



**KWAME NKURUMAH  
UNIVERSITY OF  
SCIENCE AND TECHNOLOGY**



**COLLEGE OF HUMANITIES AND SOCIAL SCIENCES  
FACULTY OF SOCIAL SCIENCES  
DEPARTMENT OF SOCIOLOGY AND SOCIAL WORK**

**Improving Access to Healthcare for Persons  
Living with Intellectual Disabilities:  
A Practical Guide for Policy Makers,  
Health Workers and Social Workers**



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## **PREFACE**

Across the globe, promoting the wellbeing of vulnerable populations is a key mandate of both governments and academics. Promoting the wellbeing of persons with intellectual disabilities is arguably one of the key responsibilities of social work academics in Ghana. In fulfilling this mandate, we have conducted a number of studies into the care and health needs of Persons Living with Intellectual Disabilities (PwIDs). We have prepared this policy brief as a way of informing policy and practice and making our research relevant to practitioners and policy makers in Ghana. Our aim is to, through this brief, bridge the divide between PwIDs and healthcare professionals. In order to achieve this, we present brief but practical recommendations aimed at improving communication and removing barriers to healthcare access and delivery for PwIDs in Ghana. This policy brief makes specific, targeted and practical recommendations for health personnel, especially nurses, social workers and other policy makers in their work with Persons living with intellectual disabilities. The brief contains specific images

and descriptions recommended for use as a communication tool between health workers and PwIDs within health care settings. We are confident that frontline health workers will find this guide relevant in their work and through that improve healthcare delivery and access for Persons living with intellectual disabilities in Ghana.

**Kwadwo Ofori-Dua (PhD)**

*Principal Investigator*

**John Boulard Forkuor (PhD)**

*Project Manager*

**Peter Dwumah (PhD)**

*Researcher*

**Jonathan Mensah Dapaah (PhD)**

*Researcher*

**Odongo Attoh Douglas (Mphil)**

*Research Assistant*

## **Purpose of the Brief**

This brief was prepared as a result of a stakeholder collaborative research on intellectual disability. It brings to light the pressing challenges of individuals living with intellectual disabilities in accessing healthcare within selected Municipalities in the Ashanti Region. This brief makes specific recommendations targeted at improving healthcare delivery for the vulnerable population. The recommendations presented are based on the findings of a research conducted from 2019-2020 and inputs from relevant stakeholders concerning healthcare access for individuals living with intellectual disabilities. The aim of this brief is to inform policy makers and major institutions such as the Ghana Health Service, the Ministry of Education and the Ministry of Gender, Children and Social Protection on pressing issues of the intellectually disabled that need immediate intervention. These needs, when addressed, will enhance their healthcare access and inclusion, which will further contribute to Ghana's effort at meeting Sustainable Development Goal 3 (SDG 3)—Good health and wellbeing.

## **Structure of the Brief**

This brief has been structured into four sections. The first section presents the executive summary, while the second section presents an overview of the background and justification of the problem underpinning this brief. The third and the final sections unveil stakeholder challenges and practical recommendations respectively.

## **Acknowledgements**

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## **Executive Summary**

Access to quality healthcare is a human right. Hence, governments have a responsibility to ensure that all citizens, irrespective of race, gender, ethnicity and ability have access to this right. Nonetheless, Persons living with Intellectual Disabilities (PwIDs) in Ghana have limited access to quality and relevant healthcare.

This project has confirmed the persistence of negative cultural beliefs and attitudes towards persons living with intellectual disabilities. The implication is that even within healthcare settings, this negative perception influences the way frontline health professionals interact with this special population. This has led to poor communication, unaddressed health needs and in some cases complete avoidance of PwIDs by some health workers. This project has further revealed that there is no dedicated department with allocated specialists within local healthcare facilities to address peculiar health challenges of the intellectually disabled. As it stands, the intellectually disabled are attended to by general nurses

and physicians (who are not specialists on issues of intellectual disabilities) when they visit health facilities. Consequently, health workers sometimes find it difficult diagnosing and prescribing relevant medications for this population. These key challenges have negative implications on the health and wellbeing of the intellectually disabled within the greater Ghanaian context.

In view of the challenges identified, this brief recommends increase in public education and awareness creation through one-on-one interactions and media platforms to help address the myths and negative stereotypes associated with the intellectually disabled and their families. This brief further recommends the establishment of a specialist department within the healthcare service, to attend to the peculiar needs of the intellectually disabled. To bridge the communication gap between the nurses and the intellectually disabled, and increase the knowledge of nurses, it is further recommended that a core course on intellectual disability be introduced for first- and second-year nursing students

within the health training institutions. Finally, this brief recommends collaborated efforts between respective stakeholders and the Red Cross and Red Crescent Societies to help organise periodic trainings and workshops for the carers in special schools in order to improve their knowledge and practice skills in attending to this population.

It is our hope that policy makers and frontline practitioners, and educators will find this brief relevant in working with this special population and in eliminating existing barriers to healthcare for this special population.

## **Background**

In Ghana, despite the existence of international and local laws and conventions, including the Persons with Disability Act 715, PwIDs continue to suffer discrimination in various aspects of their lives, especially in accessing healthcare (Inclusion Ghana, 2007). This discrimination hinders the social inclusion of PwIDs and limits their contribution to the overall development of Ghana. The Persons with Disability Act 2006, Act 715 emphasizes the right of persons with disabilities to healthcare and the responsibility of the state to eliminate all barriers to health access. As a signatory to the United Nation's Convention on the Rights of Persons with Disabilities, Ghana has a responsibility to enforce Article 25 of the Convention, which emphasizes the right of persons with disabilities to access quality healthcare without discrimination.

Even though health professionals, including nurses receive professional training, these professionals are members of Ghanaian communities where intellectual disability is perceived as a spiritual phenomenon and a

curse from the gods (Hervie, 2013; Ndlovu, 2016). This context-specific perception, emerging from the socio-cultural context, negatively influence the attitudes of health professionals in working with PwIDs. Culture plays an important role in shaping the attitude of people in society; hence, its influence on the healthcare providers cannot be underestimated (Samovar, Porter and McDaniel, 2009). In fact, the outcome of interaction between professional training and cultural socialization ultimately informs the perception and behavior of frontline health workers towards PwIDs. Unfortunately, very little research in sub-Saharan Africa explores the interaction between professional training and socio-cultural socialization. Knowledge of the outcome of this interaction and its implication for health providers' attitudes and behavior will put social workers and other stakeholders in a better position to advocate for inclusive and non-discriminatory healthcare for PwIDs. Lack of this knowledge means that advocacy for inclusive healthcare education and the elimination of discriminatory cultural beliefs will continue to have very little impact on the wellbeing of PwIDs. This lack of knowledge negatively

affects the interaction of health workers with the PwIDs, and subsequently the quality of healthcare delivery. This is because research into healthcare service delivery indicates that good communication is a requirement to ensuring the provision of quality healthcare (Ali et al., 2013).

Inclusion Ghana (2013) reveals that health facilities in Ghana lack specialist physicians to attend to the specific health needs of PwIDs. This has led to the provision of general healthcare for this population, which mostly do not meet their specific health needs. More so, some parents of children living with intellectual disabilities in Ghana have bemoaned the quality and adequacy of healthcare service available for their children (Badu, 2016; Lamptey, 2019; Varghese et al, 2015). This inadequacy in healthcare provision results from the poor relationships, which usually exist between the healthcare providers and the PwIDs, mostly because of communication barriers (Lamptey, 2019; Badu, 2016). Health providers are less equipped to interpret the signs and symbols of PwIDs, especially those with speech

difficulties. This makes diagnosis and subsequent prescription of related medication a challenge for the healthcare providers in Ghana (Abrahams, 2015; Ali, 2013; Dinsmore, 2012; Gooding, 2017). For Hervie (2013), the challenges PwIDs face in accessing healthcare in Ghana is also because of negative socio-cultural perceptions of intellectual disability among health personnel. Hervie (2013) argues that some health professionals (including nurses) perceive PwIDs as not having the competence and knowledge to contribute meaningfully to decision making about their own healthcare. This perception generally leads to exclusion and marginalization of PwIDs in healthcare access and delivery. Lamptey (2019) and Inclusion Ghana (2013) have also asserted that the negative attitudes of health professional towards the PwIDs can be attributed to their insufficient knowledge about the PwIDs.

Even though some studies have been conducted on access to healthcare for PwIDs in Ghana (Badu, 2016; Inclusion Ghana, 2013; Lamptey, 2019), not much has been done on the nature and level of knowledge of health

professionals about PwIDs and the implication of this knowledge for healthcare delivery. Again, in the various special schools, less has been explored about the healthcare provision for the PwIDs, and as such, the extent of availability of general and specialist health service to this population is unknown. In this study, we explored the nature of healthcare provision for PwIDs, and the extent of this healthcare provision in the selected special schools. We examined the quality and accessibility of healthcare for PwIDs both within the broader Ghanaian society and within special schools, using information gathered from key participants.

In the ensuing sections, we first present an overview of the challenges to healthcare access for PwIDs as revealed from this project. Subsequently, we make specific recommendations, based on the findings to inform policy and practice and to help improve healthcare access for PwIDs.

## **Existing Challenges to Healthcare Access for Persons Living with Intellectual Disabilities**

One of the key findings emerging from this study is that persons with intellectual disabilities face institutional and attitudinal barriers in accessing healthcare services. The study revealed that most of the intellectually disabled suffer discriminations which involve negative staff attitude and behaviour, and communication barriers at health centres. The study supports the assertion that the peculiar health needs of the intellectually disabled are largely left unaddressed by health workers. This is seen in instances where they enter the hospital (have access), but leaves the facility with health needs unaddressed (unsuccessful use of service).

In addition, it was realized that most of the frontline health workers (nurses) lack knowledge and understanding of the health needs of the intellectually disabled, and as such, are unable to provide adequate healthcare services to this population. This lack of knowledge results partly from the lack of academic interest among nursing students in

studying about intellectual disability, due to negative socio-cultural perceptions concerning the subject area. It is therefore important to remove negative socio-cultural perceptions concerning intellectual disability in order to promote professional and social understanding of the health needs of this special population.

Another important finding from this study is that most of the health workers in the special schools are generalist practitioners. These practitioners mostly fail to conduct health reviews (check-ups) and screening on the intellectually disabled. This leads to improper diagnosis, unaddressed health needs and delayed medication. The health workers in this study also indicated that because of communication barriers, they often rely on third-party interpreters (mostly caregivers) in order to provide healthcare for the PwIDs. Relying on these caregivers places the intellectually disabled at risk in the delivery of healthcare services since most of these caregivers do not have formal education or training on the specific health needs of the intellectually disabled. Hence, they draw on their subjective understanding and experience to

communicate the health needs of PwIDs to healthcare providers. Since their attending skills are not scientific, their interpretations may put the health needs of this group at risk. In fact, we do not seek to undermine the critical roles that the carers play in articulating the health needs of the persons with intellectual disabilities within the healthcare facilities. However, we must also not downplay the tendencies of these carers to misreport the PwIDs to the healthcare providers. This highlights the need for specialist practitioners with an in-depth understanding of the health needs and challenges of PwIDs. The specialists will contribute significantly to eliminating the PwID-specific health challenges and subsequently promote their healthcare access.

The study has revealed that health workers have assimilated the negative cultural perceptions about PwIDs. This negatively influences the way they interact with PwIDs in health settings, resulting in unmet health needs of the PwIDs. Their professional training fails to address the cultural myths and misconceptions surrounding intellectual disabilities. Consequently, the

enduring negative cultural perception affects the attitudes of the health workers, leading to fear and avoidance of persons with intellectual disabilities who seek healthcare at the various health centres. The outcome of the interplay between professional training and cultural socialization is a negative attitude and behavior towards PwIDs and their health care needs. This study reveals how the cultural structure exercises more influence over professional training. Professional health training then does not necessarily translate into professional healthcare attitude and behavior towards all patients. On the contrary, our research reveals that the professional training received by health professionals in our study context is filtered through a cultural lens, a lens that ultimately shapes the outcome of the training and the attitude of the health professional. Thus, instead of interpreting the pathological challenge of the PwID from the professional point of view, the health worker is influenced by the cultural norms, using the cultural lens of society (due to the domineering impact of the socio-cultural structure). This then leads to further marginalization of the PwID patient.

## **Policy Recommendations**

Following the identified challenges, the following recommendations are made as ways of improving access to healthcare for persons living with intellectual disabilities.

### **Enhancing Direct Communication between PwIDs and Health Providers**

One of the key challenges identified is the communication barrier between PwIDs and healthcare providers. To enhance communication between PwIDs with speech impairment and healthcare providers, we recommend the use of image-based flip charts which clearly depicts specific ailments in pictorial formats for persons living with intellectual disability to identify with when experiencing similar ailments. This will help them in their communication with carers and health workers as they can point to specific pictures depicting specific health challenges when experiencing similar health problems. This flip chart should be available everywhere in the hospital facility, and in the special schools. Within the

hospital facility, some should be available to the nurses and the doctors in their consulting rooms and at the triage areas.

The flip chart should show specific ailments at varying degrees, which can be easily comprehended by the PwIDs. For example, a poster showing someone with a headache (it can be someone holding the head with a sad face with some expressions around the head to show some form of pain) can be displayed for this purpose. The headache can further be portrayed in varying forms depicting different degrees of the ailment (mild headache or severe head ache); similar images can also be used to describe and distinguish other ailments such as stomach ache, chest burns, running stomach, menstrual cramps (for ladies), nausea (feeling of vomiting), and even hunger. For example, a picture with someone touching the stomach with a sick face and thinking of a bowl of food—hunger. The same picture can be developed to express various forms of stomach aches. To facilitate this process, we have developed specific images to serve as a guide for

frontline service providers. *See Appendix 1, for sample images for communication.*

After developing the contents of the flip chart together with the caregivers and stakeholders like health workers, the PwIDs themselves, teachers and parents must be educated on the various meanings depicted by the respective pictures. This will help them develop a common communication medium to communicate health problems concerning the PwIDs with speech impairment, because the study has confirmed that the PwIDs have unconventional ways of communicating, and as such, makes comprehension difficult, especially in relation to health matters. Community health nurses can also use the flip chart to help the larger community health and assessment centers to improve communication with the PwIDs when they visit health facilities. The flip chart can also be presented at various churches and first-aid groups with copies distributed to them since they are also key stakeholders in interacting with the PwIDs. Targeted community durbars can also be used to disseminate this information in order to educate the general population.

## **Reducing stigma through targeted and specific public education**

This research identified culturally-informed discrimination and stigma as one of the main challenges to healthcare access for PwIDs. Consequently, we recommend that social workers, social welfare officers and community development officers educate the public on the biological and medical factors that lead to intellectual disability. Through such concerted and targeted education, stakeholders can gradually but consistently eliminate the spiritual explanations, superstitions, and negative perceptions attached to intellectual disability. This will reduce the perception of ‘otherness’ attached to this population; reduce marginalization and promote the social and health inclusion of PwIDs. This public education can be made a part of the basic school educational curricular, to make the future generations understand the medical explanations for intellectual disabilities. This strategy, together with community based educational programs, will help

eradicate the culturally entrenched perspective on intellectual disability as a spiritual phenomenon.

### **Improving professional training to address the needs of PwIDs**

While the enduring negative socio-cultural structures are being reformed, the professional health structures must also be strengthened through comprehensive training of health trainees on intellectual disability in order to enhance quality healthcare provision. Social work educators and practitioners can lead this form of education. Extensive curricular on intellectual disability for health workers in the various training institutions should be introduced. Nursing training institutions together with the stakeholders in the special schools should collaborate to educate the nurses to understand the specific peculiarities of persons with intellectual disabilities. This will equip all nurses with knowledge to attend professionally to the healthcare needs of this population at the basic level of healthcare delivery. This is necessary since this study revealed that the nurses are not well equipped to attend to the peculiar health needs of

PwIDs because they do not understand them. We further recommend that intellectual disability should be introduced as a core course for all health trainees. This course can cover key issues such as ‘who they are, their specific characteristics and health needs, how to attend to them, and how to interact with parents of such children.’ Further, internships in special institutions should be compulsory for all levels of nurses in the nursing institutions to pre-expose them and other frontline health workers to PwIDs. This will enhance interaction between health trainees and PwIDs and subsequently eliminate some of the communication barriers to healthcare access. This initiative can be piloted in some selected nursing institutions, using carers, social workers and other specialist practitioners as resource persons.

### **Training for Caregivers**

The researchers further recommend periodic training for caregivers (parents, carers in special schools, social workers) since they are the first point of call for persons living with intellectual disabilities. This training should include the housemothers, teachers and parents of PwIDs,

in order to enlighten them on the scientific approach in attending to individuals with intellectual disabilities. This will help improve understanding and better caregiving practices for this population. The Red Cross and Red Crescent Societies can organize such trainings on first aid administration within the various special schools, and helplines including that of the ambulance services. In addition, experienced nurses and mid-wives who have had contacts with individuals with intellectual disabilities can also be contacted by the health department to share their experiences with the caregivers on the best professional practices to attending to this special population. In conducting trainings, simulations can be done to help give the caregivers a hands-on experience to be able deliver at the point of need.

### **Increased stakeholder collaboration in addressing persisting health needs of PwIDs**

In order to ensure sustainable improvement in addressing the health needs of PwIDs, we recommend the establishment of a specific department within Municipalities and various districts. This department

resourced with professionals from health, social welfare and community development and education will have the mandate of developing strategies to address the health needs of PwIDs and to improve access to healthcare for this population within each district. This will require the collaboration of the Ministry of Health, Ghana Education Service and Department of Social Welfare. This Department should develop a special curriculum through which specialized instructors (with knowledge and expertise on intellectual disabilities and their health needs and health seeking behavior) will be trained. This Department should also be involved in the posting of specialized health workers to special schools to attend to the health needs of persons with intellectual disabilities. As such, the Department should be resourced with branches at various regional health facilities to be easily accessed at various regions across the country. Finally, the Department should also focus on exploring and developing audio-visual resources to communicating with individuals with intellectual disabilities, as this will help address communication barriers and reduce the cases of unmet health needs at medical facilities.

### **Establishment of specialist units in all Regional, Metropolitan, Municipal and District Hospitals**

Similar to our recommendation above, we recommend that the Ministry of health, in collaboration with the Department of Social Welfare establish specialist units within all regional and district hospitals dedicated to the healthcare of PwIDs. This unit must have physicians, nurses and other allied health personnel who have studied and worked with persons living with intellectual disabilities. These experienced professionals with requisite knowledge on the peculiar health and communication needs of persons with intellectual disabilities will contribute significantly to the health needs of this special population. We also recommend that each of these units have a resident social worker trained in disability studies. These social workers can offer counselling and emotional support for persons with intellectual disabilities and their families as they seek healthcare. In addition, the social workers will make relevant input as members of multi-professional healthcare teams, contributing to the planning and delivery of healthcare as well as planning for discharge

and other post-hospitalization care needs of persons with special needs. This unit, with a multi-disciplinary team will help reduce the inequities in health care access.

## **Conclusion**

In this brief, we set out to explore the challenges faced by PwIDs in accessing quality healthcare and to make specific recommendations for stakeholders. We have explained the specific obstacles to quality healthcare access for PwIDs both within and out of institutional care. Based on the findings, we have made recommendations to specific governmental and non-governmental stakeholders to act on. We are confident that this document will prove useful to front line health workers, PwIDs and carers of PwIDs. It is our hope that this brief will lead to improved collaborative engagement among stakeholders as a way of ensuring quality healthcare for PwIDs.

## **Appendix 1: Suggested Images to enhance communication of health needs of PwIDs**

In this section, we present some images, developed as a way of beginning stakeholder discussions on ways of improving communication between PwIDs and healthcare workers. They are not prescriptive; on the contrary, they are suggestive. It is our hope that stakeholders will use these images as the basis to develop more improved ways that communicates better the presenting health challenges of PwIDs.

**Figure 1:** Expression of mild headache



The picture depicts an experience of headache, but at a less severe level (mild headache). The holding of the head and the expression of an unhappiness in the face show some kind of discomfort and pain being experienced in the head by the individual.

**Figure 2:** Expression of severe headache



## SEVERE HEADACHE

This image depicts headache at a higher level (severe headache). In this version, the headache is more painful and unbearable, as shown by the holding of the head, the gnashing of teeth, the furrowed brow, and the 'lightening' arrows on the sides of the head.

**Figure 3:** Experience of running nose



## **RUNNING NOSE/ COLD**

This picture shows an individual covering the nose with a handkerchief. The covering of the nose results from the running nose being experienced by the individual. This running nose is usually associated with cold.

**Figure 4:** Expression of signs of fever



Figure 4 shows a child with a thermometer in the mouth, a sad (sick) face, and the touching of the head. Aside the touching of the head, there are ‘lightning bolt’ and ‘zigzag’ signs surrounding the body to show high body temperature and associated headache. These signs portray symptoms such as fever and increased body temperature, as the touching of the head and the thermometer in the mouth is intended to show signs of high temperature

**Figure 5:** Expression of signs of stomach pains



The image shows an individual holding the stomach with a frowned face. This image depicts the experience of pains and discomfort in the stomach, as portrayed by the gnashing teeth, frowned face and the holding of the stomach to indicate the location of the pain.

**Figure 6:** Emotional expression of menstrual pains

## STOMACH UPSET



## MENSTRUAL PAINS

The picture reveals a woman with one hand holding the head and the other hand holding the abdomen, with an expression of sadness on her face. These signs indicate the discomfort and pains related to menstruation (menstrual pains) as most menstrual complaints include headache and various stomach discomforts.

**Figure 7:** Emotional expression of menstrual pains

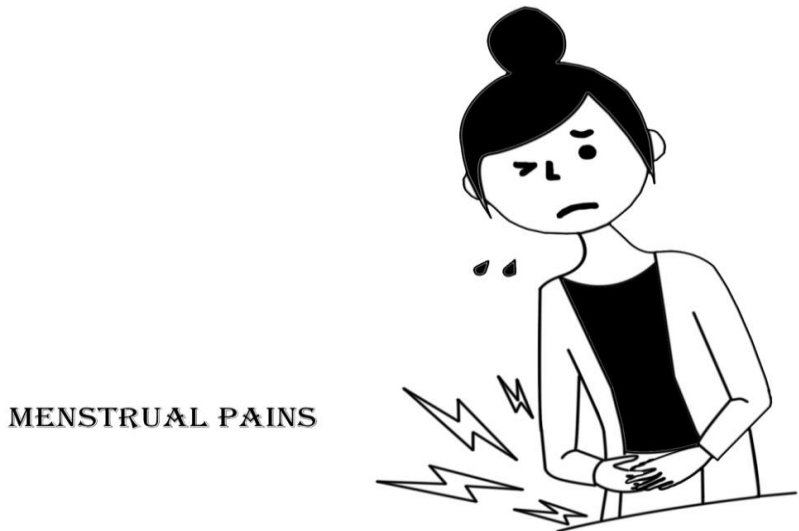


Figure 7 reveals a lady in pain as a result of the onset of her menstrual period. The hands wrapped around the abdomen with the expression of pain on the face, and the ‘lightening’ arrows around the abdominal area reveal some sort of discomfort and pain being experienced in this area.

**Figure 8:** Experience of Stomach upset



## STOMACH UPSET

The holding of the stomach with one hand coupled with the covering of the mouth with the other hand reveal some form of discomfort being experienced in the stomach area (stomach upset). Figure 8 further shows nausea conveyed by the covering of the mouth with the hand.

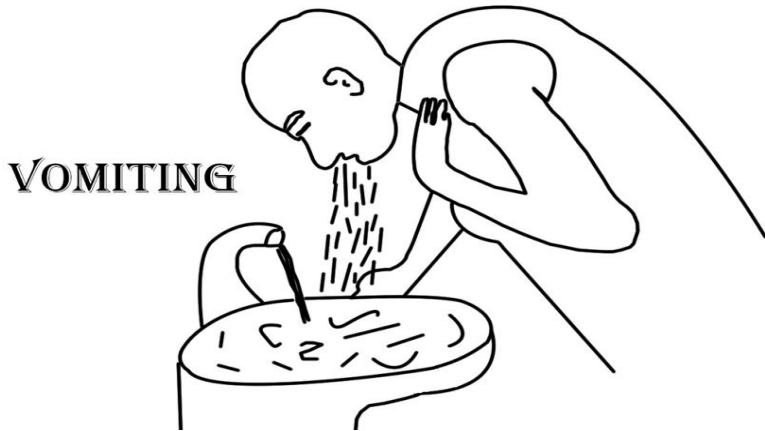
**Figure 9:** Expression of bodily pains



## **BODILY PAINSS**

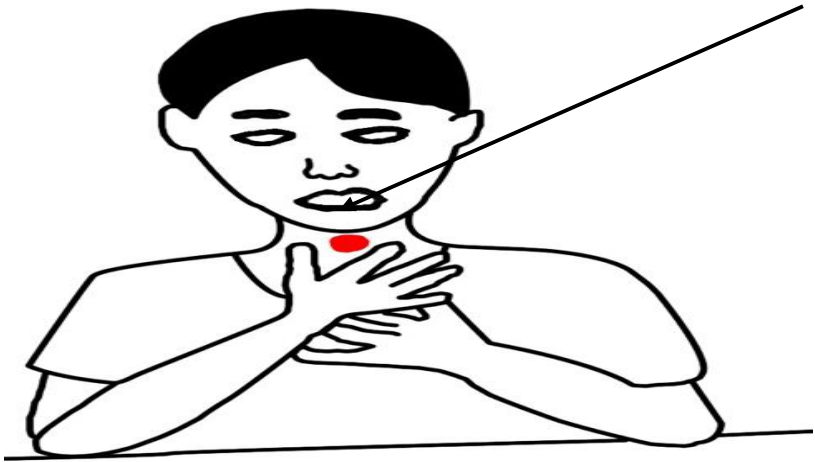
This image depicts individual experiencing bodily pains. The individual holding the neck and the lower back portray pain and uneasiness being experienced at certain parts of the body.

**Figure 10:** Signs of vomiting



This image shows an individual vomiting or throwing up into a sink/bowl. This picture portrays the vomiting as a sign of illness, or reaction to allergies, or even nausea.

**Figure 11:** Experience of sore throat



## **SORE THROAT**

The red mark around the throat/neck area of the individual shows a sore in the throat which tends to affect the process of swallowing by the individual.

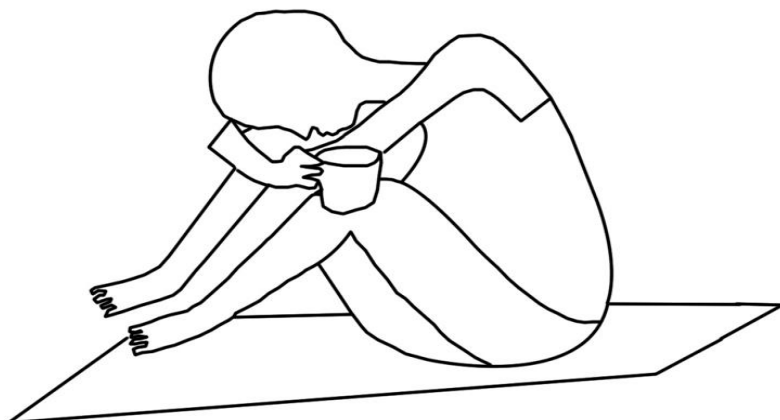
**Figure 12:** Expression of coldness or fever



## **COLDNESS / FEVER**

This image represents a feeling of coldness, as shown by the folding of the individual on the bed. The short-crooked lines around the body shows some form of shaking being experienced by the individual as a result of the coldness. This coldness being experienced can be due to sicknesses such as fever, and other ailments associated with coldness.

**Figure 13:** Feeling of weakness (bodily weakness)



## **BODILY WEAKNESS**

The folded arms and legs with the bowed head depict weakness (bodily weakness). The cup being held without being drank from, and the bowed head, further express the severity of the weakness and the person's inability to perform basic tasks.

**Figure 14:** Signs of running stomach



The holding of the stomach with the frowned face and gnashing of teeth represents problems associated with the stomach. However, the thought of visiting the toilet facility shows that there is more to the stomach pain and that the person may have running stomach.

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