

**FREEDOM OF EXPRESSION IN RELATION TO PERSONS WITH DEAFBLINDNESS IN  
UGANDA**

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**ABSTRACT**

The freedom of expression and is deemed a major human right whose protection is essential for the enjoyment of other rights and is exercised at different levels that is the home, community, and national level. According to the UN Human Rights Committee General Comment No. 34, the freedom of expression is the ‘foundation stone for every free and democratic society.’ This reiterates the internationally accepted position that this right is at the core of human existence and in particular, the wellbeing and development of persons with disabilities. Article 21 of CRPD further mandates state parties to ensure that persons with disabilities enjoy and exercise the freedom of expression. This includes the right to seek, receive and impart information through all available forms of communication.

Most persons with disabilities have single mainstream impairments which may include visual impairments, auditory loss, mental health conditions, intellectual/learning impairment, neurological, and physical impairment among others. However, there is a heterogeneous group called the Deafblind, with both auditory loss and impaired vision ranging from mild to severe. The loss usually occurs during pregnancy/in early childhood (congenital), or at a later stage in life (acquired or adventitious) either progressively or instantaneously. This impairment affects one’s ability to learn and interact with the society which are fundamental precepts of freedom of expression. It is on this basis that this article analyzes this right in relation to the Deafblind in Uganda.

**I. INTRODUCTION**

The freedom of expression is a multifaceted human right that encompasses the right seek, obtain and communicate information of any type.<sup>1</sup> The freedom of expression may be subject to certain restrictions to deal with the excesses that undermine public order, security, health, morality, and the protection of the rights of others.<sup>2</sup> However, any restriction placed on the freedom of expression must be lawful, necessary,

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<sup>1</sup> T.M Scanlon Jr, *Freedom of Expression and Categories of Expression*, 40 U. Pitt. L. Rev. (1978) at 519.

<sup>2</sup> A. Barak, *Freedom of expression and its Limitations*. 8 Keshet/4, 777-781.

and reasonably justifiable. The freedom of expression is a crucial right that is central to the enjoyment of all other human rights and freedoms,<sup>3</sup> especially for the Deafblind in Uganda. In order for such persons to reach their full potential and development (self-actualization),<sup>4</sup> there is a need to protect and enforce their freedom of expression as well as all other rights.

It is worth mentioning that the freedom of expression is closely linked to freedom of opinion, where all persons including the Deafblind, without distinction or regard to any discriminatory criteria, have the right to hold views regardless of their acceptability.<sup>5</sup> The freedom of opinion is an absolute right which may not be subjected to any limitations.<sup>6</sup> Allowing a state to interfere with the freedom of opinion is consenting to meddling with the minds and thought processes of individuals. However, it must be noted from the onset that the discussions in this paper will be limited to the freedom of expression.

### **A. Research Methodology**

This study aims to attain better understanding of the complexity of the right to freedom of expression for the Deafblind in all spheres (education, political, health and social contexts) in Uganda. To achieve this, the study adopts an exploratory research design which mainly relies on secondary data such as books, government and Non-Government Organization documents, reports, published articles, among others. This method is effective for conducting research which aims to improve the understanding of an existing problem, and where there is limited information in relation to that problem.

There is inadequate data on Deafblind persons in Uganda in relation to freedom of expression vis-à-vis other common impairments like deafness, blindness, and disorder in anatomical structures.

### **B. Scope of the Study**

This study examines the enjoyment of the freedom of expression by persons with deafblindness in Uganda. This right is exercised in various contexts (legal, economic, political, social, education, religious) and levels (home setting, community, and national). This research focuses on the actualities of the Deafblind in realizing meaningful communication regardless of whatever context they find themselves in. This is premised on the notion that social interaction is a prerequisite for meaningful communication which is central to freedom of expression.

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<sup>3</sup> It must be recalled that by nature, human rights are indivisible and interrelated. Vienna Declaration and Programme of Action, Adopted by the World Conference on Human Rights in Vienna on 25 June 1993.

<sup>4</sup> The right to self-actualization is an individual's entitlement to the realization of his or her potential, full advancement of one's capabilities and appreciation of life. See: Maslow, Abraham. "Self-actualization and beyond." (1965).

<sup>5</sup> T. Mendel, *Freedom of Information as an Internationally Protected Human Right*, 1 CMLJ 39 (2003), at 39.

<sup>6</sup> A. De Zayas & R.A. Áurea, *Freedom of Opinion and Freedom of Expression: Some Reflections on General Comment No. 34 of the UN Human Rights Committee*, 59(3) Neth. Int. Law Rev. 59 425 (2012), at 426.

This research presents discussions on both congenital and acquired Deafblindness in relation to the right to freedom of expression. This is premised on the argument that Deafblind are heterogeneous but only share combined visual impairment and hard of hearing,<sup>7</sup> which also vary depending on one's personality traits,<sup>8</sup> age of onset,<sup>9</sup> gender,<sup>10</sup> as well as external factors like environment, socio-economic and cultural background, and the suitability of the partners (caregivers), among others.

Whereas the existing literature on the Deafblind in Uganda primarily focuses on their communication within the education sector, this study adopts a broader lens by analyzing the Deafblind in relation to freedom of expression, no matter the context.

## **II. THE MEANING AND NATURE OF DEAFBLINDNESS**

An individual is diagnosed with hard of hearing once the better ear has a hearing loss which is greater than 30db. The various types of hearing loss include: conductive hearing loss which includes damage to or obstruction of the outer or middle ear; sensorineural hearing loss which results from injury to the inner ear or the auditory nerve; mixed hearing loss which is a combination of both conductive and sensorineural hearing loss; and cortical deafness which results from damage to the auditory cortex of the brain.<sup>11</sup> A conductive hearing loss can be improved with hearing aids and/or surgery whereas conductive and cortical hearing loss is usually permanent due to the nerve damage which causes sound distortions.<sup>12</sup> On the other hand, a visual impairment is when an individual's eye sight is worse than 20/70 visual acuity subsequent to correction, or a limited visual range of 45 degrees or less in the better eye. This impairment results from injury to the eye itself, the visual nerve, and/or the visual cortex.<sup>13</sup> The characteristic features of each individual with Deafblindness varies depending on the psychological and mental state of the person, and his/her environment among others.<sup>14</sup>

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<sup>7</sup> I. REDBROE, & M. JANSSEN, COMMUNICATION & CONGENITAL DEAFBLINDNESS SERIES: BOOK 1 – CONGENITAL DEAFBLINDNESS AND THE PRINCIPLES OF INTERVENTION 10 (2006).

<sup>8</sup> For more on how an individual's pre-disability character influences the level and extent of their adaptability see C.J. Boyce, & A.M. Wood, *Personality Prior to Disability Determines Adaptation: Agreeable Individuals Recover Lost Life Satisfaction Faster and More Completely*, 22(11) Psychol. 1397 (2011), at 1397.

<sup>9</sup> WORLD FEDERATION OF THE DEAFBLIND, AT RISK OF EXCLUSION FROM CRPD AND SDGS IMPLEMENTATION: INEQUALITY AND PERSONS WITH DEAFBLINDNESS/MSI 4 (2018).

<sup>10</sup> The prevalence of Deafblindness among the women is slightly higher than that in men. See: World Federation of the Deafblind, *supra* note 9, at 9.

<sup>11</sup> I.C. Hofmann, *Deafblindness*, Encyclopedia Britannica, 357 (2005), at 357.

<sup>12</sup> Hofmann, *supra* note 11, at 357.

<sup>13</sup> Hofmann, *supra* note 11, at 357.

<sup>14</sup> Redbroe & Janssen, *supra* note 7, at 10.

Discussions on the meaning and classification of disability, including Deafblindness, is predominantly contextualized within and informed by the various model systems, as discussed below.

### **A. The Models of Disability**

Prior to the late 1960's and 1970's, interpretations of disability were predominately hinged upon the medical model of disability which focused on an individual's impairments which may be structural, functional or both.<sup>15</sup> This informed medical based interventions such as rehabilitation and institutional care for persons with disability.<sup>16</sup> This model has been criticized for advancing rigid interpretations and interventions which focus on the etiology or mending the impairment. It also reinforces negative perceptions that such persons are incapable of living normal lives if the impairment cannot be fixed.<sup>17</sup>

Later between the 1970's and 1980's, there was a shift to the social model which was mainly developed by persons with disability in Britain. It views people as being disabled by society rather than by their impairments. Therefore, disability is not a product of body pathology but a single social dimension.<sup>18</sup> As such, disability and impairment are distinct with no causal link between them. The Fundamental Principles of Disability published by the Union of the Physically Impaired against Segregation (UPIAS) elaborates on this model, '*...Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society.* Moreover, the impairment is a structural or functional problem on the body whereas disability is a result of social oppression where impairments are not taken into consideration.<sup>19</sup>

In 1980, the World Health Organization (WHO), with the psychological and social dimensions of disability in mind, issued the tripartite International Classification of Impairments, Disabilities and Handicaps (ICIDH) as a tool for classification of consequences of disease. The ICIDH advanced a systematic disability model which presented impairment, disability, and handicap as distinct concepts. The first level was the

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<sup>15</sup> Scholars like Mike Oliver dispute the existence of the medical model of disability but rather medicalization which means the dominance or over reliance on medical clarifications for disability. He instead used the term 'individual model of disability' which is considered an individual deficit derived from the biomedical perspective. K. Kazou, *Analysing the Definition of Disability in the UN Convention on the Rights of Persons with Disabilities: Is It Really Based on A 'Social Model' Approach?*, 25 IJMHL (2017), at 30.

<sup>16</sup> M. Palmer & D. Harley, *Models and Measurement in Disability: An International Review*, 27 Health Policy and Planning 357 (2012), 350: For the case of Uganda, see: NATIONAL UNION OF DISABLED PERSONS OF UGANDA (NUDIPU), ALTERNATIVE REPORT TO THE UN COMMITTEE OF EXPERTS ON THE IMPLEMENTATION OF THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES (CRPD). NATIONAL UNION OF DISABLED PERSONS OF UGANDA, KAMPALA 5 (2014).

<sup>17</sup> J.H. Anthony & S. Hodge, *Disability Discourse: Overview and Critiques of the Medical and Social Models*, 68(2) Quest 193 (2016), at 195.

<sup>18</sup> D. Anastasiou & J.M. Kauffman, *The Social Model of Disability: Dichotomy between Impairment and Disability*, 38 JMP, 441 (2013), at 442.

<sup>19</sup> UPIAS was a disabled people's organisation, created in the 1970s, and is recognized for introducing an appreciation on the causes of disability. Kazou, *supra* note 15, at 26.

presence of a disease or disorder which led to an impairment which was the second level. Impairments are associated with the body structure and system functions impairments. The third was the disability level which was a result of the impairment in relation to the performance and activity of the individual and is experienced at a personal level. The fourth was the handicap level where the difficulties experienced by the individual are a product of the interactions between the impairment, disability, and the environment.<sup>20</sup> This conceptualization guided developments at legal and policy levels in various countries for example Quebec, Canada adopted a systematic approach to policies on impairment, disability, and handicap mainly influenced by the ICIDH.<sup>21</sup> The social model also influenced the policies in relation to the education of students with disability in the United Kingdom, United States and all over Europe.<sup>22</sup>

Interpretations of this model raised concerns that it does not accommodate regression from level four to two and lacks substantive details on the relationship between the levels. Moreover, the initial use of the terminology ‘handicap’ was criticized and changed to ‘disability’ in various jurisdictions based on the human rights perspective.<sup>23</sup> While the ICIDH was used for field trial purposes, its subsequent review and modifications in the 2001 International Classification of Functioning, Disability and Health (ICF) by WHO, confirms a remarkable progress in the appreciation of disability worldwide.<sup>24</sup>

The social model has been criticized for adopting the view which considers disability as a ‘social creation’ and places societal change at the center of disability interventions. This ignores individual differences and lived experiences, as well as undermine the early identification of one’s impairments, which informs the distinctive interventions that advance their development. It also ignores the relationship between impairments and social barriers.<sup>25</sup> Moreover, the social model should not be used as the only basis for any disability policies but rather create an understanding as to the causes of the difficulty. These policies should be centered on a normative framework based on combined contributions from all disability models.<sup>26</sup>

There has been a shift from the contextualization of disability as purely medical or social, to a multi-dimensional character of disability. This has been advanced as the biopsychosocial model that compromises

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<sup>20</sup> WORLD HEALTH ORGANIZATION, INTERNATIONAL CLASSIFICATION OF IMPAIRMENTS, DISABILITIES, AND HANDICAPS: A MANUAL OF CLASSIFICATION RELATING TO THE CONSEQUENCES OF DISEASE (1980).

<sup>21</sup> World Health Organization, *supra* note 20, at 3.

<sup>22</sup> Anastasiou & Kauffman, *supra* note 18, at 442.

<sup>23</sup> I. Hum, S.M. Ashadi, & A.A. Premasari, *Handicap and Disability: What is the Difference?*, 3(1) IJLLT. 163 (2020), at 164.

<sup>24</sup> The ICF belongs to the WHO’s ‘family’ of international classifications and is regarded as WHO’s framework for health and disability. The well-known member of this family is the ICD-10 (the International Statistical Classification of Diseases and Related Health Problems) which provides an etiological framework for causes of death and the ICF classifies health. WORLD HEALTH ORGANIZATION TOWARDS A COMMON LANGUAGE FOR FUNCTIONING, DISABILITY AND HEALTH: ICF, THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH 3 (2002).

<sup>25</sup> J.A. Haegele & S. Hodge, *Disability Discourse: Overview and Critiques of the Medical and Social Models*, 68(2) *Quest* 193 (2016), at 197.

<sup>26</sup> A.M. Samaha, *What Good Is the Social Model of Disability?*, 74 *U Chi L Rev.* 1251 (2007), at 1253.

between the medical and social model.<sup>27</sup> This model acknowledges that while impairments may impede the enjoyment of one's rights, the inability to do so is also influenced by existing environmental and/or social barriers.<sup>28</sup> This is reinforced by the Convention on the Rights of Persons with Disabilities (CRPD)<sup>29</sup> which in its preamble states that, '*disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others*'.<sup>30</sup> This is considerably similar to that of the ICF where disability is a result of '*...the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors)*'.<sup>31</sup>

### **B. The Model System in Relation to the Deafblind**

Firstly, the model systems have informed variations in the nomenclature used in the discourse of Deafblindness. Blindness is simply defined as the loss of sight while deafness is the exclusion of sound including speech and language.<sup>32</sup> In contextualizing Deafblindness, terms such as 'dual sensory loss' or 'multi-sensory impairments' have arguably been associated with the medical model. These terms have been criticized for being ambiguous, and their use accommodates comparative evaluations of which sense is more impaired.<sup>33</sup> This consequently undermines the recognition and protection of persons with Deafblindness.<sup>34</sup>

With the biopsychosocial model in mind, advancements in the definition of Deafblindness reflect the combined effect of the two impairments rather than separate degrees of impairments. For example, Sense International defines Deafblindness as '*a combination of sight and hearing loss that affects a person's ability to communicate, access information and get around*'.<sup>35</sup> The combinations may lead to varying effects

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<sup>27</sup> WORLD HEALTH ORGANIZATION & WORLD BANK, WORLD REPORT ON DISABILITY 4 (2011).

<sup>28</sup> K. Möller, *Impact on Participation and Service for Persons with Deafblindness*, Örebro University, at 27.

<sup>29</sup> Convention on the Rights of Persons with Disabilities (A/RES/61/106). Adopted on 13 December 2006 and opened for signature on 30 March 2007 <<https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>> (accessed 10 May 2021).

<sup>30</sup> Some scholars argue that this definition adopts the social model of disability. See C. O'Mahony, *Legal Capacity and Detention: Implications of the UN Disability Convention for the Inspection Standards of Human Rights Monitoring Bodies*, 16 J. Hum. Rights 883 (2012), at 885.

<sup>31</sup> WORLD HEALTH ORGANIZATION, TOWARDS A COMMON LANGUAGE FOR FUNCTIONING, DISABILITY AND HEALTH: ICF, THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH 10 (2002).

<sup>32</sup> T. ARNOLD, THE LANGUAGES OF THE SENSES WITH SPECIAL REFERENCE TO THE EDUCATION OF THE DEAFBLIND, DEAF AND BLIND. KEBLES GAZETTE OFFICE 15 (1894).

<sup>33</sup> Hofmann, *supra* note 11, at 357.

<sup>34</sup> National Union of Disabled Persons of Uganda, *supra* note 16, at 6.

<sup>35</sup> Sense International, *What is Deafblindness?* <<https://www.sense.org.uk/get-support/information-and-advice/conditions/deafblindness/#:~:text=Deafblindness%20is%20a%20combination%20of,access%20information%20and%20get%20a%20round.&text=It%20doesn't%20necessarily%20mean,residual%20sight%20and%20For%20hearing>> (accessed 8 February 2021).

which range from mild to complete hard of hearing and blindness,<sup>36</sup> as well as progressive or independent sensory loss.<sup>37</sup>

The World Federation of the Deafblind also provides an extensive definition of Deafblindness to mean:

...a distinct disability arising from a dual sensory impairment of a severity that makes it hard for the impaired senses to compensate for each other. In interaction with barriers in the environment, it affects social life, communication, access to information, orientation and mobility. Enabling inclusion and participation requires accessibility measures and access to specific support services, such as interpreter-guides, among others.<sup>38</sup>

This definition draws critical emphasis to deafblindness as a single disability as well as the sphere's affected in one's interaction with the environment.

Secondly, the divergence in the model system has informed constructions of the term 'Deafblindness'. It is argued that the terms 'deafblindness' or 'deaf-blindness' offer narrow interpretations that focus on the medical condition of an individual. The term *deaf/blind* is also ambiguous as it suggests that one has either deafness or blindness rather than a combined effect of the impairments.<sup>39</sup> On the other hand, the terms 'Deafblindness', 'Deaf-Blindness', or 'Deaf-blindness' which are informed by the biopsychosocial model are considered viable terms as they also factor in one's cultural/social affiliation.<sup>40</sup>

The model used in appreciating the right to freedom of expression in relation to the Deafblind in Uganda will definitely inform the conclusions drawn regarding the extent to which they are enjoying this right. For instance, the medical model addresses communication and language barriers by focusing on their problem, what they can and can't do, providing assistive devices, and rehabilitation, among others. The social model on the other hand would prioritize the identification of social barriers and how they can be removed. Each model advocates that its approach autonomously neutralizes disability, and then it can be concluded that the Deafblind are empowered to enjoy the right to freedom of expression. This segregated approach may undermine the development of inclusive and lifecycle interventions for the Deafblind towards the realization of this right.

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<sup>36</sup> T. Manga & K. Masuku, *Challenges of teaching the deaf-blind learner in an education setting in Johannesburg: Experiences of educators and assistant educators*, 67(1) SAJCD. 2225 (2020), at 2226.

<sup>37</sup> UK DEPARTMENT OF HEALTH, CARE AND SUPPORT FOR DEAFBLIND CHILDREN AND ADULTS POLICY GUIDANCE 5 (2014).

<sup>38</sup> World Federation of the Deafblind, *supra* note 9, at 4.

<sup>39</sup> Hofmann, *supra* note 11, at 357.

<sup>40</sup> *Id.*

This Article primarily adopts the biopsychosocial model as the basis of analysis and reflections in the conclusions drawn. This model as earlier discussed, strikes the balance between the medical and social model, and advances the position that disability is not solely a result of a person's impairment of Deafblindness, but is also a byproduct of interactions with existing environmental and social factors. The Article also adopts the construction of 'Deafblind' or 'Deafblindness' to refer to the culture, individual, and the community. The use of deafblindness is in exclusive reference to the medical impairment itself.

### ***C. The severity of Deafblindness***

The severity of Deafblindness has been generally categorized as totally deaf and totally blind; 'hard of hearing' and totally blind; totally deaf and partially blind; and 'hard of hearing' and partially blind.<sup>41</sup> These classifications show that Deafblindness does not automatically imply complete or total blindness and deafness.<sup>42</sup> It is constructive to primarily construe deafblindness as the combined effect of possessing more than one sensory impairment rather than narrowing it to the degree or severity of sight and/or hearing one possess.<sup>43</sup> This is elaborated in Dr Rosenblum's analysis of the five human senses that is sight, hearing, smell, touch, and taste, and their critical role in human interaction with the environment which is vital for freedom of expression. While all five senses are distinct and important to human existence, Dr Rosenblum argues that they do not play an equal role in processing information.<sup>44</sup> Of all the information perceived by human senses, sight accounts for 83%, hearing - 11%, smell - 3.5%, touch - 1.5%, and taste is only 1%.<sup>45</sup> According to this scale, the loss of sight and hearing by an individual accounts for 94% sensory loss which categorizes Deafblindness as a severe condition regardless of one's degree of sight and/or hearing. In this case, the senses of smell and touch especially for congenital and total auditory and visual loss, are usually exercised during the development of consistent communication patterns and relationships. Unfortunately, the functional or practical use of smell is usually complex to observe.<sup>46</sup> All the four categories are reflected in this research

### ***D. Classification and Etiology of Deafblindness***

Based on the age of observed impact, deafblindness is broadly categorized congenital or pre-lingual Deafblindness where an individual is born with a sight and auditory loss prior to the development of a language and communication skill. The other is acquired Deafblindness where such loss occurs subsequent

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<sup>41</sup> N. Ssenyondo, *The Deafblind: What the Geniuses!* National Association of the Deafblind in Uganda. NewsLetter (2007), at 10.

<sup>42</sup> L.J. Lieberman, T.N. Kirk, & J.A. Haegele, *Physical Education and Transition Planning Experiences Relating to Recreation among Adults Who Are Deafblind: A Recall Analysis*, JVIB, 73 (2018), at 74.

<sup>43</sup> Sense International, *supra* note 35.

<sup>44</sup> L.D. ROSENBLUM, SEE WHAT I'M SAYING: THE EXTRAORDINARY POWERS OF OUR FIVE SENSES (2011).

<sup>45</sup> *Id.*

<sup>46</sup> Redbroe & Janssen, *supra* note 7, at 14.



to the development of a language.<sup>47</sup> A third category are the elderly where the onset impact of the Deafblindness is acquired at old age.<sup>48</sup> This loss may be simultaneous or independent where one becomes deaf and later blind and vice versa,<sup>49</sup> and in other cases gradual or immediate loss. It is reported that persons who are Deafblind predominantly experience independent loss, and as such possess some basic communication competences like sign language which makes it easier for them to grasp the interaction skills used by persons with vision impairment.<sup>50</sup> Those with simultaneous visual and auditory loss form a miniature percentage among the Deafblind.

Acquired Deafblindness is usually caused by diseases like brain tumors<sup>51</sup> whereas congenital Deafblindness is caused by medical complications during pregnancy and at birth; several syndromes<sup>52</sup> such congenital Rubella, CHARGE Syndrome, Usher Syndrome;<sup>53</sup> premature birth, among others.<sup>54</sup> USHER syndrome (genetic syndrome) and Rubella (disease) are the most common causes of deafblindness.<sup>55</sup> USHER syndrome is a genetic disorder with ‘*autosomal recessive inheritance*’, and is divided into three clinical types that is I, II and III depending on the gene mutations and clinical features.<sup>56</sup> Those with Usher I are born with profound auditory impairments,<sup>57</sup> whereas those with II and III are born with auditory impairment ranging from moderate to severe although type III is normally progressive. All these types experience progressive visual impairment.<sup>58</sup>

In elaborating this difference between congenital and acquired Deafblindness, Barret highlights that a child with acquired Deafblindness maintains mental images, light, sound, shapes, which cannot be eliminated by the darkness caused by Deafblindness. These are merely tacked away in a ‘*memory sealed chamber*’ until they are awakened by associated thoughts.<sup>59</sup> For example, Abukito Agnes who lost her sight at teenage age still has recollections of the blue sky, trees, and cows which are permanently engraved in her mind.<sup>60</sup>

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<sup>47</sup> World Federation of the Deafblind, *supra* note 9, at 3.

<sup>48</sup> Möller, *supra* note 28, at 24.

<sup>49</sup> D. Russell, C. Chovaz, & P. Boudreault *Administration of Justice: The Experiences of Deaf, Deafblind, and Deaf People with Additional Disabilities in Accessing the Justice System*. Canadian Association of the Deaf, (2018) 6.

<sup>50</sup> S. Azenkot *et al*, *Enhancing Independence and Safety for Blind and Deaf-Blind Public Transit Riders*, Computer Science and Engineering (2011), at 3248.

<sup>51</sup> Ssenyondo, *supra* note 41, at 1.

<sup>52</sup> The etiology of post-lingual Deafblindness is primarily genetic with more than 50 hereditary syndromes where the gene in 40 is localized and 20 cloned Kerstin Möller (2008) *Impact on Participation and Service for Persons with Deafblindness*, Örebro University 25.

<sup>53</sup> Möller, *supra* note 28, at 25.

<sup>54</sup> Sense International, *supra* note 35.

<sup>55</sup> Hofmann, *supra* note 11, at 358.

<sup>56</sup> Möller, *supra* note 28, at 25.

<sup>57</sup> A. AUSTRALIA, TELECOMMUNICATIONS AND DEAFBLIND AUSTRALIANS. AUSTRALIAN COMMUNICATIONS CONSUMER ACTION NETWORK, SYDNEY 7 (2011).

<sup>58</sup> Möller, *supra* note 28, at 25.

<sup>59</sup> E.M. Barrett, *The Importance of Early Training for the Deaf-Blind*. 48 Am Ann Deaf 149 (1903), at 152.

<sup>60</sup> Ms Abukito Agnes in 2009 was the National Chairperson for the National Association of the Deafblind in Uganda. See *Need Africa Truth Told Well Magazine* Volume 2 October 2009, Ntinda Kampala 17.

For congenital Deafblindness, the communication competences are limited to the social and environmental spheres that they experience. These competences cannot be compared to their peers without such impairments, who develop communication through observance, copying, exploration, peer interaction, and play.<sup>61</sup> For such persons, the ‘*sensation of light has never impressed their benighted faculties*’ and ‘*no sound has ever broken the eternal stillness of their existence.*’ Therefore, they lack the initial mental image upon which to develop an idea.<sup>62</sup> This ultimately impacts on their abilities to develop thought processes, opinions, and mental representation abilities that are developed through social interaction during the sensorimotor period (between birth and the age of 2 years).<sup>63</sup> The variations in Deafblindness categories consequently determine the techniques of receptive and expressive communication.<sup>64</sup> In relation to freedom of expression, it is inferred that individuals with acquired Deafblindness may have a decent appreciation of language, communication, and visualization which may facilitate their adaptation and development of skills. This could be more complex for those with congenital Deafblindness.

### ***E. Prevalence of Deafblindness***

A population-based analysis study conducted across 22 countries reported the prevalence of Deafblindness at 0.21% out of a population of over 92.6 million.<sup>65</sup> According to the World Federation of the Deafblind Global report 2018, the Deafblind constitute representing 0.2% to 2% of the world’s population.<sup>66</sup>

In Uganda, the National Association of the Deafblind in Uganda (NADBU) reported that in 2007, Bundibugyo in western Uganda had the largest population of the Deafblind.<sup>67</sup> Later in 2009, NADBU had officially registered 470 Deafblind people,<sup>68</sup> but this was not representative of the estimates of 40,000 Deafblind within the community.<sup>69</sup> In 2014, a study by Sense International Uganda estimated approximately 81,000 to 810,000 of the total population in Uganda,<sup>70</sup> although there are no official statistics.<sup>71</sup> Absence of this data is primarily attributed to the intricacies around the identification and independent recognition of the Deafblind. Instead they are predominantly absorbed into the Deaf, Blind, Deafblind, the Disabled,

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<sup>61</sup> Redbroe & Janssen, *supra* note 7, at 11.

<sup>62</sup> Barrett, *supra* note 59, at 152.

<sup>63</sup> The limitations to exploration of their environment causes these children to resort to self-stimulating behavior resulting in rudimentary gestures or signs. Hofmann, *supra* note 11, at 360.

<sup>64</sup> UK Department of Health, *supra* note 37, at 8.

<sup>65</sup> Other lower middle-income and low-income countries include India, Ghana, Kenya, Uganda, Tanzania, Ethiopia, Malawi, Nepal, Nigeria, and Zambia, among others. World Federation of the Deafblind, *supra* note 9, at 12.

<sup>66</sup> *Id.*, at 3.

<sup>67</sup> Ssenyondo, *supra* note 41, at 5.

<sup>68</sup> Need Africa, *Truth Told Well Magazine* Volume 2 October 2009, Ntinda Kampala

<sup>69</sup> T. Kakembo, *The Plight of Deafblind Children in Uganda*, In Need Africa, *supra* note 68, at 20.

<sup>70</sup> A 2014 report by Uganda Bureau of Statistics (UBOS) projected the population to be 40.3 million by mid-year 2019. UGANDA BUREAU OF STATISTICS, *STATISTICAL ABSTRACT* (2019).

<sup>71</sup> J. KAMYA & G. TUMWINE, *THE ECONOMIC IMPACT OF CARING FOR A CHILD WITH DEAFBLINDNESS/MULTI-SENSORY IMPAIRMENT*. SENSE INTERNATIONAL UGANDA 12 (2019).

and mainstream communities. The community identified informs one's interaction strategies, which inevitably influences the enjoyment of freedom of expression. These intricacies are expounded below.

***F. The intricacy of Identification and Recognition among the Deafblind***

It is common for the Deafblind to identify themselves as either deaf or blind rather than Deafblind, and this informs the interventions sought, which may actually not be suitable in addressing their difficulties.<sup>72</sup> Some use obscure descriptions of their impairments such as '*I don't see too well or hear too well*'.<sup>73</sup> The identification of the Deafblind is further complicated in instances where there is functional use of residual vision and/ hearing which generates behavioral patterns similar to social and emotional self-stimulation by persons without Deafblindness.<sup>74</sup> Moreover, families and professionals that have no knowledge, experience or even encountered the Deafblind may find it challenging to recognize and adequately respond to Deafblindness.<sup>75</sup>

The intricacies of identification and recognition of the Deafblind are explained by *Hofmann*, who noted that individuals with congenital blindness and later become deaf usually use spoken language as the main means of communication and later add some signs, fingerspelling, Tadoma, or other forms of manual communication.<sup>76</sup> As such, they tend to initially identify themselves with the blind community or the disabled community and later on the Deafblind community. Those with congenital deafness and later become blind, they tend to use signed language and consequently identify with the Deaf community and at a later stage with the Deafblind community.<sup>77</sup>

The Deafblind may associate with the deaf; Deafblind, the Disability community in general and the mainstream community. This association depends on a number of factors such as: the severity of the auditory and vision loss, the community one grew up in; one's language preference; and what they consider as the most important aspect of their identity. Those that consider deafness as their identity are more likely to associate with the Deaf community and those with significant residual vision and hearing and rely on spoken language are more likely to associate with the mainstream community. However, the Deafblind are more likely to comfortably associate with the Deafblind community or the disability community because these groups accommodate diverse communication options which further one's interaction,<sup>78</sup> and subsequently enhance the enjoyment of freedom of expression

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<sup>72</sup> Australia, *supra* note 57, at 14.

<sup>73</sup> UK Department of Health, *supra* note 37, at 5.

<sup>74</sup> Redbroe & Janssen, *supra* note 7, at 12.

<sup>75</sup> *Id.*, 8, at 10.

<sup>76</sup> Hofmann, *supra* note 11, at 358.

<sup>77</sup> *Id.*

<sup>78</sup> Hofmann, *supra* note 11, at 359.

The above discussion brings to light fundamental intricacies that influence the identification and recognition of the Deafblind which consequently affects their interaction and effective participation as emphasized in the CRPD.<sup>79</sup> This implies that in order to engage in fair and substantive discussions around the enjoyment of freedom of expression by the Deafblind, it is imperative appreciate these intricacies and their actual role in furthering or curtailing this right.

### **III. LEGAL AND POLICY FRAMEWORK ON THE PROTECTION OF THE FREEDOM OF EXPRESSION**

#### ***A. International Protection of the Freedom of Expression***

The Universal Declaration of Human Rights (UDHR) guarantees the right to freedom of expression in Article 19<sup>80</sup> and expounds it to include the right to seek, receive and share information utilizing the available forms of media (freedom of expression).<sup>81</sup> This right may be restricted in order to protect other individuals' rights and reputations; national security; public order, health, and morality.<sup>82</sup> However, such restrictions should not erode the very essence of the right altogether<sup>83</sup> considering its centrality in the development of all persons.<sup>84</sup>

For persons with disability, Article 21 of the CRPD expressly mandates state parties to ensure that persons with disabilities enjoy freedom of expression.<sup>85</sup> In addition, states are obliged to transmit information meant for the general public to persons with disabilities in formats that they can understand without delay or additional cost.<sup>86</sup> Such formats should include Braille, alternative communication, and sign language among others.<sup>87</sup> While Article 21 of CRPD is not as detailed as the ICCPR in the protection of the freedom of expression, it contextualizes the right considering the needs of persons with disabilities vis-à-vis other so-

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<sup>79</sup> National Union of Disabled Persons of Uganda, *supra* note 16, at 14.

<sup>80</sup> Art 19 of the UDHR 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.'

<sup>81</sup> Human Rights Committee General Comment No. 34, Article 19: Freedoms of Opinion and Expression. Adopted on the 102nd session held in Geneva, (2011) CCPR/C/GC/34, §§ 11-12.

<sup>82</sup> Art 19(3) of the ICCPR.

<sup>83</sup> HRC General Comment 10, para 4.

<sup>84</sup> HRC General Comment 34, *supra* note 81 § 2.

<sup>85</sup> Art 21 of the CRPD.

<sup>86</sup> Art 21(a) of the CRPD States have the duty to protect, respect and promote human rights and freedoms. See Committee on the Rights of Persons with Disabilities, "Consideration of Reports submitted by States under Article 35, Concluding Observations – Tunisia," (May 2011) <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Session5.aspx>> (accessed 28 March 2021).

<sup>87</sup> Art 21(b) of the CRPD.

called able-bodied persons. The provision places primacy on the accessibility of information in available formats and mediums such as Braille and sign language.<sup>88</sup>

In the African context, the freedom of expression for persons with disability is also protected in Article 23 and 24 of the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa.<sup>89</sup> Within the East African Community (EAC), Partner States in Article 120 (c) of the Treaty for the Establishment of the East African Community commit to develop and adopt common approaches towards persons with disability. This is reinforced in Article 39 of the Common Market Protocol signed in November 2009, and consequently the EAC Policy on Persons with Disabilities which provides for the full realization of fundamental rights and freedoms with emphasis on a multi inclusive approach involving the EAC (Secretariat); the East Africa Legislative Assembly (EALA); and the East African Court of Justice (EACJ) as well as the national and community level.<sup>90</sup>

Deafblindness is recognized as a disability in Article 24 of the CRPD,<sup>91</sup> in relation to the adoption of an inclusive education system that promotes their development and dignity.<sup>92</sup> In the advancement of freedom of expression, the CRPD recognises methods such as tactile communication and braille, and languages, including sign languages and non-spoken languages, which may be used by persons with Deafblindness.<sup>93</sup> The Committee on the Rights of Persons with Disabilities General Comment No. 2 addressing Article 9 (2014) relating to accessibility to information and communications, also refers to the disability of Deafblindness.<sup>94</sup> The Committee further recognizes the limitation of the Deafblind in accessing information<sup>95</sup> which compromises their ability to live independently and effectively participate in society. These issues are key in the exercise of freedom of expression.<sup>96</sup>

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<sup>88</sup> Adopted and opened for signature, ratification and accession by General Assembly resolution 2200A (XXI) of 16 December 1966, entry into force 23 March 1976, in accordance with Article 49 <<https://www.ohchr.org/documents/professionalinterest/ccpr.pdf>> (accessed 10 May 2021)

<sup>89</sup> The Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa adopted 29 January 2018. Available at <[https://au.int/sites/default/files/treaties/36440-treaty-protocol\\_to\\_the\\_achpr\\_on\\_the\\_rights\\_of\\_persons\\_with\\_disabilities\\_in\\_africa\\_e.pdf](https://au.int/sites/default/files/treaties/36440-treaty-protocol_to_the_achpr_on_the_rights_of_persons_with_disabilities_in_africa_e.pdf)> (accessed 11 May 2021)

<sup>90</sup> EAC Policy on Persons with Disability. EAC Secretariat <[http://meac.go.ke/wp-content/uploads/2017/03/adopted\\_eac\\_disability\\_policy\\_march\\_2012.pdf](http://meac.go.ke/wp-content/uploads/2017/03/adopted_eac_disability_policy_march_2012.pdf)> (accessed 14 May 2021) 38. See also the East African Commission for Persons with Disability established under section 26(1) of the EAC Persons with Disability Bill. The East African Community Persons with Disability Bill. Bill supplement No. 9 31 July 2015 Available at <[https://www.eala.org/uploads/PWD\\_Bill.pdf](https://www.eala.org/uploads/PWD_Bill.pdf)> (accessed 12 May 2021)

<sup>91</sup> Art 24(3)(c) of CRPD.

<sup>92</sup> Art 24(1) of CRPD.

<sup>93</sup> Art 24(2) of CRPD.

<sup>94</sup> CRPD General Comment No. 2 (11 April 2014) Article 9: Accessibility. (CRPD/C/GC/2) Eleventh session. <<https://documents-dds-ny.un.org/doc/UNDOC/GEN/G14/033/13/PDF/G1403313.pdf?OpenElement>> (accessed 1 March 2021).

<sup>95</sup> CPRD General Comment 2, *supra* note 94 § 7.

<sup>96</sup> *Id.* § 13.

In reinforcing states compliance, the CRPD entails a complaints reporting system of self- assessment,<sup>97</sup> and periodic states reporting mechanism to the CRPD Committee.<sup>98</sup> Uganda, which is a signatory to the CRPD and its Optional Protocol submitted its initial state report in 2013, where it highlighted the plight of the deaf-blind in relation to the education sector and proposed the development of a curriculum in tactile for such persons.<sup>99</sup> In its concluding observations on Uganda's report in April 2016,<sup>100</sup> the Committee made specific reference to the Deafblind in relation to the lack of public information in Braille; scarcity in sign language interpreters and trained teachers on sign and tactile communication; and the non-recognition of Ugandan Sign Language as legally enforceable. The Committee recommended the adoption of concerted and inclusive interventions towards improving accessibility of information in all easy to read formats as well as the development of appropriate education curricula.<sup>101</sup> Unfortunately, key regional documents like the EAC Policy on Persons with Disabilities, as highlighted above, are silent on the category of persons with Deafblindness. These omissions could be attributed to the argument that the international and regional framework provides overarching guidance on freedom of expression for persons with disability in general and extended protection of specific groups like the persons who are deafblind should be reflected in national legislation and policy.

Nonetheless, the international and regional legal framework upholds the respect, protection, and promotion of freedom of expression of the Deafblind. Uganda must therefore ensure that such persons attain the highest level of potential and self-actualization.

### ***B. The Ugandan Legal and Policy Framework on the Protection of the Freedom of Expression***

The Persons with Disabilities Act, 2019<sup>102</sup> provides overarching protections for persons with disabilities in Uganda. Section 3 recognizes the fundamental rights and freedoms enshrined in the 1995 Constitution of Uganda such as freedom of expression.<sup>103</sup> In its National Objective XXIV Cultural Objectives, the state is obliged to promote the development of a sign language for the deaf. Besides, the Copyright and Neighbouring Rights Act of 2006 in Section 15(1) (k) provides copyright protection and rights to authors

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<sup>97</sup> See Article 1 and 2 Optional Protocol to the Convention on the Rights of Persons with Disability.

<sup>98</sup> Article 35 CRPD For the guidelines on state reporting to the Committee on the Rights of Persons with Disabilities, see: <<https://www.ohchr.org/EN/HRBodies/CRPD/Pages/Guidelines.aspx>> (accessed 2 March 2021).

<sup>99</sup> Committee on the Rights of Persons with Disabilities. Consideration of reports submitted by States parties under article 35 of the Convention. Initial report of State party received on 22 January 2013 Available at <<https://www.mindbank.info/item/6650>> (accessed 10 May 2021) 30

<sup>100</sup> For access to these documents, please see the United Nations Treaty Collection website. Available at: <[https://tbinternet.ohchr.org/\\_layouts/15/treatybodyexternal/TBSearch.aspx?Lang=en](https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/TBSearch.aspx?Lang=en)> (accessed 2 March 2021).

<sup>101</sup> Comment 42 on Freedom of expression and opinion, and access to information (art. 21) Concluding observations on the initial report of Uganda: Committee on the Rights of Persons with Disabilities <<https://digitallibrary.un.org/record/830776?ln=en#record-files-collapse-header>> (accessed 10 May 2021)

<sup>102</sup> In Article 35(2) of the Constitution, Parliament is mandated to enact laws for the protection of persons with disabilities.

<sup>103</sup> Article 29(1) (c-d) of the Constitution entitlement to freedom of expression without distinction. See also: Art 43(1) and (2) of the Constitution. Objective XVI of the Constitution of Uganda places a duty on states to respect rights of all persons.

of literary works. What is most notable is that the Act permits persons to transcribe any literary work into braille or sign language for educational purpose of persons with disabilities. However, the limitations of transcribing materials strictly for ‘educational purposes’ has been criticized as restricting access to information for persons with disabilities.<sup>104</sup> Moreover, this contradicts Uganda’s obligation to create mandatory limitations and exceptions otherwise prohibited under copyright law in order to benefit the world’s population of persons with print disabilities like the Deafblind and the wider community of persons with disabilities, as stipulated in the Marrakesh Treaty to Facilitate Access to Published Works for Persons Who Are Blind, Visually Impaired, or Otherwise Print Disabled.<sup>105</sup>

The Persons with Disabilities Act does not make specific reference of the freedom of expression but Section 12(6) mandates the Minister responsible for communication to ensure access to information as well as promote the development, training and use of alternative communication such as tactile, sign language, assistive devices and braille to promote access to justice and information by persons with disabilities. All these legal interventions seek to promote the enjoyment of the right to freedom of expression. The right of access to information is reinforced by the Access to Information Act, 2005 which provides the procedure of obtaining access to this information.<sup>106</sup> The 2006 National Policy on Disability<sup>107</sup> recognizes the communication challenges of the Deafblind<sup>108</sup> such as lack of appropriate interaction methods.<sup>109</sup> Emphasis was placed on the use of tactile, sign language and braille to facilitate communication with the Deafblind.<sup>110</sup>

A robust institutional framework plays a significant role in advocacy as well as service provision for the Deafblind community. At national level, Article 35(2) specifically charges Parliament with the mandate to enact appropriate laws that protect persons with disabilities.<sup>111</sup> The Ministry of Gender, Labour and Social Development provides oversight guidance in the formulation and implementation of policies for persons with disabilities. The National Council for Disability (NCD) was created to monitor the implementation of

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<sup>104</sup> National Union of Disabled Persons of Uganda, *supra* note 16, at 14.

<sup>105</sup> The Marrakesh Treaty was adopted by the Member States of the World Intellectual Property Organization (WIPO) on June 27, 2013. Available at < [https://www.wipo.int/edocs/pubdocs/en/wipo\\_pub\\_218.pdf](https://www.wipo.int/edocs/pubdocs/en/wipo_pub_218.pdf) > (accessed 10 May 2021). Uganda ratified the Marrakesh Treaty and it entered into force on 23 July 2018.

<sup>106</sup> Section 11(3), 20(5) and (7) of the Access to Information Act applies to persons with disability with regard to: the oral option when requesting access to information; and the information officer of a public body to take alternative measures to ensure that information is provided in a readable version for Persons with Disabilities unless doing so will be outrageously expensive compared to the information sought.

<sup>107</sup> THE UGANDA NATIONAL POLICY ON DISABILITY BY THE MINISTRY OF GENDER, LABOUR AND SOCIAL DEVELOPMENT (2006). Available at: <<https://afri-can.org/wp-content/uploads/2019/08/NATIONAL20POLICY20ON20DISABILITY20January2006.pdf>> (accessed 1 March 2021). It is important to note that the Policy is currently undergoing a review and we shall wait to see the changes once it is approved by Cabinet.

<sup>108</sup> National Policy on Disability of Uganda, *supra* note 107 § 4.8.

<sup>109</sup> *Id.*

<sup>110</sup> *Id.*

<sup>111</sup> Article 79(3) of the 1995 Constitution of the Republic of Uganda

the Persons with Disabilities Act and advocate for programs on the welfare of persons with disabilities; ensure availability of information in accessible formats, among others.<sup>112</sup>

The Equal Opportunities Commission (EOC) was created to eliminate all forms of discrimination and inequalities based on an individual's personal circumstance including disability.<sup>113</sup> The Uganda Human Rights Commission (UHRC)<sup>114</sup> also in 2004 constituted the Vulnerable Persons' Unit whose mandate is essential in the protection Persons with Disabilities, among others.<sup>115</sup> In terms of disability, organizations like the National Union of Disabled Persons in Uganda (NUDIPU) have contributed towards the improvement of livelihoods, inclusive participation, training, and capacity building. For activities and programs delivery specific to the Deafblind, DPO's like the National Association of the Deafblind in Uganda (NADBU)<sup>116</sup> in partnership with Sense International (SI),<sup>117</sup> have been at the forefront these efforts.

It must be noted that the visibility of the Deafblind in Uganda's legal and policy framework is still wanting. Similar concerns were raised by the Committee on the Rights of Persons with Disabilities in its Concluding Observations on the Initial Report of Uganda as has been discussed above.<sup>118</sup> Unfortunately, even the most recent Persons with Disabilities Act, 2019<sup>119</sup> preferred obsolete terminology 'deaf and blind' which obscurely suggests two distinct disabilities rather than a single disability which a result of combined effects.

#### **IV. CHALLENGES FACED BY DEAFBLIND PERSONS IN RELATION TO FREEDOM OF EXPRESSION**

The challenges faced by the Deafblind predominantly manifest in three broad thematic areas and these are: communication, independence and isolation from society.<sup>120</sup> Some specific difficulties include the inability to engage in and sustain meaningful communication as well as appreciate the consequence of their actions;

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<sup>112</sup> NCD, a quasi-autonomous and judicial body was created under Section 16 of the Persons with Disabilities Act in 2003 and operationalized in 2004, Sec 16 and 17(2)(b) of the Persons with Disabilities Act (2003). See also: The National Council for Disability website available at: <<https://ncd.go.ug>> (accessed 2 March 2021).

<sup>113</sup> The EOC is an independent statutory body created by the Equal Opportunities Commission Act in 2007, to operationalize Articles 32 of the 1995 Constitution. See the long title of the Equal Opportunities Commission Act (2007).

<sup>114</sup> A quasi-judicial body established under Article 51 of the Constitution of Uganda. UHRC was created to investigate; promote, advocate, as well as investigate human rights violations.

<sup>115</sup> For more on the units of the UHRC, see: <<https://www.uhrc.ug/about/uhrc-units/vulnerable-persons-unit/>> (accessed 2 March 2021).

<sup>116</sup> NADBU, a nonprofit was established in 2005, and its activities include: promoting the welfare of the deafblind; rehabilitation; educational services; medical services; livelihood activities; advocacy; and capacity building. For more information on NADBU and its activities, see their website available at: <https://www.deafblinduganda.org.ug/objectives.html> (accessed 26 March 2021).

<sup>117</sup> SI implements projects aimed at eradicating barriers to inclusive education for children with deafblindness. Kanya, *supra* note 71, at 10.

<sup>118</sup> Paragraph 42 and 48 Committee on the Rights of Persons with Disabilities. Concluding observations on the initial report of Uganda. 12 May 2016. CRPD/C/UGA/CO/1. <<https://digitallibrary.un.org/record/830776?ln=en#record-files-collapse-header>> (accessed 1 March 2021).

<sup>119</sup> Schedule 3 Persons with Disabilities Act, 2019

<sup>120</sup> M. Hersh, *Deafblind People, Communication, Independence, and Isolation*, J. Deaf Stud. Deaf Educ. 446 (2013), at 446.



stigmatization within family as well as the community; medical conditions that impede their development; and the inability to establish and sustain relationships.<sup>121</sup> Some of these specific difficulties are discussed in the subsections hereunder.

### **A. Difficulty in Engaging in Meaningful Communication**

It is estimated that 90% of the information one receives concerning the world is predominantly through hearing and vision.<sup>122</sup> Unfortunately, Deafblindness in some cases compromises the ability to taste, smell, and touch.<sup>123</sup> The importance of touch in breaking the isolation and initiating communication,<sup>124</sup> was highlighted by Helen Keller in her saying, ‘*Once I knew only darkness and stillness...my life was without past or future...but a little word from the fingers of another fell into my hand that clutched at emptiness, and my heart leaped to the rapture of living.*’<sup>125</sup>

Stimulation of the other remaining senses such taste and smell can also be a source of accomplishment, satisfaction, knowledge, and communication.<sup>126</sup> This emphasizes the essentiality of external stimuli in the motor development of the Deafblind. Such development can be attained by enabling interaction between the deafblind and the environment to distinctively experience, appreciate, visualize, and react to external stimuli.<sup>127</sup> Unfortunately, an impairment to the residual senses of taste, smell and touch of the Deafblind further complicates interaction and infiltrates all spheres fundamental to their entire existence and humanity.<sup>128</sup> It also undermines their emotional and social wellbeing, ability to make informed decisions, and functional independence,<sup>129</sup> which they yearn for.<sup>130</sup> Moreover, the Deafblind that communicate through touch may experience high stress levels as a result of the existing limitations in interacting with their environment.<sup>131</sup> The constant anxiety and uncertainty around safety, isolation and loneliness, support, acceptance, among others has led to severe depression,<sup>132</sup> and other mental health complications among the Deafblind.<sup>133</sup> Feelings of isolation or exclusion and subsequent withdrawal for the Deafblind usually

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<sup>121</sup> J.M. McInnes & J.A. Treffry, *University Deaf-blind Infants and Children: A Developmental Guide* (1982), at 2.

<sup>122</sup> Australia, *supra* note 57, at 8.

<sup>123</sup> Ssenyondo, *supra* note 41, at 1.

<sup>124</sup> Communication system for deaf, deaf-blind, or non-vocal individuals using instrumented glove Inventors James P Kramer, Peter Linener, and William R. George. Available at <<https://patentimages.storage.googleapis.com/26/75/36/c3c9b51f780ed4/US5047952.pdf>> (accessed 19 February 2021).

<sup>125</sup> Helen Adams Keller (27<sup>th</sup> June 1880- 1<sup>st</sup> June 1968) was an American activist, lecturer, author, and the first deafblind person to graduate from college. For more information read Need Africa, *supra* note 67, at 12.

<sup>126</sup> R.J. Smithdas, *Reflections of a Deaf-Blind Adult*, 125(8) Am Ann Deaf. 1015 (1980), at 1015.

<sup>127</sup> McInnes & Treffry, *supra* note 121, at 2.

<sup>128</sup> For example, in the social sphere of marriage, it is reported that women with deafblindness are less likely to be married compared to their counterparts with other disabilities. World Federation of the Deafblind, *supra* note 9, at 19.

<sup>129</sup> Hersh, *supra* note 120, at 448.

<sup>130</sup> Azenkot *et al*, *supra* note 50, at 3247.

<sup>131</sup> Hersh, *supra* note 120, at 448.

<sup>132</sup> Australia, *supra* note 57, at 10.

<sup>133</sup> World Federation of the Deafblind, *supra* note 9, at 19.

manifests in the absence of a partner or in a sudden change in the environment, which generates fright and a sense of a meaningless situation.<sup>134</sup>

The Deafblind in Uganda have not been an exception to the challenge of engaging in meaningful communication.<sup>135</sup> Although Uganda has made significant progress in advocating for disability rights, practical implementation of initiatives that would boost the communication of persons with Deafblindness remains limited. Within the education and health sector, research shows that there is limited access to information for persons with disabilities such as sign language and electronic aids.<sup>136</sup> Only a limited number of schools offer training for the Deafblind who often have to foot the expensive bills that come with the services. This makes communication training out of reach for the Deafblind whose development and meaningful social interaction depends on it. In addition, modern assistive technologies that would otherwise assist in communication are expensive and not readily available.<sup>137</sup>

### ***B. Non-inclusivity and Lack of Opportunities***

The challenges faced by the Deafblind are complicated by restrictive environments that do not accommodate them.<sup>138</sup> This jeopardizes their freedom of expression during interaction with various sectors like education. Educators lack adequate training such as requires psychosocial and mental skills among others.<sup>139</sup> The difficulty in teaching the Deafblind was expressed by one educator, “*It is a barrier because even though they can’t see, they can’t talk, they can’t hear, you still have to teach them sign language... But they won’t understand like ... it will take time for them to understand.*”<sup>140</sup> This disparity affects the school attendance of Deafblind children who are reportedly up to 23 times less likely to attend school compared to their counterparts with other disabilities.<sup>141</sup> In Uganda, children with Deafblindness are reportedly 17 times less likely to enroll and progress in school compared to those without disabilities.<sup>142</sup> Alison Marshall, Director of Sense International Uganda emphasized the need to support children with

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<sup>134</sup> Redbroe & Janssen, *supra* note 7, at 15.

<sup>135</sup> J. Abimanyi-Ochom, & H. Mannan, *Uganda's disability journey: Progress and challenges*. 3(1) Afr. J. Disabil. (2014), at 108.

<sup>136</sup> ACTION ON DISABILITY AND DEVELOPMENT (2005) CHALLENGES FACED BY PEOPLE WITH DISABILITIES (PWDS) IN UTILIZING HIV/AIDS COMMUNICATION AND RELATED HEALTH SERVICES IN UGANDA. Available at: <[http://www.africacampaign.info/uploads/media/add\\_reporton\\_hivaidssand\\_disability\\_01.pdf](http://www.africacampaign.info/uploads/media/add_reporton_hivaidssand_disability_01.pdf)> (accessed 10 May 2021).

<sup>137</sup> Abimanyi-Ochom, & H. Mannan, *supra* note 135, at 108.

<sup>138</sup> World Federation of the Deafblind, *supra* note 9, at 15.

<sup>139</sup> Manga & Masuku, *supra* note 36, at 2225.

<sup>140</sup> *Id.*

<sup>141</sup> World Federation of the Deafblind, *supra* note 9, at 17.

<sup>142</sup> Sense International, International Day of Education: Using Specialist Braille Technology to Support Children with Deafblindness Sense International, Kampala 24<sup>th</sup> January 2021, <<https://senseinternational.org.uk/news/international-day-education-using-specialist-braille-technology-support-children-deafblindness>> (accessed 8 February 2021).

Deafblindness in order to mitigate the communication and mobility challenges which impede their access to quality education.<sup>143</sup>

The limited opportunities in the education sector for the Deafblind affect their access to meaningful employment which negatively impacts access to resources to live a decent life as well as acquire assistive devices that could enhance interaction and development.<sup>144</sup> It is reported that in light of the socio-economic status, the Deafblind as well as their households are more likely to be poor compared to persons with other disabilities or even those without any disability.<sup>145</sup>

Within the justice system, the Deafblind experience unsatisfactory interactions with most stakeholders such as the police, probation officers, social workers, and judicial officers, who lack proficiency in communicating with them. Similar frustrations also resonate among judicial officers who expressed their limited knowledge and skill in interacting with the deaf blind within the judicial system.<sup>146</sup> The outcry for centrality of sign language interpreters to enable persons with hearing difficulties to participate in the 2021 general election process also shows a significant gap in the actualization of freedom of expression for such persons in Uganda.<sup>147</sup>

Similar frustrations in Uganda are also expressed within their everyday lives. The Deafblind hardly participate fully<sup>148</sup> or even enjoy basic/simple activities that are central to human dignity and development.<sup>149</sup> The partners, especially of those with congenital Deafblindness, are usually oblivious of the desires of such persons, and have to constantly presume what is best for example when they are hungry or need to use the washroom.<sup>150</sup> This shows the complexity of the Deafblind to communicate, the partners ability to reciprocate and consequently act upon that expression. The determination of ‘what is best’ for the Deafblind by their partners may be subjective.

### ***C. Stigmatization and Misconceptions***

Stigma can be defined as a negative attitude, prejudice, or a form of discrimination against an individual based on his/her distinguishing characteristic such as race, health condition, gender, appearance, or

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<sup>143</sup> Sense International, *World Children’s Day: Providing Vital Educational Support for Children with Deafblindness/ multi-sensory Impairments in Uganda*, (2020), <<https://senseinternational.org.uk/news/world-children-s-day-providing-vital-educational-support-children-deafblindness-multi-sensory>> (accessed 8 February 2020). For more information on mobility of the deafblind in relation to physical education see Lieberman, Kirk & Haegele, *supra* note 41, at 73.

<sup>144</sup> Australia, *supra* note 57, at 8.

<sup>145</sup> World Federation of the Deafblind, *supra* note 9, at 12.

<sup>146</sup> Russell, Chovaz & Boudreault, *supra* note 49, at 2.

<sup>147</sup> The Independent, *PWDs decry lack of sign language interpreters during campaigns*, 26 November 2020, News.

<sup>148</sup> J.P. Omugur & B.B. Awori, *Teachers’ Use of Communication Techniques for Achievement of Daily Living Activities by Learners with Deafblindness In Primary Schools*, 4 UIJER. 175 (2016), at 176.

<sup>149</sup> Australia, *supra* note 57, at 8.

<sup>150</sup> Manga & Masuku, *supra* note 36, at 2225.

culture.<sup>151</sup> There are three levels of stigma experienced by the Deafblind. The first is the social/public or enacted stigma which entails large social groups (friends, family, and community) that engage in shunning, overt discrimination, and violence, and use stigmatizing labels. Such misconceptions are entrenched into the mindsets or attitudes and behavioral patterns of society that reinforce feeling of segregation and isolation.<sup>152</sup> Secondly, structural or institutional stigma entails the laws and policies within institutions that restrict the rights and opportunities of the Deafblind either expressly or being silent.<sup>153</sup> Thirdly, the internalized, self or felt stigma where the stigmatized individuals endorse these negative stereotypes or labels about their group and accept their inferiority status as undesirable members of society while creating a perpetual expectation of humiliating treatment.<sup>154</sup>

Stigma against the Deafblind in Uganda is prevalent and occurs at different levels ranging from social, institutional, and self-felt. This not only excludes/isolates but also discriminates the Deafblind as well as their caretakers and families.<sup>155</sup> The Deafblind and their caretakers are in some cases viewed as ‘filthy’ and ‘retarded’. A lady narrated that, ‘*There is a friend with a child with Deafblindness. She used to cook chapatti for sale, but people could not buy her chapatti – commenting that, after touching the child, she touches the eats.*’<sup>156</sup> This is not an isolated case, but it reveals a serious systematic problem of discrimination of the Deafblind in Uganda. In some extreme cases, disabilities have been associated with spiritual uncleanness and a curse attributed to either the individual or his/her relatives.<sup>157</sup> Such misconceptions fueled by unfounded beliefs and traditions in Uganda inhibit the development, integration, and participation of the Deafblind in mainstream society.<sup>158</sup>

## V. DEVELOPMENTS IN COMMUNICATION STRATEGIES AND TECHNOLOGIES FOR THE DEAFBLIND IN THE FURTHERANCE OF FREEDOM OF EXPRESSION

There are diverse communication strategies and languages adopted by the Deafblind community worldwide in the advancement of communication and consequently freedom of expression. These include speech-

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<sup>151</sup> J. Dovidio, B. Major, & J. Crocker, *Stigma: Introduction and overview* (2000), at 10.

<sup>152</sup> Hersh, *supra* note 120, at 446.

<sup>153</sup> E.N. Rutondoki & P. Ojwang, *Perceptions of the Availability and Effectiveness of HIV/AIDS Awareness and Intervention Programmes by People with Disabilities in Uganda*, 7(4) *Journal of Social Aspects of HIV/AIDS* 17 (2010), at 19.

<sup>154</sup> M.A. Hersh, *Deafblind People, Stigma and the use of Communication and Mobility Assistive Devices*, 25(4) *Technology and Disability*, 245 (2013), at 247-248.

<sup>155</sup> Kanya, *supra* note 71, at 39.

<sup>156</sup> *Id.*, at 44.

<sup>157</sup> E. Okurut & H. Among, *Stigmatization, Discrimination and the Right to Health of Autistic Children in Uganda*, 6(1) *IUIU Journal of Comparative Law* 279 (2019), at 292. Available at: <<https://ir.iuiu.ac.ug/xmlui/bitstream/handle/20.500.12309/675/IUIU%20Journal%20of%20Comparative%20Law.pdf?sequence=1&isAllowed=y>> (accessed 10 May 2021).

<sup>158</sup> Okurut & Among, *supra* note 157, at 293.

based communication, letter-based communication, assistive communication technologies, sign language, visual frame interpreting, among others. These are highlighted in the discussion below.

### ***A. Speech Based Communication***

Tadoma is a technique where communication is perceived through touching and the feeling jaw movements, vibrations, and facial expressions of the speaker. In this technique, the person with Deafblindness places his or her hand on the speaker's chin, lips, or throat in order to feel their movements and vibrations as they speak.<sup>159</sup> In order to aid proper understanding, clear speaking is important. Tadoma is considered the most appropriate communication technique for Deafblind persons with some residual hearing and visual abilities which can facilitate lip reading (observing the lip shapes), gestures and even facial movement of the person speaking.<sup>160</sup>

### ***B. Letter Based Communication***

Letter based communication includes tactile sign language where the signs are indicated on the palm of the hand, tactile finger spelling which uses finger based signs following a specific pattern, and tactile alphabet which is based on spelling words, block by block indicating them on the palm of an individual's palm. Each sign represents a particular letter. Braille uses a series of raised dots that is six in two columns of three, to symbolize letters or groups of letters. This involves typing onto six fingers as a braille keyboard representing the six dots.<sup>161</sup> Braille has been developed into a digital aid with some smart phones enabling braille displays.<sup>162</sup>

### ***C. Assistive Communication Technologies***

Assistive communication technologies have considerably enhanced communication as well as mobility of the Deafblind. For example, GoBraille was developed and inbuilt into MoBraille<sup>163</sup> as a means of easing independent mobility/transit in public as well as ensuring safety for the Deafblind. GoBraille was inbuilt into the public transport systems such as buses and trains.<sup>164</sup> For persons with acquired Deafblindness, the development of cochlear implantation (CI), which is surgically inserted, has primarily enhanced their mobility and interaction with the surroundings. This advancement has consequently improved their

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<sup>159</sup> World Federation of the Deafblind, *supra* note 9, at 6.

<sup>160</sup> UK Department of Health, *supra* note 37, at 15.

<sup>161</sup> Hersh, *supra* note 120, at 447.

<sup>162</sup> UK Department of Health, *supra* note 37, at 15.

<sup>163</sup> MoBraille connects android phones to any WiFi-enabled Braille and also enables the development of third party smart phone applications even without knowledge of device-specific protocols

<sup>164</sup> *Id.* See also: Azenkot *et al*, *supra* note 50, at 3247.

behaviors.<sup>165</sup> Telecommunications devices for the deaf (TDD) and telebraille have also been developed much to the aid of the Deafblind. These devices have greatly enhanced communications especially telephone conversations but have not been practically effective as a portable or handy unit that could improve personal interactions in activities of daily life due to their.<sup>166</sup> Kramer and others developed the instrumented glove which obtains electrical signals representing an actual hand of the first individual.<sup>167</sup>

Unfortunately, some technologies such as those with speech outputs have limited practicability. For example, there is difficulty in hearing when one is in a busy public area, and there is a general lack of privacy. Therefore, some users prefer to use braille to enjoy some degree of privacy. Moreover, it is particularly inconveniencing to carry around multiple specialized gadgets which are also very expensive.<sup>168</sup> The Deafblind, no matter the degree of difficulty, have increasingly become dependent on assistive communication technologies as well as online social networking service as an aid for interaction.<sup>169</sup> This raises concerns of accessibility and affordability since these specialized devices are used by a small portion of commercial consumers which escalates the cost of production.<sup>170</sup>

In Uganda, the unsettling reality is that there are higher poverty levels among the Deafblind and their households.<sup>171</sup> The 2018 UN Report recorded a significant poverty gap between persons with disabilities at 90% and those without disabilities at 57%.<sup>172</sup> Even those with some income may not be able to afford communication equipment such as braille machines which cost 5,000,000 UGX (1,351\$); and hearing devices for the partially deaf that cost between 1,000,000 – 3,000,000 UGX (270 – 811\$). This puts most of these assistive technologies out of the reach of most of Uganda's persons with Deafblindness.

Even with these technological advancements, there is still need to balance between technological support systems, and human support<sup>173</sup> because technology on its own cannot satisfy all the needs of persons with

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<sup>165</sup> J. Dammeyer, *Congenitally Deafblind Children and Cochlear Implants: Effects on Communication*. Oxford University Press (2008), at 278.

<sup>166</sup> The VPL glove and the Grimes glove present a number of limitation. For example, the Grimes glove was limited to recognition of programmed hand formations without specifications to monitor customized finger positions. See Communication system for deaf, deaf-blind, or non-vocal individuals using instrumented glove Inventors James P Kramer, Peter Linener, and William R. George. <<https://patentimages.storage.googleapis.com/26/75/36/c3c9b51f780ed4/US5047952.pdf>> (accessed on 19 February 2021).

<sup>167</sup> *Id.*

<sup>168</sup> Azenkot *et al*, *supra* note 50, at 3252.

<sup>169</sup> Australia, *supra* note 57, at 11.

<sup>170</sup> *Id.*, at 12.

<sup>171</sup> Blindness has profound human as well as socioeconomic consequences for the individual, family and society. Global economic losses recorded were as high as US \$42 billion in the year 2000 with projections of US\$ 110 billion per year by 2020. see World Health Organization (2007) Vision 2020 Global Initiative for the Elimination of Avoidable Blindness: Action Plan 2006-2011 World Health Organization Geneva Switzerland 2-7.

<sup>172</sup> Multidimensional poverty is where one experiences multiple deprivations. UNITED NATIONS, DISABILITY AND DEVELOPMENT REPORT: REALIZING THE SUSTAINABLE DEVELOPMENT GOALS BY, FOR AND WITH PERSONS WITH DISABILITIES 34 (2018).

<sup>173</sup> Hersh, *supra* note 120, at 447.

Deafblindness.<sup>174</sup> According to Satoshi Fukushima, a Deafblind professor ‘*Most products are not designed with deafblind people in mind from the beginning, so often they are not really easy to use...in the end, machines will not solve everything, so, I think it is important that a combination of human support and technology be combined for the complete solution*’.<sup>175</sup> Moreover, the strides in technology largely focus on either persons with deafness or blindness, but not persons with Deafblind.<sup>176</sup>

The reality is that specialized human assistance in Uganda, just like anywhere else in the world, is still too expensive for most persons with Deafblindness and their households to afford. To illustrate this, the average daily rate for a sighted guide is about 50,000 UGX (13.5\$), while a tactile interpreter for the totally Deafblind charges a daily rate of about 70,000 UGX (13\$).<sup>177</sup> Due to the high costs associated with professional caretakers, most persons with Deafblindness in Uganda are taken care of by a relative.<sup>178</sup> While relatives do not usually demand payment for the care rendered to a person with Deafblindness, the time and attention required that they may have to forfeit their jobs thus losing income which undeniably undermines the welfare of the entire family.<sup>179</sup> In addition, relatives and even some educators are often ill-equipped untrained in the care and support for persons with Deafblindness and have to rely on what they think is best for individual.<sup>180</sup>

#### **D. Other Modes of Communication**

Sign language is another mode of communication and it is reported that where it is reported that there are approximately 138 documented signed language globally and these are unique to every country.<sup>181</sup> The Ugandan Sign Language (UgSL) is officially acknowledged in Cultural Objective XXIV in the 1995 Constitution of Uganda, which emphasizes the development of sign language as one of the official languages in Uganda.<sup>182</sup> The realization of this objective has been impeded by the limited government funding towards training and development of sign language,<sup>183</sup> which is still in its formative years.<sup>184</sup> Moreover, the narrow vocabulary which limits the creation of a broader lexicon coupled with the variations

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<sup>174</sup> World Federation of the Deafblind, *supra* note 9, at 5.

<sup>175</sup> Australia, *supra* note 57, at 11.

<sup>176</sup> *Id.*

<sup>177</sup> *Id.*

<sup>178</sup> Kanya, *supra* note 71, at 31.

<sup>179</sup> *Id.*, at 39.

<sup>180</sup> Manga & Masuku, *supra* note 36, at 2225.

<sup>181</sup> For example, the deafblind in Canada officially use the American Sign Language used by Anglophones and langue des signes québécoise (LSQ) by Francophones. See: Russell, Chovaz & Boudreault, *supra* note 49, at 2. In Australia, Auslan is an official sign language used among the deaf. This is a blend of Irish and British sign language. See: Australia, *supra* note 57, at 15.

<sup>182</sup> The 1995 Constitution of Uganda

<sup>183</sup> Sam Lutalo-Kiingi, 2014. A Descriptive Grammar of Morphosyntactic Constructions in Ugandan Sign Language (UgSL). A thesis submitted in partial fulfilment for the requirements of the degree of Doctor of Philosophy at the University of Central Lancashire 30-31. Sign language training is currently offered at Kyambogo University for a duration of one year.

<sup>184</sup> Mugeere, A.B., Atekyereza, P., Kirumira, E.K. & Hojer, S., 2015, ‘Deaf identities in a multicultural setting: The Ugandan context’, African Journal of Disability 4(1), Art. #69, 9 pages. <<http://dx.doi.org/10.4102/ajod.v4i1.69>> 3

in sign language across the Uganda Deaf community, has also complicated the standardization of this language.<sup>185</sup> The lack of prioritization of sign language development jeopardizes the effective communication of persons with hearing disabilities. For example in the health sector, their interaction is frustrating as many of the personnel lack training and there is absence of sign language interpreters.<sup>186</sup> In the political spheres this was witnessed during their nominations in the 2021 general elections in Uganda where the Commissioner, Disability, and Elderly-Ministry of Gender, Labour, and Social Development Emily Ajiambo acknowledged that there are few sign language interpreters, and they are very expensive to hire more less employ.<sup>187</sup>

Visual frame interpreting a form of communication used by persons with some residual vision and clear speech.<sup>188</sup> An interpreter, and cards both in standard type and braille are used especially in public areas. Such cards could say, *'I am deaf and blind. Can you help me cross the street?'*<sup>189</sup> Guide dogs have also been trained to work with the Deafblind in interpreting sign and spoken commands, and provide guide and hearing support.<sup>190</sup> In Uganda, the use of guide dogs has hardly been explored despite the advocacy around their potential to improve accessibility and participation for persons with hearing and visual difficulties.<sup>191</sup> Last but not least is the symbol system where photos pictures and objects can be incorporated to other modes of communication.<sup>192</sup>

It is important to note that there is no standard or uniform mode of communication. The Deafblind may adopt one or several forms of communication depending on: whether one has pre-lingual or post-lingual impairments, the sequence at which the impairments were attained, and the level of residual hearing and vision. For example, persons with profound visual impairments but later attain hard of hearing may have benefited from braille training whereas those with pre-lingual use different approaches to develop language and communication.<sup>193</sup>

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<sup>185</sup> Digitalizing Uganda Sign Language Project, A project by the Uganda National Association of the Deaf (UNAD) together with SPIDER, March 1st, 2017 available at <<https://spidercenter.org/tackling-inequalities-through-creation-of-digital-sign-language/>> (accessed 14 May 2020)

<sup>186</sup> Initiative for Social and Economic Rights (ISER). Civil society sue government over absence of sign language interpretation in access to health care 15 August 2017 Kampala 2

<sup>187</sup>The Disability Insider, Lack of Sign Language Interpreters Slows Nomination of Deaf People in Uganda. 27 September 2020

<sup>188</sup> World Federation of the Deafblind, *supra* note 9, at 16.

<sup>189</sup> Azenkot *et al*, *supra* note 50, at 3258.

<sup>190</sup> Hersh, *supra* note 152, at 248.

<sup>191</sup> Institutional Development Program (2016) Beyond 2015: Delivering On The Agenda For Persons With Visual Impairment in Africa Proceedings of the 6th Africa Forum Speke Resort Munyonyo, Kampala, Uganda 4<sup>th</sup> – 8<sup>th</sup> October 2015. 235. For the intricacies of guard dogs see Lloyd, J., Budge, C., La Grow, S., & Stafford, K. (2016). An Investigation of the Complexities of Successful and Unsuccessful Guide Dog Matching and Partnerships. *Frontiers in veterinary science*, 3, 114. <https://doi.org/10.3389/fvets.2016.00114>.

<sup>192</sup> UK Department of Health, *supra* note 37, at 15.

<sup>193</sup> World Federation of the Deafblind, *supra* note 9, at 4.



The various communication strategies highlighted above have been commended for their role in improving the communication abilities of the Deafblind. However, they placed limited importance towards the development of communication strategies to improve the ability of communication partners to appreciate the Deafblind.<sup>194</sup>

## **VI. MEANINGFUL SOCIAL INTERACTION: A CORE COMPONENT IN THE ENJOYMENT OF FREEDOM OF EXPRESSION FOR DEAFBLIND PERSONS**

Communication is pivotal to the enjoyment of the right to freedom of expression for persons with Deafblindness in Uganda. In this context, communication means the process of social interaction carried out between the individual, the other person and the external environment literally implying Me, You, and It. The major components of social interaction include: mutual attention and co-regulation; reciprocity; turn-taking and giving; mutual attention and proximity; rhythm and tempo; and novelty and processing.<sup>195</sup> The presence and application of these components may potentially result in coherent and sustainable meaningful social interaction.

For the Deafblind, any social interaction does not automatically imply that it is meaningful. This discussion is premised on the view that in appreciating what amounts to meaningful social interaction for the Deafblind, communication should be contextualized within the reasonableness of persons who are Deafblind rather than those without such difficulties. This will mitigate the risks of misinterpretations surrounding their behaviors and expressions as barbaric, a social disturbance, meaningless, and not '*as the natural deafblind way of expressing oneself and of making sense of the world*'.<sup>196</sup>

What others may consider as normal, obvious, and basic interactions/ platforms can be carefully translated into meaningful social interaction for the Deafblind. Some of the precepts of meaningful interaction in this context include: an enabling environment, interdependence, and access to information, among others.

### ***A. An Enabling Environment***

Communication is at the core of human development regardless of one's difficulty in doing so. Meaningful communication is hinged on one's desire to communicate, the intention or purpose of the communication, and the ability to communicate, the recipient's availability to receive what is being communicated,

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<sup>194</sup> Hersh, *supra* note 120, at 447.

<sup>195</sup> Omugur, *supra* note 148, at 178.

<sup>196</sup> Redbroe & Janssen, *supra* note 7, at 11.

appreciate, and reciprocate appropriately in relation to that communication.<sup>197</sup> Such holistic interaction can successfully be attained within an enabling environment.

One of the characteristics of an enabling environment is that it needs to be responsive towards any communication attempts made by the person who is deafblind.<sup>198</sup>

### **B. Interdependence**

Interdependence is hinged to the right to self-determination which is one of the fundamental components of freedom of expression. The realization of the right to self-determination relies on the acquisition of lifecycle and disability appropriate skills necessary for social interaction.<sup>199</sup> Interdependence does not undermine autonomy, but it fosters mutual and respectable relationships between the Deafblind and other stakeholders. It is a common practice for partners or even third parties to make decisions for and on behalf of the person who is Deafblind. This in most cases seems to be a natural reflex or instinct which is reinforced by the social and cultural perceptions as to 'what is in the best interest' of the Deafblind.<sup>200</sup>

However, the line between 'what is best' and audism could be distorted. According to Humphries, audism is '*the notion that one is superior based on one's ability to hear or behave in the manner of one who hears*'. In simple terms, it is '*an English word that is to the Deaf what 'racism' is to blacks*'. Audism is a by-product of the perceptions that the deaf lack the capability to make autonomous decisions. This can be found both at individual, and institutional levels which has been defined as '*a structural system of exploitative advantage that focuses on and perpetuates the subordination of Deaf Communities of origin, language, and culture*'.<sup>201</sup>

### **C. Access to Information**

For the Deafblind especially congenital, information first connotes access to appropriate experiences in the world. The determination of the appropriate experiences as well as the extent and technique of full access is at the discretion of the partner. Moreover, he or she must actively take part in the experience. The proper execution of these experiences will contribute the development of patterns of meaningful interaction for the Deafblind. On the other hand, the reluctance coupled with the lack of knowledge and/skill of the partner to

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<sup>197</sup> Hersh, *supra* note 120, at 447.

<sup>198</sup> S. Morgan, E. Bixler & J. McNamara, *Self-determination for children and young adults who are deaf-blind*, NTAC 1 (2002), at 3.

<sup>199</sup> Morgan, Bixler & McNamara, *supra* note 198, at 2.

<sup>200</sup> *Id.*

<sup>201</sup> The ways in which audism is expressed are; overt, where there is a big disparity of power between the majority and the minority that later do not acknowledge, care or even appreciate the effect of beliefs and attitudes of audiocentric privilege; covert, is less obvious or rather disguised for example in the job market where an excuse for not hiring is given '*We want to hire more deaf people but there just are not any deaf PhD's*'; and aversive which translates to avoidance and denial. R.C. Eckert & A.J. Rowley, *Audism: A Theory and Practice of Audiocentric Privilege*, 37(2) *Humanity & Society* 101 (2013), at 108.

stimulate interest, interaction, and ensure full participation of the Deafblind, prolongs the chaotic and meaningless state of such an individual.<sup>202</sup> Access to information embodies access to auditory as well as visual information in accessible formats which is very critical to freedom of expression for persons who are Deafblind.<sup>203</sup> This requires the adoption of a combination of technologies and methods.

## VII. CONCLUSION

This research centered on the right to freedom of expression in relation to persons who are Deafblind in Uganda. These are a special group of persons who have hearing and visual disabilities. Based on the age of onset, there are classifications of congenital and acquired Deafblindness. Of these two, congenital Deafblindness is the most severe as the individual barely have any comprehension of language and more so acquired the communication skills which is imperative in their development and expression.<sup>204</sup> Earlier discussions illustrate the difficulties faced by the Deafblind in engaging in meaningful communication and interaction towards the realization of this right. This stimulates reflections as to what could possibly amount to freedom of expression through the lens of persons with Deafblindness.

### *A. Reflections on Freedom of Expression for the Deafblind*

A reflection of the Deafblind and the right to freedom of expression stimulates complex questions that resonate especially for persons with congenital Deafblindness and those with acquired Deafblindness where the auditory loss and blindness was attained simultaneously. In reality, persons in these categories have barely had reasonable opportunities to develop the vital language, and communication skills necessary for the Deafblind to enjoy freedom of expression. The standpoint of this research is that hasty responses to the questions below could generate inaccurate conclusions that do not portray the status quo of the Deafblind in relation to this right. This unique area requires combined multi-disciplinary approaches and further research.

These questions primarily relate to the substantiality test in this context. For example, how can the Deafblind exercise freedom of expression when they barely have the relevant language and communication skills, from the onset? At what point can it be concluded that such persons are enjoying this right? Is basic interaction sufficient the minimum benchmark in the enjoyment of this right? One may suggest that an affirmative conclusion can be attained once there is reasonable and meaningful interaction. Then what amounts to reasonable interaction? Does reasonable interaction automatically make it meaningful?

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<sup>202</sup> Redbroe & Janssen, *supra* note 7, at 13.

<sup>203</sup> Morgan, Bixler & McNamara, *supra* note 198, at 5.

<sup>204</sup> *Id.*

Reasonable and meaningful interaction commences with basic interaction but further considers the nature, appropriateness, and context in which such interaction is being exercised. However, the focus on these parameters could stir ambiguities as to the parameters of meaningful, reasonable, and appropriate; and what they comprise of; and in what context. It could further introduce prejudice where reasonable interaction may be primarily contextualized within the confines of one's difficulty/impairments or even the abilities of the partners rather than the best interest of persons with Deafblindness.

Introducing the criterion of 'best interest' in determining the enjoyment of freedom of expression is equally very complex. As already highlighted in previous discussion, the line between 'what is best' and audism is vague. Audism is more less a byproduct of misconceptions that the deaf are unable to make autonomous decisions. Responses to questions surrounding 'what is best' may primarily be subjective especially for the partners and the community at large. For instance, what amounts to what is best/who determines what is best? Should the nature of impairment and level of difficulty be considered in determining what is best? Some responses to these questions may seem obvious but most of them are so complex and subjective. They may be influenced by a delicate interplay with various dynamics such as: one's financial status; environmental barriers, religious, social, and cultural backgrounds; personal characters; age; and the existence of other impairments such as mental difficulty, among others.

This study therefore draws two conclusions. Firstly, in order to logically demystifying freedom of expression for the Deafblind, it is fundamental to center all interventions on exploring and developing what such persons can do rather than focusing on what they cannot do.<sup>205</sup> This constructive approach should guide all processes in the development of tailor-made interventions addressing lifecycle difficulties that inhibit the enjoyment of freedom of expression. For instance, there shall be variations in interventions for congenital Deafblindness, acquired Deafblindness, simultaneous or independent auditory loss and blindness, and gradual or immediate loss.

Secondly, it is unrealistic to view freedom of expression exclusively from a legal viewpoint, and by those without such impairments. This may result in hasty and uninformed conclusions/responses regarding whether the Deafblind are enjoying this right or not and what can be done to realize this enjoyment. Freedom of expression for the Deafblind has no formula or modus operandi primarily because persons with such conditions are heterogeneous. Whereas the general characteristic is limitations in visual and auditory abilities, there is no standard form of Deafblindness to justify a rigid formula in contextualizing freedom of expression. As such, it is imperative to adopt a total communication approach which emphasizes the use of

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<sup>205</sup> G. LESLIE, G. (ED.). RESEARCH TO REAL LIFE: INNOVATIONS IN DEAF-BLINDNESS. THE NATIONAL INFORMATION CLEARINGHOUSE ON CHILDREN WHO ARE DEAF-BLIND, 7 (2001).

appropriate combinations of communication methods catering to individual needs towards the successful attainment of contact, information, and interaction. A good example is where one may be able to receive information through speech and signs but expresses themselves with signs and symbols.<sup>206</sup>

To sum up, the freedom of expression is a very important right for the Deafblind, which wholly depends on an individual's ability to effectively formulate and communicate such ideas to others. The ability of the Deafblind to communicate hinges on the development of communication to empower them interact with other individuals. Therefore, freedom of expression for this group is communication which, is ultimately '*in its most basic form, action and reaction, back and forth*'.<sup>207</sup> Once this complex balance is attained, then this could be the starting point to deliberations as to whether this right is being realized by the Deafblind or not. If not, then what can be done to ensure its realization? As earlier stated, the focus should be on what they can do rather than what they cannot do.

## **VIII. RECOMMENDATIONS: A PROACTIVE APPROACH TO FREEDOM OF EXPRESSION FOR THE DEAFBLIND**

### ***A. Early Intervention Strategies***

Early interventions is important because the physical, psychological, and emotional adjustments of a child who is Deafblind are far less traumatic than a person who faces this dual impairment at adulthood.<sup>208</sup> Such interventions include early identification ranging from medical screening to psychological assessments,<sup>209</sup> depending on the nature of difficulty. These are discussed below:

**1. Observations from the onset.**—For children with congenital deaf blindness, early interventions are key in the adaptability of the child and the parent/caretaker. This may entail exploring the child's residual senses from birth even when the child seems not to respond to anything. Even then, careful observation of the slightest movement of the child when stimulated could yield remarkable results in initiating communication such as in determining the child's likes and dislikes. For instance, change in muscle tone in response to external stimuli. One parent of a Deafblind physically disabled, and epileptic man aged 22 years in Uganda who developed the condition at 18 months old notes that, '*Because Bidson does not talk or hear there are things he expresses by crying or through body language as he pulls a face or stretches a limb*'.<sup>210</sup> According to Professor Deborah Chen, the process of observation for the parent

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<sup>206</sup> UK Department of Health, *supra* note 37, at 17.

<sup>207</sup> Leslie, *supra* note 205, at 3.

<sup>208</sup> Smithdas, *supra* note 126, 1015.

<sup>209</sup> UK Department of Health, *supra* note 37, at 7.

<sup>210</sup> Kakembo, *supra* note 69, at 26.

‘involves slowing down, waiting for the child to process information, have a reaction or express a need’. One example is a mother who upon discovering that her child had a good sense of smell, used it to stop or prevent his nagging by placing a cinnamon roll near his nose and giving him a taste of it.<sup>211</sup>

Observation should be accompanied with repeated patterns (routines) in order stimulate behavioral patterns that generate consistent communication pathways.<sup>212</sup> Keen observance of deictic (pointing) gestures can also provide educational opportunities that could introduce a potential language furthers participation and consequently the realization of the right to freedom of expression.<sup>213</sup> For such results to be attained, it is vital to train parents and caregivers on these skills as well as medical and legal components on freedom of expression.

**2. Early medical screening and functional assessment.**—Children need access to specialist audiology and ophthalmology services. A 2016 Sense International report revealed that there was hardly any early identification and interventions services specific to children who are Deafblind.<sup>214</sup> Medical checkups are critical towards establishing the extent of an individual’s existing and imminent impairments which informs lifecycle stimulation interventions which enhance their development as well as interaction.<sup>215</sup> Progressive functional assessments by interdisciplinary teams at different levels is also important in identifying and guiding the abilities of each person who is Deafblind.<sup>216</sup>

In February 2021, Sense International Uganda in partnership with NADBU, launched proactive health interventions such as early detection and interventions for children especially 0-3 years.<sup>217</sup> Whereas this is commendable, there is need for concerted efforts from various stakeholders in prioritizing these interventions. In addition, there is a need to raise awareness on this initiative and make these services more available at the grassroot level.

## **B. Safeguarding Strategies**

**1. Inclusion of the Deafblind in legal and policy formulation.**—There are concerns that efforts by state and non-state actors in Uganda towards the implementation of the Sustainable Development Goals as well as the CRPD generally lack special safeguarding interventions pertaining to persons who are Deafblind. These interventions primarily focus on other disability categories like persons with physical

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<sup>211</sup> Leslie, *supra* note 205, at 2.

<sup>212</sup> *Id.*

<sup>213</sup> Omugur, *supra* note 148, at 175.

<sup>214</sup> Sense International, *Key Concerns for Persons with Deafblindness in Uganda*. Briefing to the Committee on the Rights of Persons with Deafblindness. Sense International (2016), at 5.

<sup>215</sup> Hofmann, *supra* note 11, at 359.

<sup>216</sup> Redbroe & Janssen, *supra* note 7, at 18.

<sup>217</sup> SI supported and equipped 4 health centers with visual and hearing screening equipment as well as train eighty-eight health care staff to execute such duties, among others Sense International, Uganda, <<https://senseinternational.org.uk/our-work/uganda>> (accessed on 8th February 2021).

disability, hard of hearing, and visual impairments.<sup>218</sup> This is attributed to the absence of official recognition and visibility of persons with Deafblindness as a distinct group in disability statistics as well as national policy frameworks.<sup>219</sup> This profoundly proliferates their isolation,<sup>220</sup> powerlessness and vulnerability<sup>221</sup> which consequently undermines their ability to exercise freedom of expression.

One of the major steps to inclusion is the development and adoption of a standard definition of Deafblindness within Uganda's law that will also guide policy interventions. This should be accompanied by standardized sets of descriptors or guidelines for ascertaining whether one is Deafblind or not, and whether it is congenital or acquired. An example of descriptors developed by the UK Department of Health for congenital deaf blindness include: little to response to sound or light; challenges with eye contact; sluggish development of basic skills; repetitive behavior; preference to smell, touch and taste, and personalized communication techniques. For acquired Deafblindness, some indicators include no response to sound behind them, louder volumes when watching television or listening to the radio; lack of awareness of noises in public areas, use of hearing aids, need for extra lighting, unusual use of touch for mobility, difficulties with unfamiliar routes, difficulty in watching television/listening to radio.<sup>222</sup>

**2. Skills training.**—The development of basic communication and language begins at home especially between the partner and the person who is Deafblind followed by the schools, and community. As has been noted before, the majority of caretakers and households of the Deafblind lack the necessary knowledge on formal sign language or tactile communication. As such, they use improvised communication techniques such as shouting and painful touching depending on what needs to be communicated.<sup>223</sup> Even those that have the will to learn are preoccupied with providing full time care to the Deafblind at home. Such care includes guiding their movement, cleaning, feeding them, and dressing them up, among others.<sup>224</sup>

Within the school, teachers of Deafblind learners lack the necessary communications skills to communicate with, instruct, and respond in support of such learners.<sup>225</sup> The Deafblind also need to be continuously trained on the different types of communication methods. This should be coupled with psychological support to mitigate emotional and psychological distress. Sadly, there is currently no specialized school for persons with Deafblindness in Uganda. As such, children with this impairment are usually enrolled in schools for children who are deaf without speech. Others depending on the level of difficulty are enrolled in mainstream

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<sup>218</sup> Kanya, *supra* note 71, at 11.

<sup>219</sup> World Federation of the Deafblind, *supra* note 9, at 3.

<sup>220</sup> Ssenyondo, *supra* note 41, at 1.

<sup>221</sup> Kanya, *supra* note 71, at 11.

<sup>222</sup> UK Department of Health, *supra* note 37, at 14.

<sup>223</sup> Ssenyondo, *supra* note 41, at 9.

<sup>224</sup> Kanya, *supra* note 71, at 28.

<sup>225</sup> Omugur, *supra* note 148, at 184.

schools which in reality lack specialized support for them.<sup>226</sup> Within the health sector, only few health workers are able to communicate in sign language.<sup>227</sup>

**3. Deconstructing deafblindness stigma.**—Stigma in Uganda, as already discussed in section 4C, occurs at different levels ranging from social, institutional, and self-felt. This not only exclude/isolate but also discriminate the Deafblind as well as their caretakers and families.<sup>228</sup> Therefore, initiatives to tackling stigma require a tailored approach that includes legal and policy reforms; advocacy; interventions to eliminate self-stigma (internalized stigma); developing interaction strategies, and showing compassion to persons with disability especially the Deafblind.<sup>229</sup>

Corrigan and Penn proposed three approaches that can help in the fight against public stigma including dissent, education, and interaction.<sup>230</sup> They argue that often, persons with disabilities are depicted in a damaging, destitute and undesirable way that highlights their inadequacies rather than their potential and strengths.<sup>231</sup> This approach importantly relays a strong message of non-tolerance of negative stereotypes, misinformation and harmful cultures, and encourages interaction between persons with disabilities and the society to break down misconceptions. On the other hand, self-stigma (self-felt/internalized) is best dealt with by empowering the individual to counteract negativity and restore confidence.<sup>232</sup> In Uganda, most persons with disabilities are exposed to prejudice from various sources. It is therefore important to ensure that there is awareness on the condition of Deafblindness, and that the prejudicial misconceptions associated to it are deconstructed to ensure the wellbeing of persons with Deafblindness.

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<sup>226</sup> Kanya, *supra* note 71, at 35.

<sup>227</sup> Rutondoki & Ojwang, *supra* note 153, at 21.

<sup>228</sup> Kanya, *supra* note 71, at 39.

<sup>229</sup> P.W. CORRIGAN, THE STIGMA OF DISEASE AND DISABILITY: UNDERSTANDING CAUSES AND OVERCOMING INJUSTICES. AMERICAN PSYCHOLOGICAL ASSOCIATION, (2014).

<sup>230</sup> P.W. Corrigan & D.L. Penn, *Lessons from Social Psychology on Discrediting Psychiatric Stigma*, 54 *American Psychologist* 765 (1999), at 766.

<sup>231</sup> *Id.*

<sup>232</sup> Corrigan & Penn, *supra* note 230, at 770.