The Sustainable Development Goals: A framework for addressing participation of persons with complex communication needs in South Africa

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Abstract

Background: Participation in society is the cornerstone to living a meaningful, connected, and healthy life. Persons with complex communication needs, however, often have restricted opportunities to participate in everyday contexts and situations. Reasons for this include societal attitudinal barriers, as well as limited knowledge and skills about augmentative and alternative communication (AAC) to enhance participation. Enhancing participation of persons with complex communication needs requires a holistic and multi-faceted approach. The 17

Sustainable Development Goals (SDGs) with their disability-inclusive agenda provide an impetus for shaping the approach of the Centre for Augmentative and Alternative Communication (CAAC) in enhancing participation of persons with complex communication needs in South Africa.

Purpose: This paper aims to provide a reflective description and application of the work conducted by the CAAC in addressing the SDGs in South Africa.

Key findings: Research and training conducted by the CAAC is shown to be clearly aligned to five SDGs, namely zero hunger (SDG 2), good health and well-being (SDG 3), quality education (SDG 4), decent work and economic growth (SDG 8) and peace, justice, and strong institutions (SDG 16), with a focus on reaching these goals in order to benefit persons with complex communication needs. The paper demonstrates that, despite some gains in addressing the SDGs, research still needs to be done on these and the remaining SDGs. Furthermore, there is a need to also find ways to integrate the SDGs to ensure participation of persons with complex communication needs in major life activities and society.

Introduction

The overriding principles of the 17 Sustainable Development Goals (SDGs) (United Nations, 2015) are the global elimination of disparities through the improvement of situations for all people as well as a focus on sustainable development. The SDGs offer a universal agenda that is inclusive, embracing the principle that "no one is left behind" (United Nations 2015, p.1). This expressly includes persons with disabilities, and applies to everyone everywhere, namely both low- and high-income countries. The SDGs also recognize the importance of redressing inequities experienced by vulnerable and marginalized groups including persons with disabilities. As such, the SDGs provide an impetus for shaping the approach of the Centre for Augmentative and Alternative Communication (CAAC) in enhancing participation of persons with communication disabilities and specifically persons with complex communication needs in South Africa. Augmentative and alternative communication (AAC) describes a field of research, clinical and/or educational practice that aims to provide individuals who have complex communication needs with additional and/or other methods of communication that replace or supplement spoken and/or written forms of communication. AAC strategies include unaided forms of communication that do not require aid or assistive technology (e.g., natural gestures and signs), as well as aided forms, where an aid or piece of assistive technology is required (e.g., communication boards with various symbols and speech generating devices) (Beukelman & Light, 2020). This paper aims to provide a reflective description and application of the work conducted by the CAAC in addressing the SDG.

Participation in society is the cornerstone to living a meaningful, connected, and healthy life (WHO, 2001). Enhancing participation of persons with complex communication needs requires a holistic, systemic and multi-faceted approach (Dada et al., 2017). The CAAC has

applied the SDGs in their approach, and a reflection on some of this work and the opportunities and challenges in using an SDG framework is provided.

Zero Hunger (SDG 2)

Persons who experience communication /swallowing disabilities are at increased risk for food and nutrition insecurity. According to Gross (2002), food and nutrition security is achieved when there is sufficient quantity and quality of food as well as food that is safe, socioculturally acceptable, accessible and available to enhance health and well-being. Food and nutrition security risks for persons with disabilities stems from the nature of their communicative impairments where requesting food may be difficult as well as feeding or swallowing impairments which often present as comorbid conditions for persons with complex communication needs and require AAC such as children with cerebral palsy (Moore et al., 2021). Food insecurity is more prevalent in households where there is someone with a disability (Heflin et al., 2019). Caregivers of persons who experience communication /swallowing disabilities are often not able to work due to caregiving responsibilities, thus creating a tenuous economic situation for families and increasing their risk for food insecurity. This is especially pertinent in low- and middle-income countries where persons with disabilities are most at risk as they tend to come from the poorest households. In South Africa, which is a middle-income country, malnutrition is one of the leading health issues facing children (Graham et al., 2018). To address this, some schools offer their learners at least one meal per day as part of South Africa's National School Nutrition program. The COVID-19 pandemic and the resultant lockdown unfortunately greatly exacerbated food insecurity for all school children when they were not able to access this vital support. In terms of the International Classification of Functioning, Disability and Health

framework (WHO, 2001), when persons with disabilities are food and nutritionally insecure, it will affect their ability to participate since their vulnerable health status (body structures and function) and their difficulties in eating and feeding (activity) will have a knock-on effect on their functional skills.

One of the current PhD projects in the CAAC, aims to develop and validate a contextually relevant tool to accurately measure food and nutrition security in persons with disabilities specifically children. It is hoped that such a tool will help to better understand the conditions under which food and nutrition security develops in this context and with this population.

Good health and well-being (SDG 3)

Due to their disability and other coexisting conditions persons with complex communication needs, often need to access healthcare. In South Africa, English is mainly used in healthcare settings when patients are treated by healthcare practitioners with different languages or cultures to them (Johnson et al., 2022). Apart from communication disabilities, language challenges could result in patients having insufficient English vocabulary to communicate with healthcare practitioners. The CAAC research team focussed on two of the 13 targets of good health and well-being (SDG 3), namely, reducing mortality from non-communicable diseases through prevention and treatment and promoting mental health and well-being (SDG 3.4), and achieving universal health coverage, including access to quality essential health-care services (SDG 3.8).

First, pain-related vocabulary was selected to enable children with complex communication needs to communicate their pain (Johnson et al., 2016). Second, the use of AAC strategies within South African intensive care settings was researched from the perspectives of

patients (Kuyler & Johnson, 2021) and nurses (Johnson et al., 2022). Third, an e-health tool, called PicPecc, was developed using universal design principles to enable persons with long-term illnesses to participate in their health management and care (Thunberg et al., 2021) and preliminary findings confirmed PicPecc's feasibility for use in South Africa. PicPecc is available in various languages including English and six South African languages. Last, a study was conducted that focussed on the co-development of health materials with persons with complex communication needs (Dada et al., 2022). These materials were translated into six South African languages (isiZulu, isiXhosa, Sepedi, seTswana, Afrikaans and seSotho sa-lebowa) are available on the CAAC webpage https://www.up.ac.za/centre-for-augmentative-alternative-communication. All these studies emphasised the enhancement of the health and well-being of persons with complex communication needs.

Quality Education (SDG 4)

Quality Education (SDG 4) was addressed by focussing on two targets, namely eliminating all discrimination in education (SDG 4.5) ") and increasing the supply of qualified teachers in developing countries (SDG 4.C). Early descriptive work found that children with complex communication needs were primarily cared for rather than educated, and that access to AAC was extremely limited - less than 1% of 1344 students in schools for learners with special educational needs in the Gauteng province used any symbolic form of AAC (Alant, 1999). However, teachers were found to have positive attitudes towards learners using AAC (Dada, 2019). A multitude of formal and informal AAC training opportunities have been offered to teachers by the CAAC. Various AAC intervention studies affirm the positive effects of these

interventions for potential use in classrooms in South Africa (Laher & Dada, in press; Naude et. al., 2020; Tönsing, 2016). Research has also been conducted to lay the groundwork for the development of culturally and linguistically appropriate forms of AAC in various historically under resourced languages (Tönsing et al., 2019). For example, core vocabularies in South African languages have been established (Mngomezulu et al., 2019; Mothapo et al., 2021). Such systems can enhance equitable access to education for children with complex communication needs form various language backgrounds.

Although the long-term effects of teacher training on educational inclusion of children with complex communication needs have not been formally assessed, it is noteworthy that the implementation of AAC in schools in Gauteng has increased since 1999. Tönsing and Dada (2016) found that of 20 of 22 schools for learners with special educational needs had a form of aided AAC available, while McDowell & Bornman (in press) found that 13 of 18 schools for learners with special educational needs used signs from sign language. Tönsing and Dada (2016) further found that implementation of aided AAC in the classroom context is influenced by a variety of complex factors, and these factors should be considered in future training and implementation studies. Training should be provided not only to teachers but to all members of the student's support team, and long-term outcomes should be monitored.

Decent work and economic growth (SDG 8)

Persons with complex communication needs continue to face barriers in accessing employment opportunities (Morwane et al., 2021). Despite the introduction and implementation of laws and policies that facilitate participation of persons with disabilities on an equal basis as

others, many still experience challenges participating in the open labour market. Persons with complex communication needs due to presence of a communication impairment, and co-morbidity of physical or intellectual disability, experience the marginalisation in accessing education and training opportunities (Richardson et al., 2019). This further impacts on future employment prospects. The CAAC research focused on work and employment of persons with complex communication needs is represented by decent work and economic growth (SDG 8). The following targets guided the projects:

SDG 8.3 Promote policies to support job creation and growing enterprises

SDG 8.6 Promote youth employment, education and training

The CAAC has participated in training youth with complex communication needs on the development of skills required for entrepreneurial and employment. A research project interviewed eight of the participants, who after the project, reported on a desire to be formally employed and living independent lives (Sefotho et al., 2019). A second project involved interviewing employed and unemployed youth with complex communication needs and specialised recruitment agents on what they considered facilitated and hindered their participation in employment (Morwane, 2021). The participants reported factors such as the availability of services and policies as facilitators, and the presence of negative attitudes, the lack of education and skills as barriers to being employed. In the third project, specialised recruitment agents based on factors reported as facilitating when placing a person with complex communication needs in employment, developed a guiding placement checklist (Morwane, 2021). The checklist is envisioned to support successful employment of persons with complex

communication needs. The studies highlighted the importance of services such as transportation, health employment, and education in ensuring participation of persons with complex communication needs in employment.

Peace, justice and strong institutions (SDG 16)

Women and children with disability, especially those with complex communication needs, are at high risk for abuse (Marshall & Barrett, 2018). Their inability to effectively rely on speech renders them to be regarded as being voiceless and invisible in society, making them low-risk easy targets. Despite this heightened risk for victimization, which results in increased need for seeking justice, access to justice remains elusive for them. Limited communication skills hinder their ability to engage or seek the assistance of stakeholders in the criminal justice system.

Our research harnessed Peace, justice and strong institutions (SDG16), in a systematic way to provide access to justice for persons with complex communication needs. It is driven by three of the 12 targets, namely;

SDG 16.1   Significantly reduce all forms of violence

SDG 16.2   End abuse, exploitation, trafficking and violence against children

SDG 16.10   Ensure public access to information and protect fundamental freedoms, in accordance with national legislation and international agreements

Our research commenced with the development of four You can Tell and be Heard communication boards to disclose abuse (Bornman et al., 2011). The vocabulary included on these

boards were subsequently socially validated (Bornman & Bryen, 2013). Thereafter a project followed to empower police officers to take statements from victims with complex communication needs by employing AAC (Viljoen et al., 2021). This resulted in some cases now going to court. However, most courts were unaware and ill-equipped to efficiently provide accommodations that would allow individuals with complex communication needs to testify. Hence a legal scoping review of possible court accommodations for persons with complex communication needs was undertaken (White, Bornman et al., 2021) followed by empirical study (White et al., 2021). These studies all highlighted the importance of AAC in court.

Conclusion

In this commentary paper it is evident that the SDG framework clarifies the need for a comprehensive approach towards sustainable development to enhance participation of persons with complex communication needs in South Africa. The work of the CAAC spans various SDGs (SDG 2, SDG 3, SDG 4, SDG 8, and SGD 16) in an effort to move beyond impairment-focussed interventions. However, more needs to be done to build on and expand this work. Materials, guidelines, and training programs need to be implemented, evaluated and adapted through meaningful partnerships with persons with complex communication needs, families, and service institutions. Research findings need to feed into policy and legislature to ensure visibility and equity of persons with complex communication needs on this level reducing inequalities (SDG 10). Most importantly, persons with complex communication needs should not only be positioned as beneficiaries of reaching specific SDG targets, but also as active drivers in shaping and attaining these goals. Whilst it highlights some of the gains made in addressing the SDG there is still much research that still needs to be done on these and the remaining SDG.

Furthermore, there is a need to also find ways to integrate the SDG to ensure participation of persons with complex communication needs in society and various aspects of development.

References

Alant, E. (1999). Students with little or no functional speech in schools for students with severe mental retardation in South Africa. *Augmentative and Alternative Communicaitn*, *15*(2), 83–94. . https://doi.org/10.1080/07434619912331278595

Beukelman, D.R. & Light. J. (2020). Augmentative and Alternative Communication Supporting Children and Adults with Complex Communication Needs (5ᵗʰ Ed.). Paul H Brookes Publishing

Bornman, J. & Bryen, D. (2013). Social validation of vocabulary selection: Ensuring stakeholder relevance. *Augmentative and Alternative Communication*, *29*(2), 174-181. https://doi.org/10.3109/07434618.2013.784805

Bornman, J., Bryen, D., Kershaw, P. & Ledwaba, G. (2011). Reducing the risk of being a victim of crime in South Africa: You can Tell and be Heard!" *Augmentative and Alternative Communication*, *27*(2), 117-130. https://doi.org/10.3109/07434618.2011.566696

Dada, S. (2019). A Comparison of Special Education Teachers' Attitudes Toward Various Augmentative and Alternative Communication Systems. In S. Halder & V. Argyropoulos (Eds.). *Inclusion, Equity and Access for Individuals with Disabilities*, (pp. 153-178). Palgrave Macmillan.

Dada, S., May, A., Bastable, K., Samuels, A., Tönsing, K. M., Wilder, J., Casey, M. G., Ntuli, C., & Reddy, V. (2022). The involvement matrix as a framework for involving youth with severe communication disabilities in developing health education materials. *Health*

Expectations. Advance online pubication. https://doi.org/10.1111/hex.13445

Dada, S., Kathard, H., Tönsing, K., & Harty, M. (2017). Severe communication disabilities in South Africa: Challenges and enablers. In S. Halder & L. Czop Assaf (Eds.), *Inclusion, disability and culture* (pp. 169-193). Springer.

Graham, L., Hochfeld, T., & Stuart, L. (2018). Double trouble: Addressing stunting and obesity via school nutrition. *South African Journal of Child Health*, *12*(3), 90-94. https://doi.org/10.7196/SAJCH.2018.v12i3.1455

Gross, R. (2002). Food and nutrition security in poverty alleviation: Concepts, strategies, and experiences at the German Agency for Technical Cooperation. *Asia Pacific Journal of Clinical Nutrition, 11*, S341-S347. https://doi.org/10.1046/j.1440-6047.11.s1.8.x

Heflin, C. M., Altman, C. E., Rodriguez, L. L., 2019. Food insecurity and disability in the United States. *Disability and Health Journal, 12* (2), 220–226. https://doi.org/10.1016/j.dhjo.2018.09.006.

Johnson, E., Bornman, J., & Tönsing, K. M. (2016). An exploration of pain-related vocabulary: implications for AAC use with children. *Augmentative and Alternative Communication, 32*(4), 249-260. https://doi.org/10.1080/07434618.2016.1233998

Johnson, E., Heyns, T., & Nilsson, S. (2022). Nurses' perspectives on alternative communication strategies use in critical care units. *Nursing in Critical Care*, *27*(1), 120-129. https://doi.org/10.1111/nicc.12612

Kuyler, A., & Johnson, E. (2021). Patient and nurse content preferences for a communication board to facilitate dialogue in the intensive care unit. *Intensive and Critical Care Nursing*, *63*, 103005. https://doi.org/10.1016/j.iccn.2020.103005

Laher, Z., & Dada, S. (accepted). The effect of aided language stimulation on the acquisition of receptive vocabulary in children with complex communication needs and severe intellectual disability: A comparison of two dosages. *Augmentative and Alternative Communication.*

Marshall, J., & Barrett, H. (2018). Human rights of refugee-survivors of sexual and gender-based violence with communication disability. *International Journal of Speech-Language Pathology, 20*(1), 44-49. https://doi.org/10.1080/17549507.2017.1392608

McDowell, A. & Bornman, J. (2022). Using unaided augmentative and alternative communication strategies to support learners in South African schools: A study of teachers' perceptions. *Augmentative and Alternative Communication, 38*(2), 106-122. https://doi.org/10.1080/07434618.2022.2071763

Mngomezulu, J., Tönsing, K. M., Dada, S., & Bokaba, B. (2019). Determining a Zulu core vocabulary for children who use augmentative and alternative communication. *Augmentative and Alternative Communication, 35*(4), 274–284. /https://doi.org/10.1080/07434618.2019.1692902

Moore, R., Dada, S., Emmambux, M. N., & Samuels, A. (2021). Food and nutrition security in persons with disabilities. A scoping review. *Global Food Security, 31*, 100581. https://doi.org/10.1016/j.gfs.2021.100581

Morwane, R. E., Dada, S., & Bornman, J. (2021). Barriers to and facilitators of employment of persons with disabilities in low- and middle-income countries: A scoping review. *African Journal of Disability*, *10,* 1-12. https://doi.org/10.4102/ajod.v10i0.833

Morwane, R. E. (2022). Barriers to and facilitators of employment of persons with complex commuincation needs: Perspectives from persons with complex commuincation needs and

specialised recruitment agents. [Doctoral dissertation]. University of Pretoria

Mothapo, N. R. B., Tönsing, K. M., & Morwane, R. E. (2021). Determining the core vocabulary
used by Sepedi-speaking children during regular preschool activities. *International Journal of Speech-Language Pathology, 23*(3), 295–304.
https://doi.org/10.1080/17549507.2020.1821774

Naude, T., Dada, S., & Bornman, J. (2020). The effect of an augmented input intervention on
subtraction word-problem solving for children with intellectual disabilities: A preliminary
study. *International Journal of Disability, Development and Education*. Advance online
publication. https://doi.org/10.1080/1034912X.2020.1840530

Richardson, L., McCoy, A., & McNaughton, D. (2019). "He's worth the extra work": The
employment experiences of adults with ASD who use augmentative and alternative
communication (AAC) as reported by adults with ASD, family members, and employers.
Work, 62(2), 205–219. https://doi.org/10.3233/WOR-192856

Sefotho, M., Morwane, R. E., & Bornman, J. (2019). Inclusive employment plight of youth with
complex communication needs. In S. Halder & V. Argyropoulos (Eds.), *Inclusion, Equity and Access for Individuals with Disabilities* (pp. 281–296). Palgrave Macmillan.

Thunberg, G., Johnson, E., Bornman, J., Öhlén, J., & Nilsson, S. (2022). Being heard –
supporting person-centred communication in paediatric care using augmentative and
alternative communication as universal design: A position paper. *Nursing inquiry*, e12426.
https://doi.org/10.1111/nin.12426

Tönsing, K. M. (2016). Supporting the production of graphic symbol combinations by children
with limited speech: A comparison of two AAC systems. *Journal of Developmental and Physical Disabilities, 28*(1), 5–29. https://doi.org/10.1007/s10882-015-9425-5

Tönsing, K. M., & Dada, S. (2016). Teachers' perceptions of implementation of aided AAC to

support expressive communication in South African special schools: A pilot investigation.

Augmentative and Alternative Communication, *32*(4), 282–304.

https://doi.org/10.1080/07434618.2016.1246609

Tönsing, K. M., van Niekerk, K., Schlünz, G., & Wilken, I. (2019). Multilingualism and

augmentative and alternative communication in South Africa – Exploring the views of

persons with complex communication needs. *African Journal of Disability,* 8, a507.

https://doi.org/10.4102/ajod.v8i0.507

United Nations (2015). Sustainable Development Goals: 17 Goals to transform our world.

https:// www.un.org/sustainabledevelopment/sustainable-development-goals/

Viljoen, E., Bornman, J. & Tönsing, K. M. (2021). Interacting with persons with disability:

Police officers' knowledge, experience and perceived competence. *Policing: A Journal of

Policy and Practice*, *15*(2), 965–979. https://doi.org/10.1093/police/paaa084

White, R., Bornman, J., Johnson, E., & Msipa, D. (2021). Court accommodations for persons

with severe communication disabilities: A legal scoping review. *Psychology, Public

Policy, and Law, 27*(3), 399–420. https://doi.org/10.1037/law0000289

White, R., Johnson, E. & Bornman, J. (2021). Giving voice to the voices of legal practitioners

with disabilities. *Disability and Society*. Advance online publication.

https://doi.org/10.1080/09687599.2021.1997719

World Health Organization (2001) *International classification of functioning, disability and

health (ICF).* World Health Organization.