were accessed via the public website (Parliament of Australia, 2014). Every submission was read by one or more of the researchers to determine suitability for inclusion. All researchers then read and confirmed the appropriateness of the final 17 personal accounts for addressing the aims of this research.

Analysis

An interpretative phenomenological analysis was used in which six steps were undertaken to examine individual experiences and explore patterns across individuals' accounts (Smith, Flowers, & Larkin, 2009):

Step 1: Reading and re-reading the case

All researchers read each of the 17 personal accounts multiple times over a period of one to two weeks in

order to gain a sense of the individual's experience. This enabled immersion in each individual's accounts and a heightened awareness of each individual's key messages.

Step 2: Initial noting: Exploratory comments

Notes (typically in the form of codes) were made alongside the written accounts in order to identify the key messages individuals conveyed, particularly through their vocabulary and phrases (linguistic choice) and/or the particular focus within the account (semantic choices). All researchers noted comments on an initial sample of six submissions and met to discuss the key messages that they had identified and the consensus of their coding. The researchers had identified the same key messages although these were sometimes labelled differently. A single researcher then coded the remaining submissions (steps 3–5).

Step 3: Developing emergent themes

Codes were transformed into emergent themes to capture the core meaning being conveyed by each individual. Themes emerged as the researcher read and reflected on the codes from step 2, examined connections and contradictions, and determined words/phrases that encapsulated the message, drawing on the individual's own words where possible. Emergent themes from each individual's account were entered into a spreadsheet with one or more quotes that illustrated the meaning.

Step 4: Searching for connections across emergent themes

The list of emergent themes was interrogated to examine associations between themes. This involved re-examining the list of emergent themes and quotes approximately one week after the themes were developed, looking for overlaps and/or similarities in the meanings expressed by the themes and re-reading the illustrative quotes to determine whether these reflected the sense of connection. Superordinate themes, sub-themes, and interconnections between themes emerged through this process of reflection and interpretation.

Step 5: Moving to the next case

Once this process had been completed for one individual's account it was repeated for all others using the same interpretative phenomenological analysis approach. Initial ideas generated by the analysis of previous accounts were bracketed to prevent interference with subsequent analyses. All researchers met to discuss the emergent themes; they reflected on the illustrative quotes, considered whether the themes captured the messages

adequately and with appropriate emphasis, and reached a final consensus through this reflective process.

Step 6: Looking for patterns across cases

Finally, the list of each individual's super-ordinate themes was scrutinised to look for patterns across the sample. Individual Excel datasheets were generated for each theme and notes and quotes from each submission that reflected the particular theme were added to the datasheet to enable an exploration of consistencies and differences. A model was generated that illustrated the themes and connections. Each theme and each individual's account were then examined in light of the model to determine whether they were still represented. The model was shared with the research team and confirmed as reflective of the team's interpretation of the individuals' experiences.

Results and discussion

Four themes arose from the analysis, which will be described and discussed in this section with reference to sections of the Universal Declaration of Human Rights (United Nations, 1948), to Lundy's (2007) framework, and other literature. The themes were:

- (1) I am a person; I have a communication disorder.
- (2) My communication disorder impacts how I interact with others, and how they interact with me.
- (3) Help can change me, change communication disorders, and change lives.
- (4) My life would be different if I didn't have a communication disorder.

Theme 1: I am a person; I have a communication disorder

The first theme identified the individuality of people with communication disorder, while recognising similarities in the way in which these difficulties presented; often hidden to others or the individuals themselves. As such, two subthemes emerged: Me and Hidden (Figure 1).

Me: "I am an intelligent adult with a series of communication issues"

Across all of the submissions authored by adults ($n=9$) and half of those authored by children ($n=4$), a sense of individuality, competence, and humanity was emphasised. Many of the individuals commenced their submissions with an introduction of who they were; their name, age, occupation, qualifications, married status, family composition, and/or cultural background. While inclusion of this information may reflect the purpose for which they were writing (i.e. providing background to contextualise their submission) this information overlaps

with many facets of human diversity that the Universal Declaration of Human Rights recognises and protects in Article 2. For the individuals, including this information also reflected their sense of themselves as unique, intelligent, and capable individuals first, and as people with communication disorder second. One child commented; "I may have had no speech but I was really quite smart" (S170D), while an adult made a similar point: "I believe I am a very intelligent person who has great potential to achieve greater goals in life and serve the community in a very productive manner" (S07). This idea that people with a communication disorder are individuals first and foremost resonates with other personal accounts in the literature. For instance, Sadruddin and Wahab (2013) reported meeting Joseph, a man with mild intellectual impairment, who wanted his researchers to know "I am a NORMAL human being... Though I have minor physical disability and can't communicate clearly; that doesn't mean that I am abnormal." Joseph, like the adults and children in the current paper, wanted to be recognised as individuals, not communication disorders.

When they did describe their communication disorder, the individuals did so in terms of the diagnosis and/or the symptoms they experienced, for instance; "I have a stutter" (S133), "I have never been able to spell" (S11), "I couldn't talk good" (S99Z). For some, these difficulties were still a part of who they were, but only a part: "I am an intelligent adult with a series of communication issues" (S11). However, they did note the way in which the communication disorder resulted in feelings of inadequacy ("I always thought I was dumb" (S56)), sadness, or frustration that others failed to look beyond the communication disorder to see them as real people; "They treat me like I'm mentally challenged and incapable of doing any meaningful work and earning an income" (S133). The experiences that individuals describe show the emotional and behavioural consequences of their right and ability to communicate being challenged, which has been widely reported in the research literature (Brinton, Fujiki, & Robinson, 2005; Carrigg et al., 2015; McCormack et al., 2010, 2012).

Hidden: "Years of holding back from showing the real you"

It was evident from the submissions that when a communication disorder is present, it can hide an individual's skills, abilities and indeed a part of their humanity. As one child described it: "your child might be like me and have lots of ideas hidden in a secret place in their brain" (S170D). At times, the cause of their communication disorder was hidden from the individual themselves: "It is hard to explain what is going on inside my head when I am often

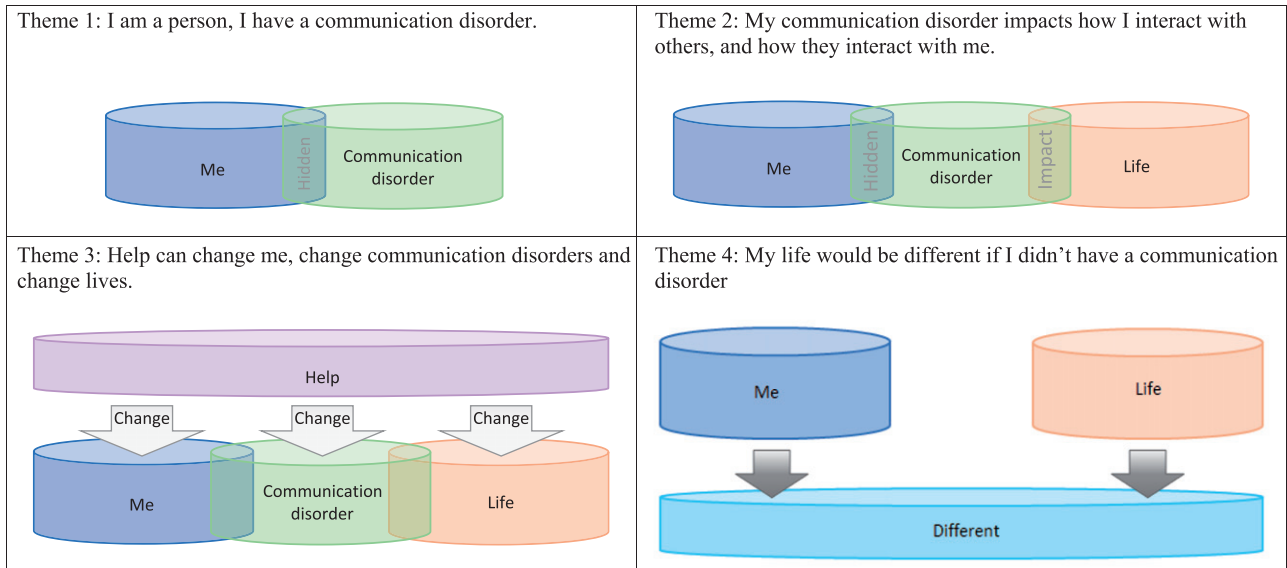


Figure 1. Four themes on life with a childhood communication disorder.

unaware of it myself” (S11). Some children explained the “frustration” associated with this: “I couldn’t say anything right ... I couldn’t hear what I said wrong” (S99R). The frustration associated with communication disorder has been previously identified in research with pre-school children, and the cause of the frustration (both ‘speaking’, and “listening” problems) was similar too (McCormack et al., 2010).

At other times, individuals attempted to hide their communication disorder in a desire to fit in. This was particularly evident among the individuals with fluency disorders: “I used to substitute the words I couldn’t get out ... I often pretended to go to the bathroom before it was my turn [to read class novel aloud]” (S06). Individuals described the “fear” of being found out and the subsequent “embarrassment” if they were. As a consequence, some individuals noticed themselves “withdrawing” from interactions with others and “holding back from showing the real you” (S21). This idea that a communication disorder can mask the real person, constraining the ability or desire to share thoughts, needs, and feelings is consistent with previous personal accounts (Carrigg et al., 2015; McCormack et al., 2012). Collectively, such accounts reveal how the hidden nature of communication disorder and the consequences of that disorder ironically conceal the challenge to the right to communicate being enacted. Furthermore, when the problem is hidden, the need for solutions remains hidden also.

Theme 2: My communication disorder impacts how I interact with others, and how they interact with me

The second theme reflected the uniqueness of individuals’ life experiences and the ways in which

a communication disorder can impact the individual’s life, especially interactions with those around them. Two subthemes were evident within this second theme: Life and Impact (Figure 1).

Life: “My life is pretty busy. I have lots of different activities and hobbies”

Within their submissions, individuals described their lives in terms of their interests and their hopes for the future. This theme, like the first, emerged as evidence of their desire to claim an identity outside of their communication disorder. Children and adolescents described their enjoyment of sports and engagement in hobbies and community events. They described potential future employment pathways such as teaching and computer animation, and recognised their ability to contribute to society. One child commented, “I believe that even though we are only children we can still really make a difference in the world ...” (S170D). Then continued, “... being able to communicate has helped me to talk to people about my ideas”. For this child, communication was key to realising Article 29 of the Universal Declaration of Human Rights in which “Everyone has duties to the community in which alone the free and full development of his personality is possible”. Adolescents and adults described their paid employment, but also their voluntary work, often assisting others with communication disorder through coaching (S21) and mentoring (S13).

This idea of individuals with a communication disorder living a busy life and aspiring to engage in employment, hobbies, and community events accords with previous accounts. For instance, Sadruddin and Wahab (2013) reported in their case study of Joseph that he had an aspiration to develop a business decorating bottles and earn a

living to financially support his family. Carrigg et al. (2015) reported in their study that BJ, a young man with a severe speech sound disorder, had an aspiration to “have a career that will help people” (p. 46). However, a communication disorder can affect the realisation of these aspirations.

Impact: “My communication disorder has had a significant and profound impact on my life”

The presence of a communication disorder was generally recognised as influencing an individual’s life experience: “Growing up with a communication disorder was extremely difficult” (S175). It was clear that a communication disorder in childhood could affect how individuals undertake life activities, interact with other people, and the way in which others interact with them. Such comments affirm recollections by others reported in the literature on the impact of a communication disorder of their life (Carrigg et al., 2015; McCormack et al., 2010, 2012; Sadruddin & Wahab, 2013). One child recognised this within his own experience; “I know that life can be a bit tricky for me” (S170D) while one young adult recognised that he was not alone in his experiences; “. . . craniofacial anomalies affect the lives of thousands of children in our world” (S13).

The individuals reflected on tasks that were difficult during the school years: reading aloud, answering teacher’s questions, doing show-and-tell, reading, understanding, and completing tasks on time. While the “right to education” ensured in Article 26 of the Universal Declaration of Human Rights was enacted for these individuals, the experience was often not positive. One explained how “all talking used to be very terrifying” (S170D) and others described how they “dreaded” going to school. One explained how he “was unable to communicate with my teachers or other children, which really impacted my ability to learn and to socialise” (S175). Such comments were consistent with previous reports in the literature. For instance, in recollecting his experience of high school, BJ noted “I was often intentionally put in many distressing and upsetting situations by my teachers” (Carrigg et al., 2015, p. 46).

As a result of their difficulties, children sometimes felt sad and withdrew from social activities; “I was really nervous, too nervous to go up to people playing . . .” (S99R). However, at other times they had no choice and were actively left out, teased and bullied: “When I was at school, I can remember spending every lunch time sitting by myself because no one will even try to talk to me” (S175). Adolescents and adults were disappointed by teachers who made them feel “stupid” and embarrassed, or failed to recognise their academic difficulties reflected an underlying communication disorder. This suggests their rights under Article 5 of

the Universal Declaration of Human Rights, which protects individuals from “degrading treatment”, were not being met. In some cases, this was experienced more through passive actions such as neglect: “unfortunately most teachers didn’t even notice . . . wouldn’t even question why my marks were so bad” (S56).

Some adults provided specific examples of how their adult lives had been impacted, for instance, one described how she changed her lunch order every day in order to avoid saying words that she produced dysfluently. Another described how he changed jobs due to the fear of making errors, and a third explained how his choice of career was influenced by the “. . . belief that you could not pursue a career that involves verbal communication” (S21). Again, these accounts reiterate others from the literature. For instance, Brinton, Fujiki and Robinson (2005, p. 349) noted how Cody, a 19-year-old man with a language disorder, was coming to a realisation that being a novelist was not a realistic goal, and that he “will not be able to do the things that he would like to do”.

Other adults felt that a failure to understand their communication disorder had led potential employers to disregard them in job interviews: “It is hard for me to communicate effectively during job interviews because I missed out on jobs that require reasonable communication skills” (S07). In cases such as these individual’s “right to work, to free choice of employment” (Article 23) was challenged due to their communication disorder. These submissions show the importance of providing individuals with communication disorder with *space* (opportunities) to share their ideas, and with an *audience* that listens (Lundy, 2007).

Theme 3: Help can change me, change communication disorders and change lives

The third theme recognised the types of help that were provided to individuals and the way in which the provision of help might need to be altered in order to be more effective. This theme also recognised the changes that result from the provision of timely and effective help. Consequently, there are two subthemes: help and change (Figure 1). These themes did not relate specifically to the Universal Declaration of Human Rights, but demonstrated how help supported the enactment of a range of human rights which require communication to be realised.

Help: “It’s good for people to learn how to speak and help people to understand you”

A strong and recurrent theme that emerged across the submissions reflected the need for help. All submission authors described the help that they had sought or received or help that had been sought on their behalf to address their

communication disorder. This included formal assistance such as medication, speech-language pathology intervention, consultations with other health professionals, provision of aids, workshops/courses, and surgery. Help was generally considered “good” and “important”, although limitations or challenges were also noted, in terms of cost, effort, availability, and effectiveness: “... I was still unable to retain any information which made me feel horrible for wasting my mum’s money” (S56). Individuals also recognised the value of informal help through relationships with others who could provide them with information, strategies and support.

Many also identified a need for the provision of help to change, listing recommendations, based on their experiences: “I think there should be more readily available and accessible services and programs to aid children with communication disorders and their families” (S175). The inclusion of such information is perhaps not surprising, given the purpose of writing these submissions was to inform the Australian Government Senate Inquiry about service provision and need; however, the type and focus of these recommendations was broad and insightful, including research, education, funding, mandatory testing and more frequent services, as well as better recognition/marketing of effective programs.

Change: “The [intervention] course changed my life for the better”

It was clear from the submissions that help can directly change an individual’s communication disorder, their self-perception and/or their life. Some individuals described the way that help had improved their communication skills: “Now I can talk really good” (S99Z). However, the majority described how help had improved their lives. For instance, children reported having more friends, and being able to participate in activities that were once difficult such as answering questions in class, sharing their ideas, asking to play games with other children or helping children who were hurt, which they had not been able to do previously. As a result, their sense of self altered too, as they reported changing from anxious and fearful speakers to happy and confident ones. These accounts provide further testimony to the fact that when communication disorders are addressed, lives can be transformed through widespread changes in day-to-day activity and participation (Thomas-Stonell, Oddson, Robertson, & Rosenbaum, 2009).

Children and adults recognised that change takes time: “I was a big man when I talked good” (S99D). For some adults, they had made improvements but still had work to do. However, others had experienced “life-changing” benefits. Like the children, the adults described changes to their lives as a result

of effective help, with one pursuing a new career, and others feeling more confident in their daily lives. Two also experienced changes in how they perceived themselves as a consequence of understanding their communication disorder, through the help they had received: “I have a greater understanding and newfound respect for my own determination ...” (S11). These submissions highlight the way in which help can create change, for individuals, their communication disorder and their lives. This information, coupled with the empirical evidence on the effectiveness of interventions for communication disorders, should *influence* us to become better advocates for change in policy and service delivery (Lundy, 2007).

Theme 4: My life would be different if I didn’t have a communication disorder

Throughout the submissions, there was a sense that individuals felt different from their peers as a result of having a communication disorder, and felt that their lives would have been different if the communication disorder did not exist or had been addressed earlier. This theme of “difference” is shown in two subthemes: Different Me and Different Life (Figure 1).

Different me: “I hated being different”

Individuals reflected on their desire to be like “everyone” else and their sadness in being different to others. Some identified the confusion they experienced in trying to figure out why: “I never understood how everyone understood everything but me” (S56). Others commented on how they used strategies to appear “normal” (such as substituting words). In addition to hiding their difficulties, some individuals also described how they attempted to hide their receipt of help: “I didn’t tell my friends I did it [speech therapy]” (S279). Others hid the informal strategies that they relied upon on to get by, such as “copying the other children” in the class (S56). This appeared to reflect their desire of not appearing different or incapable. The struggle of not wanting to be different but feeling and/or being different accords with previous research on the experiences of children with a communication disorder (Brinton et al., 2005; Havstam, Laakso, & Ringsberg, 2011). For instance, Havstam et al. noted how young adults growing up with a cleft and a speech impairment, desired to fit in yet saw themselves as different. Similarly, Cody – a young man with a language disorder – perceived his social life as like riding a tricycle, while his peers drove sports cars (Brinton et al., 2005). In order for the right to communicate to be upheld, differences in communication styles/abilities need to be acknowledged without stigma (Merrick & Roulstone, 2011).

Different life: “What if? where would I be now?”

There was a sense that life would be different if an individual’s communication disorder was recognised, an accurate diagnosis was made, and appropriate help was given: “I believe my life would have been very different if my disorder had been picked up earlier” (S56). However, individuals noted that help was not provided due to a lack of awareness and understanding about communication disorder: “Communication issues are invisible in the classroom unless you have a trained eye” (S11). Thus, there was a sense of needing to help potential helpers (e.g. teachers) to see what was “hidden”. One individual had only received effective help as an adult, despite accessing other services as a child. He reflected that his life might have been different if this help had been received earlier: “What if? Where would I be now?” (S21). Thus it is clear that the difficulties experienced by people with communication disorder may be exacerbated by violations of other rights, such as the right to medical care and social services for health and wellbeing (Article 25).

Summary

While each theme is independent, the interconnections highlight the complex way in which personal identity, communication disorder, life, and help blend in unique and dynamic ways. The individuals saw themselves as people first (“Me”) with communication disorder that impacted their lives. They recognised that their humanity and their communication disorder could be invisible to others (“Hidden”) due to the very nature of the problem. However, they also recognised that their communication disorder could be hidden by their own actions, taken due to a desire to be acknowledged for who they were (“Me”) rather than how they might otherwise be perceived (“Different Me”). They saw the value of support and intervention (“Help”) in addressing the impact of communication disorder and altering life outcomes (“Different Life”). However, for this to occur, communication disorders and their consequences (“Impact”) needed to be made visible.

Limitations

The number of personal accounts analysed in this study was small, and participant checking of themes, to ensure that they accurately reflected individual’s experiences, was not undertaken. These limitations were due to the nature of the dataset from which the sample was taken. Further research with a larger sample would be useful in determining whether the themes that emerged from this research could be applied to other children and adults with

communication disorder. Furthermore, the relationship between human rights attainment and specific types of communication disorder could be explored.

Conclusions

Article 19 of the Universal Declaration of Human Rights (United Nations, 1948) ensures “the right to freedom of opinion and expression” for all people, and the Preamble stipulates the role we all play in promoting and securing this right for others. For health/education professionals, we have a particular role in supporting individuals with communication disorder, whose right to communicate may be challenged by the lack of an effective means of communication. However, supporting them to gain an effective *voice* (means of communication) is only part of our role. We also need to consider how we provide them with a space, an audience and an influence. To undertake our role effectively, it is imperative that we understand how communication disorder constrains the right to communicate, and by extension, the enactment of other rights. Additionally, we need to understand how these constraints are, or can be, overcome.

The individuals with communication disorder who made submissions to the Australian Government Senate Inquiry revealed how communication disorder can impact the right to communicate and other human rights. Their accounts, and their insights into service provision and access, have the potential to inform our policies and improve our practices, but only if we become an *audience* who listens, and advocates for this *influence*. Seventy years after the creation of the Universal Declaration of Human Rights it remains the responsibility of all of us to seek out, listen to, and *act on* the voices of those who are typically the least likely to be heard.

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Declaration of interest


No potential conflict of interest was reported by the authors.

Note


1. Note: Participants have been referred to as “Individuals” throughout the paper as they were not participants in a research study, rather individuals sharing their stories. In

the Results section, excerpts from the submissions (S) are referenced with numeric codes taken from the numbers assigned to the original submissions. When more than one account was included in a single submission, the first initial of the author has been added (e.g. S99A referred to one child's account in submission 99; S99K refers to another child's account within submission 99).

ORCID

Jane McCormack  <http://orcid.org/0000-0001-9133-9023>

Elise Baker  <http://orcid.org/0000-0002-9973-5925>

Kathryn Crowe  <http://orcid.org/0000-0003-3496-5129>

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