Challenges & Supports for Women & Girls with Disabilities in South Africa: Intervention Strategies & Organisational Responses During COVID-19

August 2024

Engendering Disability-Inclusive Development/

Genre handicap et développement inclusif (EDID/GHDI)

Acknowledgements

We would like to extend our deepest gratitude to all the organizations that contributed to this report on the challenges and supports for Women and Girls with Disabilities in South Africa. The survey would not have been possible without the valuable contributions and insights shared by these organizations on critical issues that are at the intersection of gender, disability, and social inclusion.

Our sincere thanks to the following contributors:

- Autism South Africa (ASA)
- Epilepsy South Africa
- Learning Empowerment Network-LEN
- Muscular Dystrophy Foundation SA
- QuadPara Association of South Africa (QASA)
- Rare Diseases South Africa (RSSA)
- South African Federation for Mental Health (SAFMH)
- South African National Council for the Blind
- South African National Deaf Association

We greatly appreciate the partnership with the South African Disability Alliance (SADA) who enabled the project. Through this information the challenges that women and girls with disabilities face are heard and represented.

Last but not least, a special thanks to Sharlene Cassel, Chairperson, SADA and Karen Robinson, National Office Liaison, Epilepsy South Africa who facilitated this study, on behalf of the Engendering Disability-Inclusive Development (EDID/GHDI) project. The EDID/GHDI project is funded by the Social Sciences and Humanities Research Council of Canada (SSHRC).

Citation: Cassel, S., Robinson, K., Black, D., DeMatosAla, J., Kenyon, K. H., Wilson, L., Kahn, N., & Agyare, L. (2024).

Challenges & Supports for Women & Girls with Disabilities in South Africa: Intervention Strategies & Organisational Responses During COVID-19. [Working Paper]. EDID-GHDI, University of Guelph.

For more information about the project: https://edid-ghdi.ca/en/

Executive Summary

Engendering Disability-Inclusive Development/Genre handicap et développement inclusif (EDID/GHDI) is a seven-year project (April 2020 – March 2027). The project is a partnership between the University of Guelph (Canada) and more than 20 organizations and researchers in Canada, South Africa, Vietnam, and Haiti. Funded by the Social Sciences and Humanities Research Council of Canada (SSHRC) it focuses on the distinctive, and distinctively onerous challenges facing women and girls with disabilities. This intersectional research, knowledge mobilization, and building relationships is necessary to understand and successfully address these challenges.

The South African Disability Alliance (SADA) is a partner coalition in the EDID/GHDI project. The objectives of this national study were to draw on SADA member experiences and insights to: (a) identify challenges facing South African women and girls with disabilities; (b) describe member organizations' intervention strategies, and (c) document the impacts of the COVID-19 pandemic on both those who are served by SADA members and by the organizations themselves. This national study builds on the successful pilot study conducted in May 2022, led by the National Director and Western Cape social development manager of Epilepsy SA with participation from the social development staff of Epilepsy South Africa (Epilepsy SA).

Data were collected using the Opinio online survey software, which is hosted on a Dalhousie University server. The link to the survey was shared during the recruitment process. The survey was open from Monday, October 10th to Friday, December 30, 2022. Nine organizations and 18 participants completed the surveys. These organizations were: (1.) Autism South Africa, (2.) Muscular Dystrophy Foundation SA, (3.) Learning Empowerment Network (LEN), (4.) QuadPara Association of South Africa, (5.) Rare Diseases SA, (6.) South African Federation for Mental Health, (7.) South African National Council for the Blind, (8.) South African National Deaf Association, and (9.) Epilepsy SA.

Data collection: Organizations surveyed used both paper and online forms to collect data. Most organizations collected information daily and at the national/country level as well as the regional level. Organizations tended to summarize data and/or prepare reports on a quarterly and/or annual basis. The main challenges were beneficiaries not wanting to share their information, incorrect details or the length of time that takes for organizations to get these details, contacting the clients for clarification, and the lack of a common national management information system. Support needed to improve data collection included: (a) creation of a user-friendly national information management system, (b) support for on-the-ground workers to engage with beneficiaries and collect the information, and (c) training and research on data collection.

Beneficiaries being supported: In total, 19338 people were provided with services by the organizations surveyed. Of the total number of beneficiaries provided with services, 9384 (48.53%) were female, 9730 (50.32%) were male, and 224 (1.16%) were not specified. People in middle adulthood (41-65 years) - females (n=5308) and males (n=4021) had the highest overall numbers supported and received services in all provinces. Children (0-11 years) - both female (n=44) and male (n=60) - had the overall lowest numbers and were represented in six of the 10 provinces. Based on the numbers that were reported by province, except for middle adulthood females, more males were provided with services across all other age categories.

Impairment distributions: Just over 50 percent of impairments were physical (53.30%), followed by neurological (19.35%). Overall, middle adulthood males and females (41-65 years) were the most frequently reported age category (44.27%), followed by adolescence (31.47%), and young adults (20.36%). Within each age category, young adult males, middle adulthood males, and adolescent males were more frequently receiving services than females. There were slightly more female children and senior citizens than males receiving services.

Beneficiaries' characteristics: Of a total of 16908 reported beneficiaries by population group, 60% (n=10098) identified as black, 24% as colored (n=4139), 10% (n=1747) as white, and 5% (n=934) as Indian/Asian. Of the 10626 reported beneficiaries by community type, most people lived in informal areas (n=3617, 34%), followed by tribal areas (n=2816, 26.50%), Urban areas (n=2672, 25.15%), and Rural areas (n=1521, 14.31%). From a total of 8228 beneficiaries by education level, the largest categories were adolescent males (n=877, 10.66%) and females (n=865, 10.51%) who had attended primary school. The next three highest categories were adolescent females (n=646, 7.85%), males (n=639,

7.77%), and middle adulthood females who had never attended school (n=617, 7.5%). From a total of 8794 beneficiaries by employment status, the most frequently reported were those unemployed and receiving social grants (61.8%). The top four categories were: adolescent males (n=1681, 19.2%), adolescent females (n=1646, 18.72%), middle adulthood females (n=1098, 12.49%), and middle adulthood males (n=1002, 11.39%).

Priority issues: ***Safety and Security needs*** (i.e., protection against gender base violence and femicide, access to justice for victims of gender base violence, employment, and health) and ***Biological and Physiological Needs*** (i.e., basic life needs-air, food, drink, shelter, warmth, sex, and sleep) were the two priorities ranked most highly (average of 7) **Interventions:** The most frequently used interventions to address ***advocacy, empowerment, and development needs*** were (1) Advocacy and human rights programmes (2) Advocacy and lobbying with national government, (3) Awareness campaigns and empowerment services, and (4) Disability forums. Interventions most often used to address ***health, education and work*** needs included (1) Inclusive education, (2) Health and welfare services, Health education, Job access workshops/work readiness, and (3) Entrepreneurial training. ***Psychosocial support, and counseling services interventions*** most frequently used were (1) Support groups, (b) Family therapy, and (c) Parent's support groups.

Interventions that made the most difference, factors making interventions more difficult, and gaps in the interventions: These are difficult to summarize because of the diverse needs and missions of the organizations surveyed. For example, the South African National Deaf Association sees the need for greater availability of and access to South African Sign Language (SASL) as a critical, disability-specific gap. However, support groups for both parents and people affected by disabilities were seen as effective and valuable, highlighting the importance of peer support. On the other hand, several organizations noted the absence of disability-specific research as a key gap.

Broad challenges for organizations: Being understaffed and not being able to capture and report on specific data (e.g., gender, race) when beneficiaries do not volunteer or respond to these questions. Not being able to provide South African Sign Language (SASL) interpretation and relevant information that is in an accessible format.

Evaluation and referrals: Client feedback and evaluation forms were the most used approach for assessment (34.78%). In the two months prior to the launch of the survey in October 2022, 3965 referrals were made, the most frequent being related to (a) general health, (b) education, and (c) funding/social service agencies. Based on the organization that provided responses, most clients indicated that they were satisfied with the referrals that have been made.

Impact of COVID-19: The main impacts were (a) the disruption of services to clients, including cancellations and reduced services, (b) financial constraints and short-falls, and (c) COVID-19 regulations on specific vulnerable beneficiaries such as people with autism, deaf and hard of hearing, and those who are blind or have limited vision. The most important impacts of COVID-19 on organizations were reduced staff hours (and reduced income), high turn over of staff, fewer interventions and services being delivered, and the limitations of technology in supporting specific programs.

Discussion and Recommendations:

The varied missions and distinctive needs and challenges of the organizations surveyed need to be recognized. Nevertheless, several areas of common concern emerged. These include:

- Improved and (where possible) harmonized data collection practices, giving appropriate attention to privacy concerns of beneficiaries.
- Focused consideration of the particular needs of 'age extremes': children and mature (66+ years) adults.
- Focused attention to the balance between programming focused on material needs and on advocacy and sharing of lessons learned between member organizations in both areas.
- Contingency planning for prolonged disruptions of regular programming, learning from the lessons of COVID-19 and drawing on new technologies and communication strategies.
- The need for relevant research focused on how to best meet pressing needs and challenges of organizational communities, including greater collaboration between disability sector organizations and researchers, and/or greater research capacity within disability sector organizations themselves.

Table of Contents

1.0 Introduction

Persons living with disabilities are widely known to be excluded and face many challenges across the globe. However, the magnitude of the challenges faced depends on one's location, gender, sexuality (Sins Invalid, 2019), and age (Groce, 2004). Disabled persons in global South countries like those in Africa are generally known to face more difficulties than those in the global North (Meekosha & Soldatic, 2011). Similarly, women and children with disabilities, tend to experience severe difficulties and those in countries like South Africa, can experience the worst of these hardships (Emmett & Alant, 2006). The challenges of disabled people in South Africa, like any other global South country, cut across violence, inaccessibility, poverty, and education and employment, just to mention a few.

Engendering Disability-Inclusive Development/ Genre handicap et développement inclusif (EDID/GHDI) is a seven-year project (April 2020 – March 2027). The project is a partnership between the University of Guelph (Canada) and more than 20 organizations and researchers in Canada, South Africa, Vietnam, and Haiti. Funded by the Social Sciences and Humanities Research Council of Canada (SSHRC) it focuses on the distinctive, and distinctively onerous challenges facing women and girls with disabilities. This intersectional research, knowledge mobilization, and building relationships is necessary to understand and successfully address these challenges.

The South African Disability Alliance (SADA) [1] is a partner organization in the EDID/GHDI project, together with the individual South Africa country team members listed below[2]. The objectives of this national study were to: (a) identify challenges facing South African women and girls with disabilities; (b) describe member organizations' intervention strategies, and (c) document the impacts of the COVID-19 pandemic on clients and organizations. Prior to the launch of the study, ethics approval was received from the Dalhousie Research Ethics Board (REB # 2022-6232).

This national study builds on the successful pilot study conducted in May 2022, led by the director of Epilepsy South Africa and social development manager of the Western Cape Branch of Epilepsy SA, in collaboration with the social development staff of Epilepsy South Africa branches throughout the country (Epilepsy SA). A summary of the main findings of the pilot study is provided in section 2.2.

Combined with the pilot study, nine organizations and 18 participants completed the surveys. These organizations were:

1. Autism South Africa
2. Muscular Dystrophy Foundation SA (four respondents)
3. Learning Empowerment Network (LEN)
4. QuadPara Association of South Africa
5. Rare Diseases SA
6. South African Federation for Mental Health
7. South African National Council for the Blind
8. South African National Deaf Association
9. Epilepsy SA (seven respondents, representing the six branches)

Unless noted, there was one respondent per organization. A short description of the organizations and their websites can be found in Appendix 1.

Five respondents were at the executive leadership level (e.g., National Director, National Secretariat and Research, Chairperson & CEO, Management board & former CEO, Head of Department of Social Development), five were managers (e.g., Social work supervisor, Centre manager, and Programme manger), five were social and/or auxiliary workers (including a community social worker), two were project leaders (e.g., Advocacy and Awareness, and Disability), and one was a support staff.

On average, respondents had worked for their organization for 5.5 years. Two respondents had worked for less than a year (four and eight months). The number of years worked ranged from 20 years to four months. The median number of years worked was 4. Appendix 2 provides a summary of participants roles and responsibilities.

[1] Composed of Autism South Africa; Blind SA; Cheshire Homes South Africa; Epilepsy South Africa; Muscular Dystrophy Foundation of South Africa; Down Syndrome South Africa; National Council of and for Persons with Disabilities; Occupational Therapy Association of South Africa; National Association for Persons with Cerebral Palsy; National Association of Blind & Partially Sighted Persons; South African Federation for Mental Health; Quadpara Association of South Africa ; Quadriplegic & Paraplegic Charitable Trust; Stroke Survivor Foundation; Western Cape Network on Disability; South African National Council for the Blind; South African National Deaf Association; Shonaquip Social Enterprise.

[2] David Black (Dalhousie University, Canada) – co-lead; Jacqueline (Jacqui) de Matos Ala (University of the Witwatersrand) – co-lead, Sharlene Cassel and Karen Robinson (Epilepsy South Africa), and Kristi Heather Kenyon (University of Winnipeg, Canada)

2.0 Background

2.1 Literature summary

Violence, especially towards women with disabilities, is regarded as one of the greatest concerns in South Africa. There is a high prevalence of gender-based violence. A survey done in 2016 by Statistics South Africa (Stats SA) revealed that at least one out of every five 'ever-partnered' women faced physical violence with about 26% of them encountering different forms of violence (Stats SA, 2017). The situation becomes worse when the women are disabled. Some scholars have identified that the most frequent violence against women with disabilities is forced sterilization (Humphrey, 2016), psychological, sexual and financial violence, and that those who usually abuse them are their so called intimate partners (Van der Heijden et. al., 2019). However, sexual violence in some extreme cases also occur on public transport, as many young women rely on the famous/infamous mini-bus taxis, which are the most patronized means of transportation in South Africa (Martin, 2022; Ncama et. al., 2013). Humphrey (2016) notes that some of the causes of abuse are rooted in intersectional factors like the women's poverty status, their disabilities, and their gender, coupled with the inadequacy of "services and state-sponsored support" for poor disabled women.

Another issue that acutely disturbs persons with disabilities in South Africa is accessibility. Many public facilities like hospitals (Tshaka et. al., 2023), schools (Vincent & Chiwandire, 2017) and office spaces are not equipped with disability ramps to facilitate free movement. Tshaka and their colleagues confirm in their study that healthcare services are rarely patronised by persons with disabilities because many hospitals do not have adequate rehabilitation resources (Tshaka et. al., 2023) and therefore end up becoming unattractive and/or inaccessible to disabled people. Transportation services are also mostly not accessible to mobility and visually impaired persons and people with other types of disabilities. Mini-bus taxis have over the years been adopted as the major means of transport in many parts of Africa, including South Africa (Behrens & Görgens, 2019; Adjei-Amoako, 2016). These buses are usually not disability friendly and most of them have also not received any improvements to make them accessible to all (Behrens & Görgens, 2019).

Access to education and employment are also challenges that disabled people, especially women and children, encounter in South Africa. In many African countries, disabilities in children are sometimes regarded as consequences of spiritual curses (Ngubane-Mokiwa, 2018; McKenzie, 2013) and hence, many families with disabled children prefer hiding them, preventing them from going through basic developmental activities like education. Due to their lack of education, they end up gaining little or no knowledge and skills which eventually affects them in competing with their able-bodied peers in the job market when they become young adults. Sometimes, those who are fortunate to receive some level of education are still discriminated against in the job market and are considered as not 'worthy' to be employed due to the lack of knowledge that many employers and fellow employees have about disabilities (Maja et. al., 2011). The situation of women with disabilities is worse, regardless of the skills they have, due to their gender and their disabilities (Goldblatt, 2009). Another reason why disabled people are discriminated against with regards to education and employment is due to the ableist perceptions and attitudes of people within South African and other societies. Many people internalize ableism (Slayter et. al., 2023) since they grow up in ableist societies. They therefore tend to regard all other bodies that seem to be 'outside of the norm' as 'not normal' and for that matter, not capable of achieving success in their activities.

Relevant Policies

Meekosha and Soldatic (2011), note that global South countries usually have their own bigger problems to solve at the country level, and this makes it difficult for them to focus on the challenges faced by their populations of persons with disabilities even though they may have policies to guide them. In South Africa, state-developed policies like the Policy on Disability from the Department of Social Development, and the Early Childhood Development policy (Storbeck & Moodley, 2011) exist to cater for the general developmental needs as well as inclusive education requirements for both disabled and non-disabled people. Other international legal provisions and initiatives adopted by the state such as the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the Africa Decade of People with Disabilities (Dube, 2005) also serve as a guide for developmental practices for disabled people. In addition to these policies, there are a range of disabled people's organizations like Disabled People South Africa (DPSA), the various members of the South African Disability Alliance (SADA), and other non-governmental organizations like Lawyers for Human Rights (LHR) that advocate and fight for the rights and development of disabled people (Dube, 2005). Notwithstanding all these, persons with disabilities in South Africa do not seem to have experienced significant improvements with regards to their development since these policies are frequently not implemented, or only partially implemented (Dube, 2005; Storbeck & Moodley, 2011; Maja et. al., 2011).

2.2 EDID/GHDI South Africa Pilot study

A pilot study was conducted in May 2022 with the social development staff of Epilepsy South Africa (Eastern Cape, Gauteng, Mpumalanga & Limpopo, South Cape Karoo, and Western Cape branches). The objectives of this pilot study were to: (a) identify challenges facing South African women and girls with disabilities; (b) describe branch intervention strategies, and (c) document the impacts of the COVID-19 pandemic on the clients and organization.

Main findings from this exploratory study indicated that in a 12-month period, 10,887 beneficiaries (Girls 23%, Women 33%, Boys 21%, and Men 23%) had received services. Reporting on the different types of impairments (reaching 7660 beneficiaries), Women (14%) and Men (12%) required the largest share of services relating to neurological impairments, followed by Girls (10%) with physical impairments. Beneficiaries who requested fewest services (i.e., 1%) were Boys (for intellectual impairments), and Men (for sensory and psychosocial impairments). The study also noted that the main needs of girls and women were Safety and security (e.g., protection against gender base violence and femicide, access to justice for victims of gender base violence, employment, and health), followed by Biological and Physiological needs (e.g., basic life needs-air, food, drink, shelter, warmth, sex, and sleep).

Interventions that made the most difference were (a) Supportive groups, including parent groups, legal counselling, availability of residential and day care facilities, and virtual support, (b) Awareness, Advocacy, and Communications approaches (e.g., disability, mental health and well being forums, protective workshops, gender-based violence programmes, and job shadowing programmes), and (c) The 24-hour help line and child protection strategies, which were very important interventions in Mpumalanga as girls and women are still facing discrimination in employment and health care services. Issues affecting the success of interventions included (a) Dealing with unemployment in the face of covid-19 pandemic as many companies closed or retrenched staff, (b) Lack of participation in some support groups, and (c) A perception that research lacked discernible impact.

The top three intervention gaps identified were (a) Communication and awareness programmes and (b) Funding and research, and (c) Specific resources needed for a few of the branches (e.g., reliance on food banks). Relating to communication and awareness gaps, suggestions included the need for more awareness programmes and projects, implemented inclusively. Examples included communicating in their mother language, and gender-based violence work, beyond the 16 days of activism campaign. Contributing to gaps in communications and awareness programmes was the lack of funding, research, and resources. Branches identified the need for more South Africa Social Security Agency (SASSA) grants, bursary opportunities and research to address intervention gaps and strengthen existing programmes.

The main impacts on service delivery from COVID-19 were that beneficiaries either could not access, or had limited access to offices and services, and social workers could not effectively do their jobs. Other impacts included reduced donations, and the reallocation of budgets to pay for COVID-19 related expenses. Services to vulnerable beneficiaries were delayed when branches closed or were limited by staff availability or resources. Trainings and awareness campaigns were done virtually which may not have been the most effective approach for beneficiaries and staff.

Three priority recommendations for Epilepsy SA were to: (1) develop a national strategy to address the mental health and well being of their staff, and marketing and fundraising strategies that will help with the sustainability of the organization. (2) design, test, and implement a more standardized and user-friendly information and data collection systems, and to engage in more consistent evaluation practices. (3) encourage staff to support and participate in research.

3.0 Study approach

3.1 Participant recruitment

In addition to email invitations, information sessions were conducted by the Chairperson of SADA with member organizations. Follow-up emails were sent by the Chairperson during the survey to promote and increase the response rate.

3.2 Data collection

The survey format and content largely followed the pilot study. Questions in the pilot were grouped into the following categories: demographics, issues faced by girls and women, interventions being implemented, intervention

effectiveness, and impacts of COVID-19. As a pilot for the larger South Africa survey of South African Disability Alliance (SADA) member organizations, participants were also asked to identify potential problem areas and deficiencies in the content and design of the survey.

The national survey questionnaire (Appendix 2) followed the pilot study format and content, with three minor changes: (1) seven new questions were added at the start of the survey focusing on how data is collected, documented, and used, including challenges and opportunities; (2) locations were aligned with the 2011 South Africa Census categories, and (3) age categories were further disaggregated using the psychosocial development life stages scale (Erickson, 1963). A short Opinio survey including only the seven new data questions were sent to the Epilepsy SA branches in February 2023. The Western Cape was the only branch that provided feedback.

Data were collected using the Opinio online survey software, which is hosted on a Dalhousie University server. The link to the survey was shared during the recruitment process. The survey was open from Monday, October 10th to Friday, December 30, 2022.

3.3 Data analysis

As the pilot study had respondents from six branches, the data were first aggregated into one dataset and then added to the national study. The combined data set were analyzed using descriptive statistics and thematic coding.

To align both datasets, the age categories in the pilot study were reorganised as presented in Table 1. The national study follows the age categories described by Erickson (1963). In the pilot study, except for one question, demographic data did not capture age categories, but only whether they were girls, women, boys, men, or other. The one question that did ask for this information related to the total number of beneficiaries for these age groups who were receiving services. As such, data from girls and boys in the pilot study were aligned with adolescence (male and female) 12-18 years in the National study. Similarly, data from women and men in the pilot study were aligned with middle adulthood 41-65 years (male and female) in the national survey.

Table 1: Alignment of beneficiaries age categories

Pilot study (May 2022)	**National study (October – December 2022)**
Infancy (birth to 18 months), Early childhood (2-3 years), Pre-school (4-5 years), incl male/female	• Child 0-11yrs, female • Child 0-11yrs, male
School age (6-11 years) incl male/female	• *Not included*
Adolescence (12-18 years, incl male/female)	• Adolescence 12-18yrs, female • Adolescence 12-18yrs, male
Young adulthood (19-40 years) incl male/female	• Young adulthood 19-40yrs, female • Young adulthood 19-40yrs, male
Middle adulthood (41-65 years) incl male/female	• Middle adulthood 41-65yrs, female • Middle adulthood 41-65yrs, male
Maturity (66 years and up) incl male/female	• Maturity 66+yrs, female • Maturity 66+yrs, male

A limitation with this approach is that data for girls and boys could also have included information that might have been a better fit under the child or young adulthood categories. Similarly, data from women and men in the pilot study could also have included information that would have been a better fit to young adulthood, or maturity categories. However, as this age information breakdown was not captured in the pilot study it could not be realigned across these categories at this stage of the analysis.

Another factor that could be contributing to gaps in the data is that some organizations, although they do collect data on age categories, may not have done so using the same groupings as asked in the survey. For example, Autism SA noted that "*We do not capture this data*" and the South African Federation for Mental Health indicated that they "*Do not capture this level of disaggregated data*".

Organizations such as the Learning Empowerment Network (LEN) provided a brief statement describing their beneficiaries, whereas other organizations did not provide any data/explanations, beyond completing the numeric question.

3.4 Lessons learned.

Below are the comments from the participants in response to questions relating to their overall experience with completing the survey.

Q.1. Did you feel excluded from the survey at any point? For example, did you feel that there were key issues, interests, or groups of importance to you that were overlooked in the survey. Was the language difficult to understand? Were there ways in which the technology being used made it difficult to complete?

- **Autism South Africa – Yes** - Not a very clear understanding of neurodevelopmental disabilities in this survey. Autism is not even listed. It is becoming more and more prevalent. The data you are asking for is not readily available. We collect data as per our funder's requirements. We simply cannot waste more time on data mining even further. We have very limited resources.

Q2. If you did not complete the survey, please tell us why?

- **Autism South Africa and QuadPara Association of South Africa** I was not able to access the information needed to answer some questions.
- **Learning Empowerment Network-LEN -** Not all questions are appropriate to my organization**.**

Q3. Are there any other questions that you think would be helpful to include in this type of project?

- **Autism South Africa** - Please be mindful of our hectic schedules and trying to keep our NPOs operational.
- **South African National Council for the Blind** - Forums that cater specially for issues that affects the blindness sector.

Q4. Is there anything else that you would like to share with us that could help make the survey better?

- **Autism South Africa** - Please tell us what data you want LONG before the time.
- **South African Federation for Mental Health** - Nothing that I can think of. Looking forward to hearing about how the findings will practically influence the implementation of data collection in South Africa.

4.0 Data collection, challenges, and support needed.

The questions in this section asked about how data are collected, how often, and when. Challenges and suggestions for addressing these issues were also covered.

4.1 Data collection methods

All nine organizations responded to this question (Figure 1a). The most common used form of data collection (Figure 1a) were paper forms and online forms (seven organizations). Two organizations used other data collection software, e.g., customer relationship management. Additional comments from the organizations are provided under Figure 1a

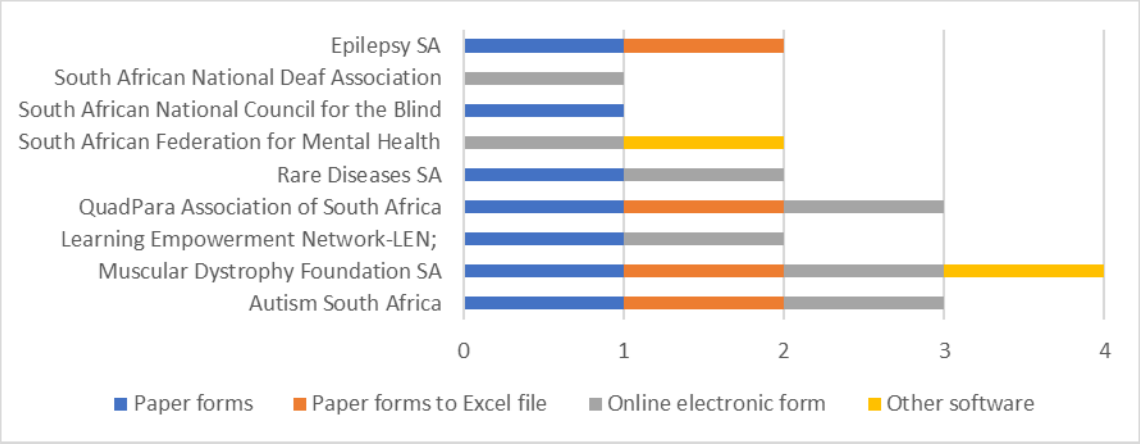


Figure 1a: Data Collection Approaches

Comments

Muscular Dystrophy Foundation SA

- We receive referrals from hospitals where persons who live with disability attend clinic appointments. Some clients contact our organization telephonically when they hear about it and the services we offer to our clients.
- Referrals are mostly received from hospitals, especially Red Cross Children's Hospital and Tygerberg Hospital. Beneficiaries are then contacted telephonically, and their information collected.
- Telephonic contact - we receive clients from hospitals, and some contact the organization telephonically

Learning Empowerment Networks - LEN

- We have an online training facility where students must register. We also have paper forms that can be completed for classroom training.

South African Federation for Mental Health

- SAFMH is a national advocacy and awareness organization. To this end, we do not have beneficiaries as many community-based mental health organizations would have. We target our efforts at the general South African population or national governments and alliances. We run a help desk where members of the public can contact us with questions, and we provide them with referrals. This is the closest we come to work one on one with individuals which can be seen as beneficial. We capture information on the people who reach out to us with questions.

South African National Deaf Association

- We print and record in hardcopy.

4.2 Timing of data collection

Most organizations (Figure 1b) collected information daily, followed by monthly (three organizations), and quarterly (two organizations). Autism South Africa also noted that they collected data after training sessions - as and when training takes place. Muscular Dystrophy Foundation SA also noted that data is collect when the social services staff attends neuromuscular clinics and during school support groups where our clients attend school.

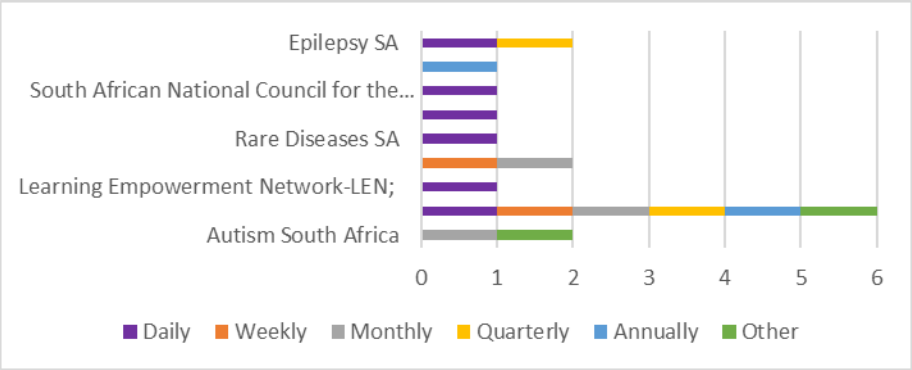


Figure 1b: Timing of Data Collection

Comments

Autism South Africa

- We have an online new parent register that the provincial staff are meant to keep updated. These are updated after each new contact - or - they are supposed to be.

Muscular Dystrophy Foundation SA

- Anytime new referrals are received and as needed.
- Any time new referrals are received and as needed.

Learning Empowerment Network-LEN

- All students must register online to complete the assessments to be able to obtain the certificates.

South African Federation for Mental Health

- Every time someone reaches out to us via our help desk, we record that on our CRM (Salesforce).

4.3 Level at which the beneficiaries' information is collected.

Most organizations (Figure 1c) collected data at the national/county level (seven organizations) and regional level e.g., by branch (six organizations). Two organizations collected information at the provincial level.

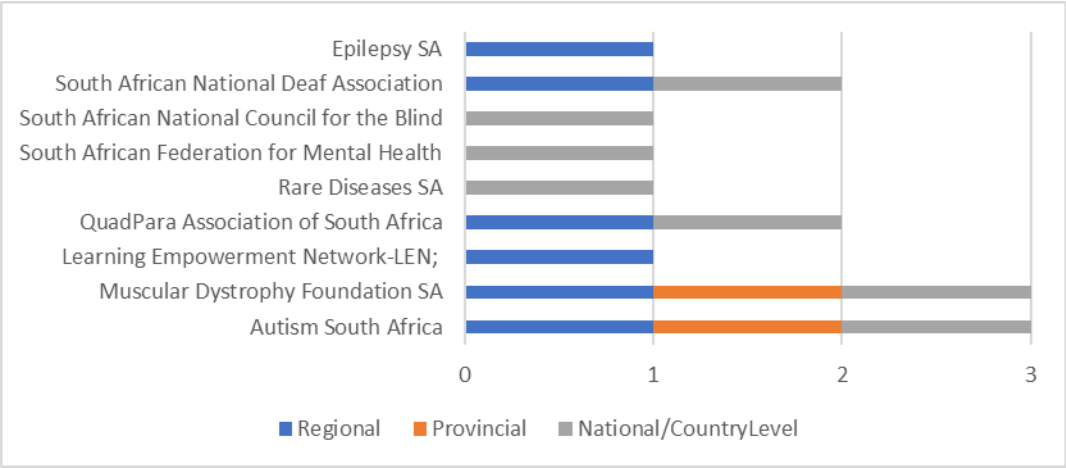


Figure 1c: Information Collection Level

Preparation and frequency of information summaries and/or reports

Most organizations summarised data and/or prepared reports on a quarterly and/or annual bases, followed by monthly reports (Figure 1d).

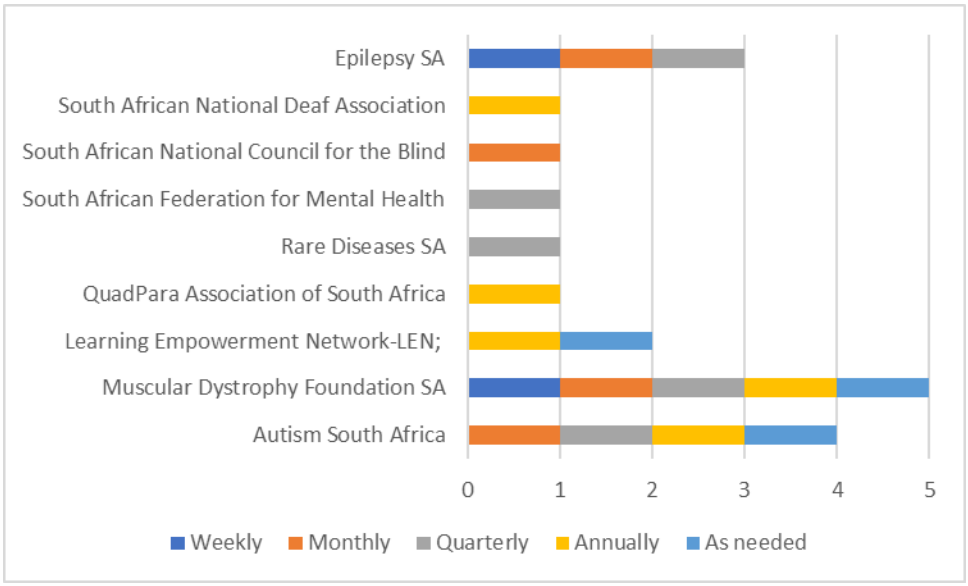


Figure 1d: Frequency of Reports and Summary Preparations

Comments

Autism South Africa

- Government Reports Director's report to the ASA Board. Annual NPO Report to NDSD. Annual Report for AGM Funder's reports. As and when for M and E For staff KPA meetings. CPD point allocations for professionals who attend of CPD accredited course and workshops.

Muscular Dystrophy Foundation SA

- To track services and to update our national office about services rendered during that specific period. It is also used for donor and for government reports.
- To track services and to update our National Office on services rendered at Muscular Dystrophy Foundation (Cape branch). Donor and Government reports.
- To track services and to update our national office about services rendered.

Learning Empowerment Network-LEN.

- Used for our annual report structure, donor reports as well as for issuing of certificates.

Epilepsy SA

- Reports for funders. Weekly reports for manager to track services and whether the social development team met their objectives for the week. Also used as a time management tool on a weekly basis for the social development team

4.4 Challenges to collecting and reporting beneficiaries' information.

Organizations that responded yes, were (a) Autism South Africa, (b) Muscular Dystrophy Foundation SA, (c) QuadPara Association of South Africa, (d) Rare Diseases SA, (e) South African National Council for the Blind, (f) South African National Deaf Association, and Epilepsy SA. The Learning Empowerment Network (LEN) was the only organization that indicated not having to face any challenges.

The main challenges were beneficiaries not wanting to share their information, incorrect details or the length of time that takes for organizations to get these details, contacting the clients for clarification, and the lack of a national management information system. For example, Epilepsy SA noted that branches use their own collecting and reporting tools, which can make it difficult to collate and integrate the data at the national level. The large size of some groups where awareness campaigns are being conducted also makes it difficult to collect the information. Additional details are noted as follows:

Autism South Africa

- Many beneficiaries do not want to share biographical information with us. The Protection of Personal Information Act (PoPI Act) is also a factor to considered.
- Punctuality, time for providing these data by our beneficiaries sometimes not on time.

Muscular Dystrophy Foundation SA

- Some of the beneficiaries are not easily accessed because they change contact details and do not inform the organization. Some clients are not willing to share their personal details like identity numbers.
- Some of our beneficiaries reside in the Eastern Cape and Northern Cape, hence they can only be contacted telephonically. Some beneficiaries change contact details and do not inform the organisation. Some beneficiaries are resistant to provide their personal details, e.g., Identity numbers.
- Clients don't want to give their personal information e.g., id number.
- Some are lost to be contacted due to change of contact numbers and change of residential address.

QuadPara Association of South Africa

- trying to contact members, trying to get members to respond to emails and WhatsApp.

South African National Deaf Association

- Punctuality, time for providing these data by our beneficiaries sometimes not on time.

Epilepsy SA

- We do not have a national management information system and therefore our Branch uses our own collecting and reporting tools e.g., weekly planners, daily activity logbooks, monthly statistical reports, quarterly planners, nonfinancial data e.g. registers completed by the participants. This is what is used by the social development manager to write a report to management monthly and helps for quarterly reports to funders.
- When doing awareness with very big groups we cannot give out registers and therefore we will either give the school a form that we developed we they can complete the statistical information about demographics of the beneficiaries in some cases especially when at hospitals or clinics they give an estimation of the number of clients reached. We also cannot evaluate services when we are doing awareness campaigns especially when the groups are very big.

4.5 Support needed for data collection.

The main types of support needed to improve data collection were (a) having a national information management system (Autism South Africa, Epilepsy SA), (b) support for on the ground workers to engage with beneficiaries and collect the information (Muscular Dystrophy Foundation SA, QuadPara Association of South Africa), and training and research around data collection (South African National Council for the Blind, South African National Deaf Association). The Learning Empowerment Network did not need any support at this time. Additional details are noted as follows:

Autism South Africa

- An NPO specific and well-designed software program that can be used across multiple platforms. Providing training to our beneficiaries.

Muscular Dystrophy Foundation SA

- Having an organization car would help support our organization as we can easily go and do home visits wherever our clients live. Having a sponsor for a petrol card to use when the staff uses their own cars as they do not afford petrol or maybe the increase on the travel claim tariffs.
- Currently we are using our own personal vehicles for official purposes, such as conduct home visits, hospital visits, support groups at special needs schools, etc. It would definitely help if the organization had its own vehicle for staff to use for official purposes.
- Transport
- Having Transport.

Learning Empowerment Network-LEN

- Nothing thus far.

QuadPara Association of South Africa

- people on the ground engaging the beneficiaries/members.

South African National Council for the Blind

- Research and data collection.

South African National Deaf Association

- Providing training to our beneficiaries.

Epilepsy SA

- Having a national information management system to capture data and ensure standardization across the Branches. It will also provide a national profile of our beneficiaries.

5.0 Profile of beneficiaries/clients

5.1 Beneficiaries who were provided with services in the last 12 months.

Table 2a presents the overall number of beneficiaries (by province) who were provided with services from organizations in the last 12 months. Six organizations provided responses to this question: Autism South Africa (Autism SA), Epilepsy South Africa (Epilepsy SA), Muscular Dystrophy Foundation SA (MDFSA), QuadPara Association of South Africa (QPASA), South African National Council for the Blind (SANCB), and the South African National Deaf Association (SANDA).

In total, 19338 people were provided with services. Of the total number of beneficiaries provided with services, 9384 (48.53%) were female, 9730 (50.32%) were male, and 224 (1.16%) were other. Percentages were calculated from the total numbers extracted from age categories. Western Cape (n=5196) and Gauteng (n=4529) had the most beneficiaries, whereas South Cape/Karoo (n=159) and Limpopo (n=224) had the fewest= numbers. South Cape/Karoo represents a branch of Epilepsy SA.

Of the 11 age categories[3], middle adulthood (41-65 years) - females (n=5308) and males (n=4021) had the highest overall numbers and received services in all provinces. Children (0-11 years) female (n=44) and male (n=60) had the overall lowest numbers and were represented in six of the 10 provinces. Based on the numbers that were reported by province, except for middle adulthood females, more males were provided with services across all other age categories.

Notes:

- Data from the pilot study (Epilepsy SA) was not collected by age groups, but by girls, boys, women, and men. To align the data with the national study (as an estimate) girls and boys were grouped under adolescent (12-18 years) females and males, and women and men under middle adulthood (41-65 years) females and males.
- **Not specified**: (n=77) is because the beneficiaries did not provide their information to the organization (Muscular Dystrophy Foundation). There was no explanation for the second occurrence of not specified (n=147).
- **South African Federation for Mental Health** does not capture this level of disaggregated data.
- **Learning Empowerment Network** - many of their students are from all over the country, as they study via the online platform. This includes male and females from South Africa between the ages of 18 years to 65 years.

[3] Child 0-11yrs, Adolescence 12-18yrs, Young adulthood 19-40yrs, Middle adulthood 41-65yrs, Maturity 66+yrs

- **Autism South Africa** - It is simply going to take too long to retrieve this data. We collate all stats nationally once a month. This is what we can provide: an average MONTHLY number of people each RDO has dealt with. Some of the beneficiaries are seen every month. So, you cannot generalise that it is 12 x that number to get an annual amount. We are relooking at how we capture demographic stats. We collect data on these age groups: 0-18, 19-35 years, 36-65 years 66 and older I have added the figures according to this at each higher age group. For example - all children added under column for 11-18 years. I am not convinced that the RDOs are reporting correctly. Also - there are more males diagnosed as autistic than females. The reasons are debatable. There was one person working in Limpopo and Mpumalanga from Gauteng.

Table 2a: Number of beneficiaries provided with services in the last 12 months.

Age categories	Eastern Cape	Free State	Gauteng	KwaZulu-Natal	Limpopo	Mpumalanga	North West	Northern Cape	South Cape/Karoo	Western Cape	Total (n=age)
Child - female	3	3	4	4	3	2	2			23	44
Child - male	2	3	5	3	4	3	2			38	60
Adolescent - female	924	12	113	45	9	804	29	9		728	2673
Adolescent - male	686	162	100	66	32	996	112	4		696	2854
Young adult -female	65	16	396	114	8	11	50	212		248	1120
Young adult - male	58	71	774	422	22	34	131	93		844	2449
Middle adulthood - female	684	357	1428	165	51	420	84	745	91	1283	5308
Middle adulthood – male	244	154	1652	129	78	216	56	268	68	1156	4021
Matured - female	68	28	15	15	5	7	6	61		34	239
Matured-male	69	36	42	32	12	10	12	64		69	346
Other						147				77	224
Total (n=province)	**2803**	**842**	**4529**	**995**	**224**	**2650**	**484**	**1456**	**159**	**5196**	**19338**

Summary of services provided to beneficiaries (by organization)

Figure 2 (Percentage of Services) and Table 2b (% & numbers) provide an overview of services rendered to beneficiaries (by gender) in the last 12 months (n= 19338). Organizations that had a high percentage of female beneficiaries were Epilepsy SA (30.91%), Autism SA (7.27%) and QPASA (4.89%). Providing services to male beneficiaries, organizations with the highest percentages were also Epilepsy SA (24.63%), QPASA (16.91%), and Autism SA (4.11%). MDFSA, SANDA and SANCB provided approximately the same percentage of services to male and female beneficiaries.

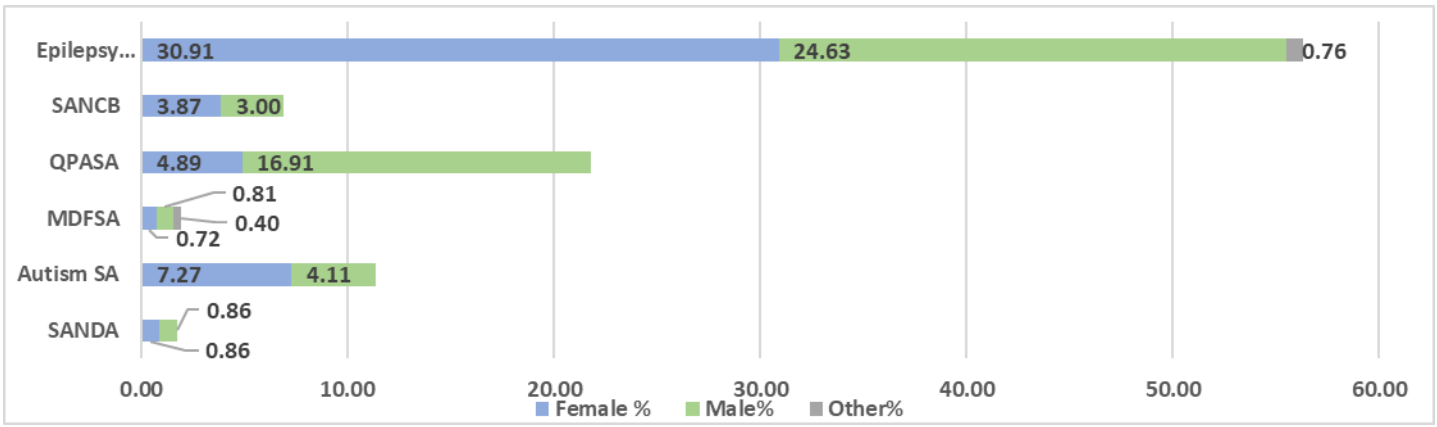


Figure 2: Percentage (%) of Services Provided by Organizations to Beneficiaries (by gender), n=19338

Table 2b: Services (% and number) provided by organizations to beneficiaries (by gender), n=19338

Org	Female	Female %	Male	Male%	Other	Other%	Total (n=org)	%
SANDA	167	0.86	167	0.86			334	1.73
Autism SA	1405	**7.27**	794	**4.11**			2199	**11.37**
MDFSA	139	0.72	157	0.81	77	0.40	373	1.93
QPASA	946	**4.89**	3270	**16.91**			4216	**21.80**
SANCB	749	3.87	580	3.00			1329	6.87
Epilepsy SA	5978	**30.91**	4762	**24.63**	147	0.76	10887	**56.30**
Total (n=gender)	**9384**		**9730**		**224**		**19338**	

Organizations providing the highest percentage of services overall were Epilepsy SA (56.3%), QPASA (21.8%), and Autism SA (11.4%). These percentages could also reflect the size of the organization (e.g., staff, resources), number of branches of a specific organization, the size and location of the community/population where services are being provided, or a combination of these factors.

Table 2c provides the percentage and numbers of services provided by the organizations to their beneficiaries (by age categories). Based on the responses to this question:

- **SANDA**'s top three categories were young adult (male), adolescent (female), and adolescence (male)/young adult (female).
- **Autism SA** focus was on middle adulthood (female), adolescent (male), and young adult (female).
- **MDFSA** highest percentage of services were to young adults (female), adolescent (male), and young adult (male)/middle adulthood (female).
- **QPASA** most requested services were from young adult (male), middle adulthood (male), and young adult (female).
- **SANCB** highest percentage of services were to middle adulthood (female), middle adulthood (male), and young adult (male), and
- **Epilepsy SA** focus was on middle adulthood (female), middle adulthood (male)/adolescent (female), and adolescent (male)

Table 2c: Services (% and number) provided by organizations to beneficiaries (by age category), n=19338

Age category	SANDA	SANDA %	Autism SA	Autism SA %	MDFSA	MDFSA %	QPASA	QPASA %	SANCB	SANCB %	Epilepsy SA	Epilepsy SA%	Total (n=age)
Child - female	23	0.12			21	0.11							44
Child - male	24	0.12			36	0.19							60
Adolescent - female	49	**0.25**	99	0.51	15	0.08			35	0.18	2475	**12.80**	2673
Adolescent - male	40	**0.21**	468	**2.42**	47	**0.24**			23	0.12	2276	**11.77**	2854
Young adult - female	41	**0.21**	356	**1.84**	48	**0.25**	654	**3.38**	21	0.11			1120
Young adult - male	58	**0.30**	181	0.94	43	**0.22**	2018	**10.44**	149	**0.77**			2449
Middle adulthood - female	37	0.19	937	**4.85**	43	**0.22**	230	1.19	558	**2.89**	3503	**18.11**	5308
Middle adulthood - male	36	0.19	141	0.73	23	0.12	1050	**5.43**	285	**1.47**	2486	**12.86**	4021
Matured - female	17	0.09	13	0.07	12	0.06	62	0.32	135	0.70			239
Matured - male	9	0.05	4	0.02	8	0.04	202	1.04	123	0.64			346
Other		0.00		0.00	77	0.40					147	0.76	224
Total (n=org.)	**334**		**2199**		**373**		**4216**		**1329**		**10887**		**19338**

Organizations reporting information on children were SANDA and MDFSA. Children and Senior (maturity) categories had the lowest percentages, which could suggest there are gaps in the services available, and/or issues with access to, and/or awareness of these services. Alternatively, these services may not be the focus of a specific organisation due to other priorities and/or may not be needed in a specific community/area.

Collectively, the top five age categories requesting services were reported by **Epilepsy SA**: middle adulthood (females, 18.1%), middle adulthood (males, 12.8%)/Adolescent (females, 12.8%), adolescent (males, 11.8%), and **QPASA**: young adult (males, 10.4%) and middle adulthood (males, 5.4%).

5.2 Categories of disabilities

Organizations providing information (Figure 3 & Table 3) were: South African National Deaf Association, Muscular Dystrophy Foundation SA, QuadPara Association of South Africa, South African National Council for the Blind, and Epilepsy SA. Examples for each impairment are as follows:

- **Intellectual impairment:** For example, Foetal Alcohol Syndrome Disorder, Down Syndrome, and severe brain injury
- **Neurological impairment**: For example, epilepsy, dementia, and autism
- **Physical impairment**: For example, paraplegia, quadriplegia, spina bifida, latent effects of polio, muscular dystrophy, stroke, cerebral palsy, multi sclerosis, dwarfism/short stature, and amputees
- **Psychosocial impairment:** For example, bipolar disorder, depression, schizophrenia, anxiety, eating disorders, personality disorders and post traumatic disorders.
- **Sensory impairment**: For example, deaf, hard of hearing, hearing impaired, deafblind, visual impairment and legal blindness.

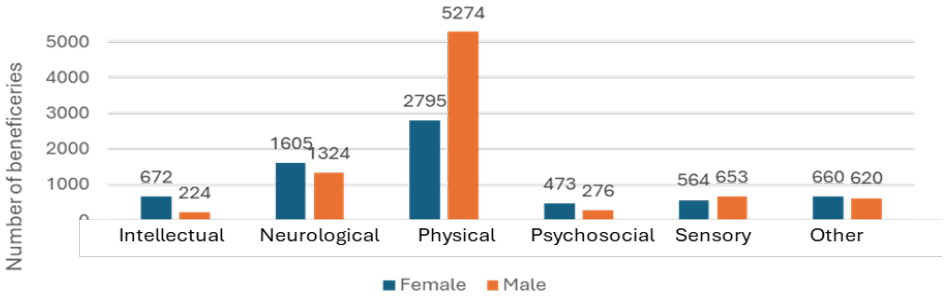


Figure 3: Number of Beneficiaries Receiving Services by Impairment (n=15140)

Table 3: Categories of disabilities by age and gender

	Intellectual	Neurological	Physical	Psychosocial	Sensory	Other	Total (n=age)	Age %	Gender %
Child	**2**	**89**	**89**		**49**		**229**	1.51	
Female	2	50	50		25		127		55.46
Male		39	39		24		102		44.54
Adolescence	**499**	**735**	**2366**	**376**	**789**		**4765**	31.47	
Female	405	424	1047	164	325		2365		49.63
Male	94	311	1319	212	464		2400		50.37
Young Adult	**5**	**129**	**2733**		**95**	**120**	**3082**	20.36	
Female		57	658		40		755		24.50
Male	5	72	2075		55	120	2327		**75.50**
Middle Adulthood	**390**	**1943**	**2724**	**373**	**262**	**1010**	**6702**	**44.27**	
Female	265	1048	972	309	159	580	3333		49.73
Male	125	895	1752	64	103	430	3369		50.27
	Intellectual	**Neurological**	**Physical**	**Psychosocial**	**Sensory**	**Other**	**Total (n=age)**	**Age %**	**Gender %**
Maturity		**33**	**157**		**22**	**150**	**362**	2.39	

Female		26	68		15	80	189		52.21
Male		7	89		7	70	173		47.79
Total(n=impairment)	**896**	**2929**	**8069**	**749**	**1217**	**1280**	**n=15140**		
Impairment %	5.92	19.35	**53.30**	4.95	8.04	8.45			

Impairment percentages are calculated from the totals of each impairment category and the total number of beneficiaries (n=15140). Age categories are calculated from the totals of each age category and the total number of beneficiaries. Gender percentages are calculated based on the totals within each age category – for example, within the child category, females n=127 (55%) of 229 (total number for this category).

Just over 50 percent of impairments were physical (53.30%), followed by neurological (19.35%). Overall, Middle adulthood males and females (41-65 years) were the most frequently reported age category (44.27%), followed by adolescence (31.47%), and young adults (20.36%). Within each age category, young adult males, middle adulthood males, and adolescents were more frequently receiving services than females. There were slightly more female children and senior citizens than males receiving services.

Comments

- **Autism South Africa (no data)** - Autism is not listed in your criteria above!!!! It is a neurodevelopmental disability. Most of our beneficiaries are autistic, or parents of autistic children.
- **Muscular Dystrophy Foundation SA** - Muscular Dystrophy is a neurological condition which affects the affected person's physical health and, in some instances, their intellectual abilities.
- **Learning Empowerment Network-LEN** - Unfortunately, we do not collate information on disabilities.
- **South African Federation for Mental Health** - We do not capture this level of disaggregated data.
- **Epilepsy SA**:
    - Some of the persons have more than one impairment and in the other category the persons have cognitive impairment not due to the conditions listed under Intellectual impairment.
    - Our statistics from our awareness campaign it is quite challenging to capture as we reached 1800 people with epilepsy and affected by epilepsy. 800 was part of our epilepsy and sensitization training and some do not have a disability and there is also some that does.

Note: Muscular Dystrophy Foundation SA reported that under Other Physical impairment (n=128), Neurological impairment (n=128), and Intellectual impairment (n=10).

5.3 Race

Organizations responding: Epilepsy SA, Muscular Dystrophy Foundation SA, QuadPara Association of South Africa, South African National Council for the Blind, and South African National Deaf Association.

Of a total of 16908 reported beneficiaries, 60% (n=10098) identified as black, 24% as coloured (n=4139), 10% (n=1747) as white, and 5% (n=934) as Indian/Asian.

With regards to gender and race (Table 4 and Figure 4), the top three reported categories were: (a) 16. 85% (n=2849) black middle adulthood male, (b) 14.94% (n=2526) black middle adulthood females, and (c) 12.01% (n=2030) black adolescent males.

Comments:

- **Autism South Africa**: Many beneficiaries do not want to share their biographical information. The figures here are percentages NB per age group, and NOT actual figures. This data is only available per age group and not gender based. So, it is indicated below: **Children** 0-18 years: Black - 97%, White - 3%, **Youth** Black - 85%, Coloured - 10%, White - 5% **Men** Black - 68%, Coloured - 18%, Indian/Asian - 4%, White - 10% **Women** Black - 72%, Coloured - 10%, Indian/Asian - 2%, White - 16%, **Elderly** Black - 60%, Coloured - 40%
- **Muscular Dystrophy Foundation SA**: Some beneficiaries do not want to provide their identity numbers or date of birth; hence their age is unknown.

- **Learning Empowerment Network-LEN**: Students include all races, from the various provinces, both male and female from all provinces of South Africa
- **QuadPara Association of South Africa**: people with spinal cord injury live shorter lifespans
- **South African Federation for Mental Health**: We do not capture this level of disaggregated data.

Table 4: Summary of beneficiaries by race/age/gender

Category/Race	SANDA	MDFSA	QPASA	SANCB	Epilepsy SA	Totals	%
Black							
Child-female	23	24				47	0.28
Child-male	24	10				34	0.20
Adolescent-female	47	8	10		1056	1121	6.63
Adolescent-male	40	38	50		1902	2030	12.01
Young adulthood-female	41	15	200			256	1.51
Young adulthood-male	55	32	1000			1087	6.43
Middle adulthood-female	37	3	200	388	1898	2526	14.94
Middle adulthood-male	35	9	900	290	1615	2849	16.85
Matured-female	17		20			37	0.22
Matured-male	9		50			59	0.35
Other		52				52	0.31
Indian/Asian							
Child-female						0	0.00
Child-male						0	0.00
Adolescent-female	2		5		32	39	0.23
Adolescent-male		1	10		51	62	0.37
Young adulthood-female		2	200			202	1.19
Young adulthood-male	1	1	400			402	2.38
Middle adulthood-female			30		51	81	0.48
Middle adulthood-male		2	60	13	29	104	0.62
Matured -female			10			10	0.06
Matured-male			20			20	0.12
Other		4				4	0.02
White							
Child-female		4				4	0.02
Child-male		6				6	0.04
Adolescent-female		4	5		196	205	1.21
Adolescent-male		12	10		255	277	1.64
Young adulthood-female		10	100			110	0.65
Young adulthood-male		9	200			209	1.24
Middle adulthood-female		19	40		326	385	2.28
Middle adulthood-male		6	60		241	307	1.82
Matured -female		16	10			26	0.15
Matured-male		5	30		103	138	0.82
Other		36			44	80	0.47
Coloured							
Child-female		22				22	0.13
Child-male		23				23	0.14
Adolescent-female		27	10		592	629	3.72
Adolescent-male		47	40		261	348	2.06
Category/Race	**SANDA**	**MDFSA**	**QPASA**	**SANCB**	**Epilepsy SA**	**Totals**	**%**
Young adulthood-female		30	300			330	1.95

Young adulthood-male	2	31	500	20		553	3.27
Middle adulthood-female		21	100	170	769	1060	6.27
Middle adulthood-male	1	14	400	278	408	1101	6.51
Matured -female		10	5			15	0.09
Matured-male		2	20			22	0.13
Other		36				36	0.21

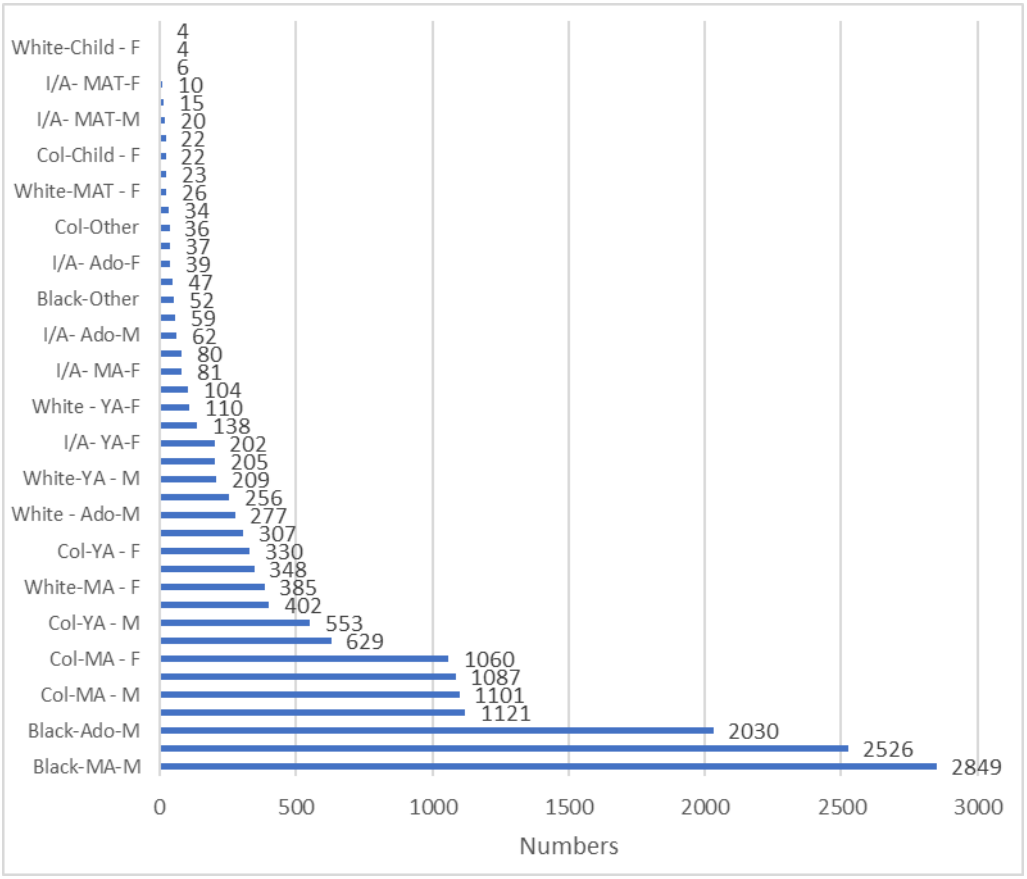


Figure 4: Summary of Beneficiaries

5.4 Location

Organizations responding: Muscular Dystrophy Foundation SA, QuadPara Association of South Africa, South African National Deaf Association, and Epilepsy SA. Of the 10626 reported beneficiaries, 47.51% (n=5048) identified as female, 49.91% (n=5303) as male, and 2.59% (n=275) as other. Appendix 2 provides further details on age and gender responses. A summary of this information is provided in Table 5a.

Table 5a provides a breakdown of the information by age and gender. The largest percentage of beneficiaries were middle adulthood (54.81%, n=5824), with a slightly higher percent of males (53.97%, n=3143). Adolescent were the next highest category (38.61%, n=4130), with slightly more females (52.47%, n=2153).

Table 5a Age and gender summary

Category	Age -total #	Age %	Female #	Female %	Male#	Male%
Child	136	1.28	73	53.68	63	46.32
Adolescent	4103	38.61	2153	52.47	1950	47.53
Young adulthood	229	2.16	98	42.79	131	57.21
Middle adulthood	5824	54.81	2681	46.03	3143	53.97
Matured	59	0.56	43	72.88	16	27.12
Other	275	2.59				

Table 5b presents the responses reporting on the location where beneficiaries lived. Most beneficiaries lived in informal areas (n=3617, 34%), followed by tribal areas (n=2816, 26.50%), Urban areas (n=2672, 25.15%), and Rural areas (n=1521, 14.31%). Area definitions are as follows:

- **Urban settlement** (Big city/small town) - A formal urban settlement is structured and organised. Land parcels (plots or erven) make up a formal and permanent structure. A local council or district council controls development in these areas. Services such as water, electricity and refuse removal are provided, roads are formally planned and maintained by the council. This category includes suburbs and townships.
- **Informal settlement (**Township**)** - Informal settlements or 'squatter camps' occur on land which has not been surveyed or proclaimed as residential, and the structures are usually informal. They are usually found on the outskirts of towns or in pockets of 'infill' inside towns, or along railways and roads. Some informal areas are also found in tribal areas (e.g., in Mpumalanga) and in townships. Although informal settlements occur within rural areas all EAs of this type were classified as urban informal in 2001.
- **Formal rural** (Farms)- A rural area is an open swath of land that has few homes or other buildings, and not very many people. A rural areas population density is very low. In a rural area, there are fewer people, and their homes and businesses are located far away from one another. Agriculture is the primary industry in most rural areas. Most people live or work on farms or ranches.
- **Tribal-Traditional Areas** (Villages)- Villages that fall within a tribal area. Villages look like pockets of houses/huts clustered throughout the area with large areas of grassland and/or fields in between. The appearance of such settlements varies in different parts of the country. Tribal villages are similar in looks in these provinces. Most of the land is flat and the houses are neatly arranged in square gardens and within square roadblocks. Each household is usually neatly fenced with any material (reed, thatch, wire, aloes, or other material). Within each plot, there may be more than one house structure, and houses vary in size from village to village and from plot to plot. Livestock is kept within the boundaries of each household.

Table 5b: Areas where beneficiaries lived.

Areas	MDFSA	SANDA	SANCB	Epilepsy SA	Area sub-total	Area total	Area %
Informal-Child-female	20	8			28		
Informal-Child-male	13	7			20		
Informal-Adolescent-female		9		679	688		
Informal-Middle adulthood-female	3	16		1058	1077		
Informal-Middle adulthood-male	5	13		1004	1022		
Informal - Adolescent-male	34	10		649	693		
Informal - Young adulthood-female	5	16			21		
Informal -YA-Young adulthood-male	10	17			27		
Informal - Matured-female		5			5		
Informal - Matured-male		2			2		
Informal - Other	32			2	34	**3617**	**34.04**
Rural-Child-female		2			2		
Rural-Child-male		5			5		
Rural-Adolescent-female	3	8		76	87		
Rural-Adolescent-male	3	7		124	134		
Rural-Young adulthood-female		5			5		
Rural-Young adulthood-male		6			6		
Rural-Middle adulthood-female		5		88	93		
Rural-Middle adulthood-male		3	1100	34	1137		
Rural-Matured-female		4			4		
Rural-Matured-male		3			3		
Rural-Other	26			19	45	1521	14.31
Tribal-Traditional areas-Child-female					0		
Tribal -Traditional areas-Child-male					0		

Area	MDFSA	SANDA	SANCB	Epilepsy SA	Area sub-total	Area total	Area %
Tribal-Traditional areas-Adolescent-fe		4		1071	1075		
Tribal-Traditional areas-Adolescent-m		1		759	760		
Tribal-Traditional areas-Middle adultl female		4		586	590		
Tribal-Traditional areas-Middle adultl male		6	78	213	297		
Tribal-Traditional areas-Matured-fem		6			6		
Tribal-Traditional areas-Matured-mal		2			2		
Tribal-Traditional areas-Other				84	84		
Tribal-Traditional areas - Young adult female					0		
Tribal-Traditional areas - Young adult male		2			2	2816	26.50
Urban-Adolescent-male	61	22		280	363		
Urban-Child-female	30	13			43		
Urban-Child-male	26	12			38		
Urban-Adolescent-female	36	28		239	303		
Urban-Young adulthood-female	52	20			72		
Urban-Young adulthood-male	63	33			96		
Urban-Middle adulthood-female	40	12		869	921		
Urban-Middle adulthood-male	22	14		651	687		
Urban-Matured-female	26	2			28		
Urban-Matured-male	7	2			9		
Urban-Other	70			42	112	2672	25.15

Comments:

- **Autism South Africa**: We do not have this data available.
- **Learning Empowerment Network**-LEN: Unknown information
- **QuadPara Association of South Africa**: these figures would not be accurate so difficult to tell.
- **South African Federation for Mental Health**: We do not capture this level of disaggregated data.
- **Epilepsy SA**: Mpumalanga branch - We only cover Mpumalanga, and numbers are the same as indicated above.

5.5 Education status

Organization responding: Muscular Dystrophy Foundation SA, South African National Council for the Blind, South African National Deaf Association, and Epilepsy SA. The five education status categories were: (a) Never attended school; (b) Primary school (Grade 7); (c) High school (Grade 10), (d) High school (Grade 12); (e) Certificate (at least one year); and (f) Diploma Degree/Postgraduate

From a total of 8228 beneficiaries, the most frequently reported categories (table 6) were adolescent males (n=877, 10.66%) and females (n=865, 10.51%) who had attended primary school. The next three highest categories were adolescent females (n=646, 7.85%), males (n=639, 7.77%), and middle adulthood females who had never attended school (n=617, 7.5%).

Table 6: Education status

Education status	MDFSA	SANCB	SANDA	Epilepsy SA	Totals	%
Primary school-adolescent-male	32	58		787	877	10.66
Primary school-adolescent-female	10			855	865	10.51
High school G10-adolescent-female	16		41	589	646	7.85
High school G10- adolescent -male	33		30	576	639	7.77
Never attended school-middle adulthood-female		248	2	367	617	7.50

The less frequently reported categories included – young adults (male/female) who had never attended school, those who had diplomas (matured male/females), and males with degree/postgraduate qualifications. Please see Appendix 3 for additional information.

Comments:

- Autism South Africa - We do not capture this data.
- Muscular Dystrophy Foundation SA – Others - some beneficiaries are in practical classes in special needs school.
- Learning Empowerment Network-LEN - All students have a high school education.
- QuadPara Association of South Africa - We don't know these figures.
- South African Federation for Mental Health - We do not capture this level of disaggregated data.
- Epilepsy SA: (Others/ No School 359)

5.6 Employment status

Organizations responding to these questions were: South African National Council for the Blind, South African National Deaf Association, and Epilepsy SA.

From a total of 8794 beneficiaries (Table 7), the most frequently reported were those unemployed and receiving social grants (61.8%). The top four categories were: adolescent males (n=1681, 19.2%), adolescent females (n=1646, 18.72%), middle adulthood females (n=1098, 12.49%), and middle adulthood males (n=1002, 11.39%).

Employment status categories were: Unemployed with no income (UNI); Unemployed with a social grant (USG); Casual worker (CW); Part-time employee (PTE); Full-time employee (FTE); Self employed (SelfEmp); At school; Studying at a tertiary institution (TI); Retired; and Dependent.

Table 7: Employment status

Employment status	SANDA	SANCB	Epilepsy SA	Totals	%
USG-adolescent-male	37		1644	1681	19.12
USG-adolescent-female	44		1602	1646	18.72
USG-middle adulthood-female	14	680	404	1098	12.49
USG-middle adulthood-male	33	560	409	1002	11.39
At school -adolescent-female	42		726	768	8.73
At school-adolescent-male	36		505	541	6.15
Dependent-middle adulthood-female			403	403	4.58
UNI-matured-male	8		308	316	3.59
UNI-matured-female	7		113	120	1.36
Retired-matured-female	4		100	104	1.18
USG-young adult-female	23	80		103	1.17
USG-young adult-male	29	70		99	1.13

Employment categories with less than 1% of reported beneficiaries included: casual work (middle adulthood, adolescents, young adults); dependents (matured, young adults, middle adulthood, children, adolescents); self-employed (adolescents, middle adulthood, matured, young adults); part-time employment (middle adulthood, young adults, adolescents); unemployed with a social grant (mature); at school (young adults and children); full-time employment (middle adulthood, young adults); tertiary education (young adults, middle adulthood, adolescents); unemployed with no income (young adult, matured); and retired (middle adulthood, matured). Please see Appendix 4 for additional information).

Comments:

- Autism South Africa - We do not capture this data.
- Learning Empowerment Network-LEN - Some students are unemployed and do the courses to get computer literate to enhance their chances to employment. Others are employed and upgrading their literacy.
- QuadPara Association of South Africa - We don't have these figures.
- South African Federation for Mental Health - We do not capture this level of disaggregated data.

6.0 Key findings

This section presents the key findings from the national survey. It is divided into three main areas: (a) Priority issues, (b) Intervention strategies, and (c) Referrals and beneficiary satisfaction on the quality of service.

6.1 Challenges facing South African women and girls with disabilities – Priority issues.

Figure 5 presents participants' assessments of the current issues that girls or women with disabilities are facing in South African society. Issues are ranked from 1-8, with 1 being the least important, and 8 being the most important. **Safety and Security needs** (i.e., protection against gender base violence and femicide, access to justice for victims of gender base violence, employment, and health) and **Biological and Physiological Needs** (i.e., basic life needs-air, food, drink, shelter, warmth, sex, and sleep) were the two top priorities ranked most highly (average of 7).

The next three priorities were **Love and Belonging Needs** (i.e., family, affection, relationships, work groups and sexual intimacy), **Esteem Needs** (i.e., achievement, status, responsibility, and reputation) and **Cognitive Needs** (i.e., knowledge and understanding and self–awareness), with an average rank of 5. The lowest ranked priorities were **Self-Actualization Needs** (i.e., (Personal growth and self-fulfillment) with an average rank of 3, followed by **Transcendence** (i.e., helping others to self-actualize) and **Aesthetics** (i.e., beauty, balance, and form) needs, both with an average rank of 2.

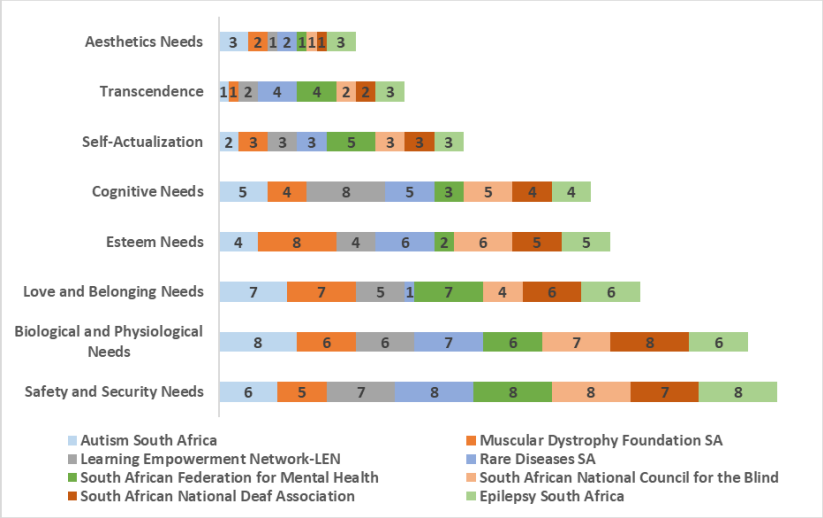


Figure 5: Current Issues that Girls and/or Women with Disabilities are Facing in Societies.
Issues ranked from 1-8, with 1 being the least important, and 8 being the most important. (Erickson, 1963).

Comments:

- **Autism South Africa** - Autistic women struggle to find meaningful and suitable employment opportunities.
- **Muscular Dystrophy Foundation SA** - Some women with disabilities often feels misunderstood by their loved ones. Beauty is important to women with disabilities but for most women, it is not one of the main concerns.
- **Learning Empowerment Network-LEN**- Women and girls need protection at all times. They need knowledge and understanding of others to understand them, and this will create self-awareness in a safe environment.
- **QuadPara Association of South Africa** - we don't have this data.
- **Rare Diseases SA** - A lot of them are not given the opportunity to succeed within society therefore they're not given prosperity of the future.
- **South African National Council for the Blind** - Women and girls with disabilities need protection and safety and awareness on disability issues.
- **Epilepsy South Africa**
    - The issues affect girls and women with disabilities, and it dents their self-esteems and confidence.
    - This affect how they are seen in society and why the continued exclusion (i.e., employment) hinders them from taking part in things meant for them.
    - If their basic needs cannot be met, then this impacts on all level of functioning and, they cannot get to the other needs. Stigma attached to the disability impact on societal attitude and at times lead to discrimination and then girls/women cannot access basic resources.

- They sometimes are not able to help themselves and they need help from the family members and protection...love and affection.

6.2 Intervention strategies

Advocacy, Empowerment, and Development Intervention Strategies

Figure 6 describes the different forms of advocacy, empowerment, and development intervention strategies used by the organizations surveyed. The most frequently used interventions (implemented by eight organizations) were (1) Advocacy and human rights programmes (2) Advocacy and lobbying with national government, (3) Awareness campaigns and empowerment services, and (4) Disability forums.

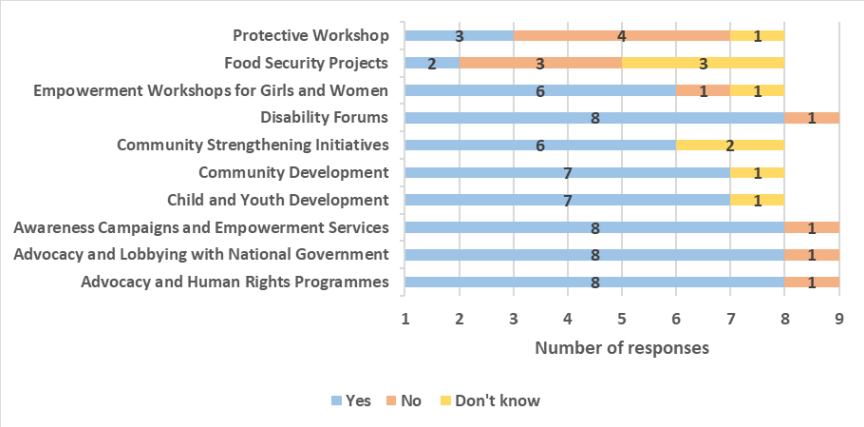


Figure 6: Advocacy, Empowerment, and Development Interventions

The least used interventions were (1) Protective workshops (3 organizations), followed by Food security projects (used by Epilepsy SA and SANDA) and Victim empowerment programmes (implemented by SANCB and SANDA). The South African Federation for Mental Health noted a non-applicable response to this question.

Comments

- **Autism South Africa** - Parent empowerment
- **Rare Diseases SA** - The resources association majority focuses on medical intervention and how they can assist in terms of medical information.
- **South African Federation for Mental Health** - We have awareness and advocacy efforts aimed at women and at people living with disabilities. Both these include women with disabilities. We do not have advocacy and awareness efforts *only* targeting women with disabilities. This is because they are a national office.
- **Epilepsy South Africa** - Under Protective workshop we have a Day care program. We also do a lot of awareness campaigns e.g. Yes, 6 Days, Gender Base, and Child Protection Week Campaign.

Health, Education, and Work Interventions

Figure 7 describes the health, education, and work interventions used by different organizations. The most frequently used interventions were (1) Inclusive education (seven organizations), (2) Health and welfare services, Health education, Job access workshops/work readiness (six organizations) and (3) Entrepreneurial Training (five organizations). The least used interventions (four organizations) were Mental health and wellbeing, Orientation and mobility services and employment programmes, including Sector Education and Training Authorities (SETAS)[4]. Autism South Africa also noted that this is an emerging part of their services, as more males than females are diagnosed as autistic.

[4] SETAs are established under the Skills Development Act, 1998 with a role of developing and implementing a sector skills plan, within the national skills development strategy, by establishing sector workplace skills plans by means of the skills development grants. SETAs promote learnerships by identifying workplaces for practical work experiences. SETAs have the function to monitor the quality of education and training in their sectors.

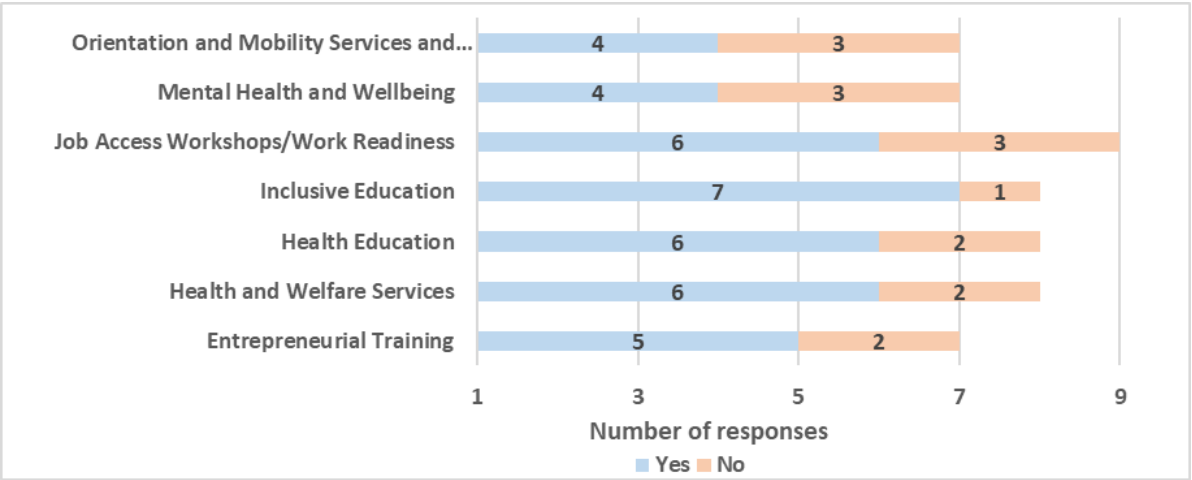


Figure 7: Health, Education, and Work Interventions

Psychosocial support, and counseling services interventions

Figure 8 presents the responses by different organizations on the psychosocial support and counseling services interventions that are used. The most frequently used interventions were Support groups (seven organizations), followed by Family therapy, and parent's support (six organizations). Substance abuse, shelters, and physiotherapy (two organizations) were the least implemented interventions.

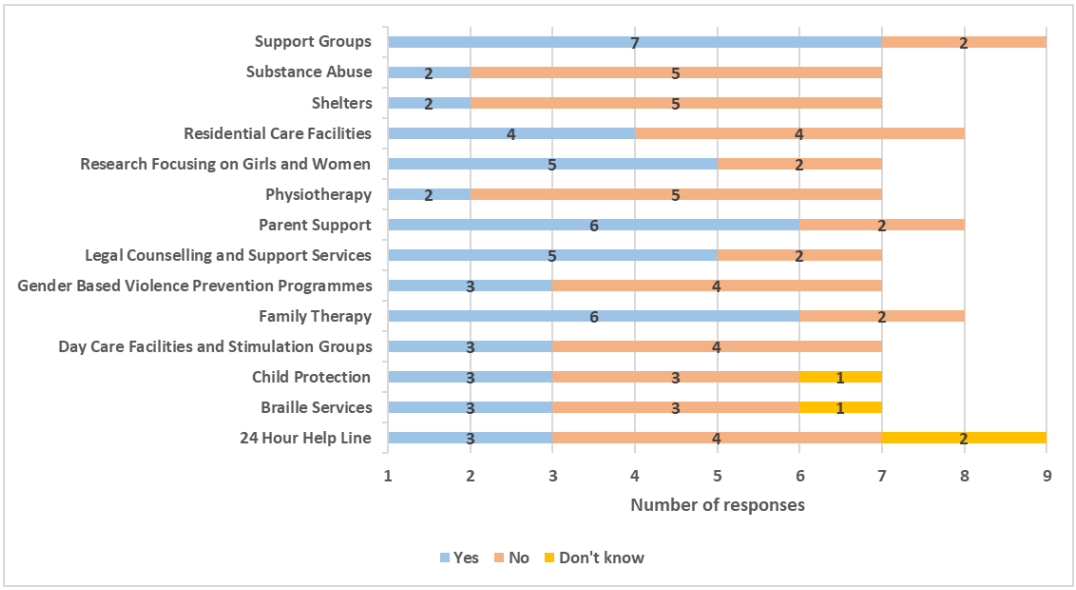


Figure 8: Psychosocial Support, and Counselling Services Interventions

Comments:

- **Epilepsy SA**: For physiotherapy and substance abuse persons are referred to the appropriate organization for assistance. Disability forums in different communities that will be like an advocacy group.

6.2.1 Interventions that made the biggest difference.

- **Autism South Africa** - As stated previously, autistic girls and women go undiagnosed. This area requires more research and ongoing engagement.
- **Muscular Dystrophy Foundation SA** - Family therapy, Parent support groups and Support groups made the biggest difference for women and girls at our organization as these intervention strategies help them to come to terms with the disability of the affected person, educates them, improves their quality of life, and empowers them.
- **Rare Diseases SA** - Support groups especially for parent's support as mothers often feel very alone. Counseling services for young women who need someone to talk to.
- **South African National Council for the Blind** - FET College for skills development and training.

- **South African National Deaf Association** - Needs more action and access to South African Sign Language (SASL) interpreter services.
- **Epilepsy South Africa** - (a) Supportive groups, including parent groups, legal counselling, availability of residential and day care facilities, and virtual support, (b) Awareness, Advocacy, and Communications approaches (e.g., disability, mental health and well being forums, protective workshops, gender-based violence programmes, and job shadowing programmes), and (c) The 24-hour help line and child protection strategies, which were very important interventions in Mpumalanga as girls and women are still facing discrimination in employment and health care services.

6.2.2 Factors making interventions more difficult:

- **South African National Council for the Blind** – Absence of research focusing on blind girls and women based on the fact that there is no evidence that is provided in places like police stations and sexual health and reproductive rights and access to justice and information available in an accessible format.
- **South African National Deaf Association** - No difference yet, we are still struggling with the availability of South African Sign Language (SASL) interpreter services.
- **Epilepsy South Africa** - Issues included (a) Dealing with unemployment in the face of covid-19 pandemic as many companies closed or retrenched staff, (b) Lack of participation in some support groups, and (c) A perception that research lacked discernible impact.

6.2.3 Gaps in interventions

Except for Muscular Dystrophy Foundation SA, Learning Empowerment Network-LEN, and Rare Diseases SA, all other organizations indicated that there are gaps in their interventions.

- **Epilepsy South Africa** - The top three gap areas focused on (a) Communication and awareness programmes, (b) Funding and research, and (c) Specific resources. Relating to communication and awareness gaps, suggestions included the need for more awareness programmes and projects, implemented inclusively. Contributing to gaps in communications and awareness programmes was the lack of funding, research, and resources. For example, there is a need for more South Africa Social Security Agency (SASSA) grants, bursary opportunities and research to address intervention gaps and strengthen existing programmes. Specific resources needed for Gauteng and Western Cape branches related to foodbanks and shelters, as branches either do not have their own (Gauteng) or have difficulty sustaining the programme (Western Cape). Another gap identified by the Western Cape branch is the need for leadership opportunities, especially for girls and women outside the 18-28 age category, which could greatly enhance their employment opportunities. For the South Cape/Karoo branch there is a need for a neurologist to strengthen the services available to their beneficiaries. The branch is also dealing with transport limitations, which constrain their ability to effectively deliver services to their beneficiaries.
- **South African National Council for the Blind:** relevant information available in an accessible format. Other stakeholders are not able to assist our clients due to sensitization.
- **South African National Deaf Association:** No difference yet, we are still struggling with the availability of SASL interpreter services.

Broader issues that organizations are facing:

- **Autism South Africa**: Not enough. Understaffed.
- **QuadPara Association of South Africa**: we don't keep data on effectiveness.
- **South African Federation for Mental Health:** SAFMH continues to struggle to capture and report on certain fields related to the make-up of persons making enquiries. This problem arises as people do not always volunteer this info or respond when they are asked to provide such details [for example gender, race or place of geographical location]. SAFMH cannot however make it compulsory for people to provide this info as we recognise that asking people a range of mandatory, personal questions might very well alienate / frighten / intimidate people making enquiries, especially those who might be vulnerable and/or reaching out for help for the first time. SAFMH is thus exploring new ways to try and ensure that more details can be captured about people making enquiries without the process becoming unnecessarily time-consuming, complicated, invasive or intimidating. Assessing the impact of advocacy and awareness initiatives can prove challenging. We could be more regulated and consistent about the metrics we use to assess impact in advocacy. We look forward to strengthening this in 2023.

- **South African National Council for the Blind**: relevant information available in an accessible format. Other stakeholders are not able to assist our clients due to sensitization.
- **South African National Deaf Association**: Reasonable accommodation in the form of providing SASL interpreter services at all levels.

6.3 Approaches used to assess beneficiaries' satisfaction and quality of service.

Except for QuadPara Association of South Africa, all other organizations provided responses to this question (Figure 9). Client feedback and evaluation forms were the most used approach for assessment (34.78%, n=8 organizations) followed by Assessment tools (information on these tools was not provided) (21.74%). The least used approach was client/practitioner dialog (8.70%, n=2 organizations).

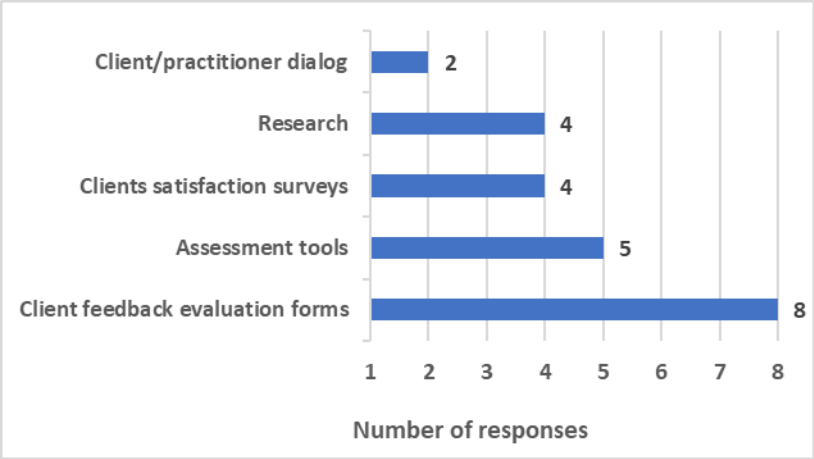


Figure 9: Approaches to Assess Beneficiaries' Satisfaction and Quality of Service.

Comments

- **Epilepsy South Africa** - Four of the six branches used client satisfaction surveys and assessment tools. Client/practitioner dialogue and Client feedback evaluation forms were used by at least three branches. Research and Intrusion detection and prevention system (IDPs) were the least used approaches.

6.3.1 Referrals supporting beneficiaries.

Except for the South African Federation for Mental Health which does not generally provide direct service to beneficiaries, all other organizations provided referrals for girls or women facing problems that could not be addressed by their organization. Table 8a describes the number of referrals made to other organizations in the two months prior to the launch of the survey in October 2022. Based on the reported information, 3965 referrals were made.

Table 8b provides details on the number of referrals made, coded by the type of services provided by the organization and/or department/agency. General health, education support, funding needs and social services were the top four reasons for referring beneficiaries to other organizations/departments/agencies. Note: the total number of reported referrals in this information is 3960.

Table 8a: Number of referrals made to other organizations.

Organization	**Number of referrals**
QuadPara Association of South Africa	20
South African National Council for the Blind	3635
South African National Deaf Association	19
Epilepsy SA	291

Table 8b: Types of services and referral organizations

Types of services	**Organization/department/agency**	**Number of referrals**
General health	Department of Health, Thembalethu Clinic, White Location Clinic/ Knysna Hospital	2320

Education	Department of Education	1000
Funding	Quadriplegic and paraplegic charitable trust of SA, South African Social Security Agency (SASSA)	249
Social services	Alfred Nzo Deaf Association, Department of Social development, Services for Persons with Disability	205
Information and counselling	eThekwini Deaf Association, Families South Africa (FAMSA), George Deaf Association, Mopani Deaf Association, Treatment Action Campaign (TAC), Victim empowerment	82
Food security	Gift of the Givers	40
Housing	Belfast Russord retirement home, Cheshire homes, Services for Persons with Disability	21
Justice	Department of Justice	20
Mental health	Cape Mental Health, Kwa-thema Psyche clinic, Mental health Mpumalanga	6
Mobility	Rehab	5
Substance support	Khayelitsha Deaf Association, South African National Council in Alcoholism and Drug Dependence (SANCA)	5
ASL assistance	Sedibeng Deaf Association	4
Research	Ehlanzeni Deaf Association, Mangaung Deaf Association	3

Comments:

- **Autism South Africa** - Referrals are made to medical practitioners for adult diagnosis of autism, for access to education, for in-depth counselling and for workplace support.
- **Epilepsy South Africa** - Within the 2-month period from approximately March-April 2022, all branches had referred girls and women with disabilities to other organizations/agencies based on the needs of their beneficiaries.

6.3.2 Beneficiaries' satisfaction rate with the referral process

The four organizations that provided responses to this question generally received favorable satisfaction rates from their beneficiaries.

Comments:

- **Epilepsy South Africa:** Three of the branches obtained positive assessments from their beneficiaries, scoring between 98% (out of 200+ referrals) and 100% (n=3 and n=25 referrals). Two branches reported 85% (n=45 referrals) and 70% (n=8 referrals) beneficiary satisfaction, followed by one branch with a 30% (n= 4 referrals) rating.
- **Muscular Dystrophy Foundation SA:** made 2 referral follow-ups, with one person reporting satisfaction.
- **South African National Council for the Blind**: 80% of the referral follow up is made, with 77% reporting satisfaction.
- **South African National Deaf Association**: made 17 follow ups on the above referrals. 80% reported satisfaction, and about 20% had no response.

7.0 Impact of COVID-19 on services and the organization

7.1 Impacts on services

The main impacts of COVID 19 on services were (a) the disruption of services to clients, including cancellations and reduced services, (b) financial constraints and short-falls, and (c) COVID-19 regulations on specific vulnerable beneficiaries such as people with autism, people who are deaf and hard of hearing, and those who are blind or have limited vision. Although technology such as Zoom was used to help deliver some services, this approach was not helpful to those who were deaf and/or hard of hearing and caused miscommunication.

Comments

- **Epilepsy South Africa:** The main impacts on service delivery were that beneficiaries either could not access, or had limited access to offices and services, and social workers could not effectively do their jobs. Other impacts included reduced donations, and the reallocation of budgets to pay for COVID-19 related expenses.
- **Autism South Africa:** Depleted our financial reserves. Autistic people were NOT prepared for the sudden and far-reaching change to their routines. Structure and routine are very important to reduce anxiety and preparation for change is critical. Lack of access for assessments and diagnosis of autism at medical facilities. Medication for co-occurring conditions running out during lockdown. NO access to speech and occupational therapy, setting progress made before lockdown very, very far back. Family stress when people were confined to their homes. Access to education when a family did not have access to internet and data charges were too high.
- **Muscular Dystrophy Foundation SA:** Contact was made telephonically; no support groups and very few awareness sessions took place during that period.
- **Learning Empowerment Network-LEN**: Classroom activities was non-existent.
- **QuadPara Association of South Africa**: QASA staff worked from home and lost touch with members' needs.
- **South African Federation for Mental Health**: Challenges to us, and our community-based mental health care affiliates are captured in this documentary: https://youtu.be/CBGvcWzqga4
- **South African National Council for the Blind**: Our clientele uses hands to navigate so due to covid-19 regulations most of our clientele lost their jobs, funding and mobility.
- **South African National Deaf Association**: It impacted negatively on our ability to provide services due to lockdown, we received many complaints regarding communications accessibility due to lack of understanding of SASL which is a visual language, the use of masks that prevented facial expression and lipreading. Infected Deaf people unable to contact families. Organization did not receive government financial support for covid related assistance. Zoom and Microsoft team virtual meeting are not Deaf-friendly, and communication caused communication breakdown due to weak network in some areas.

7.2 Impacts on member organizations

The most important impacts of COVID-19 on organizations were reduced staff hours (and reduced income), high turn over of staff, fewer interventions and services being delivered, and the limitations of technology in supporting specific programs.

Comments

- **Epilepsy South Africa -** The most important impacts on staff were (a) salary cuts or delays resulting in a high turnover of staff, and (b) Increased anger and frustration, leading to employee burnout.
- **Autism South Africa:** The same as above.
- **Muscular Dystrophy Foundation SA:** Fewer interventions telephonically were done.
- **Learning Empowerment Network-LEN:** Classroom activities was non-existent.
- **QuadPara Association of South Africa:** Services terminated for at least 12 months.
- **South African Federation for Mental Health:** We do not deliver services directly to the public, including girls and women with disabilities.
- **South African National Council for the Blind:** Blind and partially sighted person are behind with issues of technology so most of the information shared about Covid-19 was not accessible.
- **South African National Deaf Association**: Inability to reach out to affected girls and women in the communities and lack of funding including resources needed to minimise the impact.

8.0 Discussion and Recommendations

Data collection:

There are limitations in the capacity to provide needed information by some SADA members. Member organizations deal with all kinds of workload challenges, financial instability and administrative inconsistencies, and this causes data collection challenges. It would serve the interests of SADA member organizations individually and as a group to seek to ensure more consistent and comprehensive data collection practices. This would enable more effective self-reflection, adaptation, and advocacy with donors and government.

Private Information Protection:
A closely related issue is the sensitivities of beneficiaries concerning protection of personal privacy, underpinned in legislation by the Protection of Personal Information Act (For detailed information about the Act, see Appendix 7). Several organizations said those they work with feel very reluctant to share personal information. Insufficient information sharing influences effective programming and accountability to the government, funders and other stakeholders involved. This raises the question of how organizations' protection of privacy practices can be effectively communicated.

Age categories:
The work of the organizations surveyed is concentrated on people in the age categories of adolescence, young adult, and middle adulthood. In contrast, the categories of child (0-11 years) and maturity (66+ years) are under-represented. There are many possible reasons for this, and explanations were not explored in this survey. However, it raises the question of whether these age groups are relatively neglected and require more focused attention.
For example, it is possible that disabled children are being neglected because they are not getting the support they need since most of them are not in regular schools, despite the government's claim to have achieved full (100%) primary enrolment of school children. Similarly, since 'mature' adults are neither of working nor reproductive age, they may be overlooked and neglected. In both cases, consideration should be given to how their distinctive needs can and should be addressed.

Material Needs *versus* Advocacy Intervention Strategies:
The most pressing needs of women and girls with disabilities identified were concrete material ones whereas the interventions seen in some member organizations were largely advocacy interventions that do not directly address material needs. Some of the member organizations are also not well equipped to meet the demanding challenges of material needs and the government does not provide for these needs either.

On the other hand, since government should be most responsible for meeting material needs of women and girls with disabilities, advocacy interventions may be the most effective and efficient way for organizations in the disability sector to make a meaningful difference for their clients.

In short, the balance and relationship between a focus on material needs vs. advocacy will be a continuing challenge for the non-profit organizations in the disability sector.

COVID-19 and sectoral vulnerability:
This disability sector is populated by exceptionally dedicated but under-resourced organizations. This limits capacity for self-reflection, and the ability to respond to sudden shocks or disruptions**.** The COVID-19 pandemic and associated lockdowns had serious impacts on both the services of those surveyed, and the viability of the organizations themselves. The sector is by no means unique in this respect, but the repercussions for their communities of members and beneficiaries were severe. Given this, attention should be given to how to prepare for comparable (if hopefully less severe) disruptions in future. Some of these provisions could involve the adoption and adaptation of new technologies and data collection practices to maintain contact with beneficiaries when sustained emergencies limit mobility, and capacity for face-to-face programming.

Recommendations:
- SADA should work with member organizations to improve capacity for data collection and the consistency of the data available, giving appropriate attention to privacy concerns. In addition, SADA should lead the development of a standardized, user-friendly national disability information management system, with built-in training and technical support for staff across member organizations. This would reduce duplication, improve comparability of data, and create stronger evidence for policy advocacy.
- Capacity limitations should also be tackled through a consolidation of the individual organizations' efforts and collaboration with those in other sectors, around the most urgent needs facing people with disabilities.
- The needs of both children and mature adults with disabilities should be given focused attention. Future program design and funding proposals should explicitly include early childhood interventions (0–11 years) and elder support services (66+). Additionally, indicators disaggregated by age should be collected and monitored to ensure accountability.

- Attention should also be given to the ongoing balance between programming focused on material needs, advocacy and sharing of lessons learned between member organizations. To strengthen this balance, organizations should pursue partnerships with food banks, social security offices, and local businesses for short-term material support, while sustaining advocacy campaigns to ensure that systemic change and state responsibility remain central.
- Contingency planning should be undertaken for prolonged disruptions of regular programming, learning from the lessons of COVID-19 and drawing on new technologies and communication strategies. For example:
    - Develop **continuity of care plans** for service disruptions (pandemics, natural disasters, strikes), including backup systems for counselling, medication delivery, and crisis support.
    - Expand **digital access programmes** (data vouchers, accessible online platforms, SASL interpretation online) to reduce exclusion during emergencies.
- There is a need for relevant research: organizations in the sector are caught between responding to urgent practical needs, and a lack of relevant research into what those needs are and how to meet them. Greater collaboration should be encouraged between disability sector organizations and researchers, as well as the development of greater research capacity within disability sector organizations themselves.

Key Takeaways:

1. Establish a national disability research hub or working group, co-led by SADA and academic partners, to prioritise applied research on urgent issues (e.g., gender-based violence, economic inclusion, ageing).
2. Advocate for dedicated government budget allocations for disability-inclusive programmes, with monitoring to ensure funds reach grassroots communities.

9.0 Bibliography

Adjei-Amoako, Y. (2016). Promoting inclusive development in Ghana: disabled people's and other stakeholders' perspectives. *Development in Practice, 26(7),* 865-875.

Behrens, R., & Görgens, T. (2019). *Challenges in achieving Universal access to transport services in South African Cities.* The Palgrave handbook of disability and citizenship in the Global South, 183-196.

Dube, A. K. (2005). *The role and effectiveness of disability legislation in South Africa*. Samaita Consultancy and Programme Design, 1-89.

Emmett, T., & Alant, E. (2006). Women and disability: exploring the interface of multiple disadvantage*. Development Southern Africa, 23(4)*, 445-460.

Erikson, E. H. (1963). Childhood and society (2d ed., rev.). *New York: W. W. Norton*.

Goldblatt, B. (2009). Gender, rights, and the disability grant in South Africa. *Development Southern Africa, 26(3),* 369-382.

Groce, N. E. (2004). Adolescents and youth with disability: Issues and challenges. *Asia Pacific Disability Rehabilitation Journal, 15(2)*, 13-32.

Humphrey, M. (2016). *The intersectionality of poverty, disability, and gender as a framework to understand violence against women with disabilities*: A case study of South Africa. Master Thesis.

Maja, P. A., Mann, W. M., Sing, D., Steyn, A. J., & Naidoo, P. (2011). Employing people with disabilities in South Africa. *South African Journal of Occupational Therapy, 41(1),* 24-32.

Martin, J. H. (2022). Exploring the affective atmospheres of the threat of sexual violence in minibus taxis: the experiences of women commuters in South Africa. *Mobilities, 17(3)*, 301-316.

Maslow, A. H. (1970). In W. G. Holtzman & G. Murphy (Eds.), *Motivation and personality* (2nd Ed.). New York: Harper & Row.

McKenzie, J. A. (2013). Disabled people in rural South Africa talk about sexuality. *Culture, health & sexuality, 15(3),* 372-386.

Meekosha, H., & Soldatic, K. (2011). Human Rights and the Global South: the case of disability. *Third World Quarterly, 32(8)*, 1383-1397.

Ngubane-Mokiwa, S. A. (2018). Ubuntu considered in light of exclusion of people with disabilities. *African Journal of Disability, 7(1)*, 1-7.

Sins Invalid. (2019). What is disability justice? In *Skin, Tooth, and Bone: The Basis of Movement is Our People*

Slayter, E., Kattari, S. K., Yakas, L., Singh, R. C. B., Goulden, A., Taylor, S., Wernick, L. J., Simmons, L. D., & Prince, D. (2023). Beyond ramps, curb cuts, and captions: A call for Disability Justice in social work. *Social Work, 68(1)*, 89-92

Statistics South Africa (2017). *South Africa Demographic and Health Survey 2016: Key Indicator Report*.

Storbeck, C., & Moodley, S. (2011). ECD policies in South Africa–What about children with disabilities? *Journal of African Studies and Development, 3(1)*, 1-8.

Tshaka, B., Visagie, S., & Ned, L. Y. (2023). Non-use of healthcare services among persons with mobility impairments in Cofimvaba, *South Africa. African Journal of Disability,* (12), 1112.

Van der Heijden, I., Abrahams, N., & Harries, J. (2019). Additional layers of violence: the intersections of gender and disability in the violence experiences of women with physical disabilities in South Africa. *Journal of interpersonal violence, 34(4)*, 826-847.

Vincent, L., & Chiwandire, D. (2017). Wheelchair users, access, and exclusion in South African higher education. *African Journal of Disability, 6(1),* 1-9.

10.0 Appendices

Appendix 1: Organization profiles

Autism South Africa (ASA): Autism South Africa aspires to achieve "a society in which autistic people enjoy all rights and opportunities to meet their needs and fulfil their potential, throughout their lives, as loved and valued members of their families and communities." It was founded in 1989 by concerned parents and professionals as a lobbying and networking organization. It is now the recognized national body for autistic people in South Africa. A;SA has a footprint representation in eight provinces. A;SA strives to: celebrate and champion the diversity and creativity of persons with ASD; partner with and be relevant to persons with ASD and their families and communities; identify and address the differing and changing needs of babies, children, adolescents and adults with ASD; promote the rights and advance the interests of all those within the autism community; lead ASD awareness, education, therapy and advocacy throughout South Africa; and draw on and contribute to national and international experience and expertise in the field of ASD, while retaining a regional and local focus on challenges and opportunities.
Website: https://aut2know.co.za/

Epilepsy South Africa: Epilepsy South Africa promotes human rights and an inclusive society for persons with disabilities, primarily persons with epilepsy. Epilepsy SA was established in 1967 as the South African National Epilepsy League (SANEL). It is the only national organization in South Africa offering specialized and comprehensive services to persons with and affected by epilepsy and other neurological disorders. Their aim is to enhance and improve the quality of life of their target groups. The organization comprises a coordinating National Office and six regional branches: Eastern Cape, Free State/North West, Gauteng, Mpumalanga & Limpopo, South Cape Karoo and Western Cape.
Website: https://epilepsy.org.za/

Learning Empowerment Network-LEN: LEN is a non-profit initiative working since 2015 to offer free and open online courses to all who want to learn. The LEN project initiated from a shortage of skills and work opportunities. At LEN you can earn a digital certificate of completion that you can use to enhance your resume. We offer a variety of short and full-length courses at the school, college, and professional levels, each built by subject matter experts. All courses are available to complete at your pace, on your schedule, and free of cost.
Website: https://learningempowermentnetwork.co.za

Muscular Dystrophy Foundation SA: The mission of the Foundation is to support people affected by Muscular Dystrophy and Neuromuscular disorders and endeavor to improve the quality of life of its members. The Muscular Dystrophy Research Foundation of South Africa was founded in 1974 by Mr and Mrs Newton Walker who had a son affected with Duchenne Muscular Dystrophy. They, together with Wally Gough of the Rotary Club of Potchefstroom and representatives of Cripple Care Association formed the Foundation. Today the Muscular Dystrophy Foundation of South Africa is a registered non-profit organization consisting of a national office and three branches which operate in the nine provinces of South Africa.
Website: https://www.mdsa.org.za/

QuadPara Association of South Africa (QASA): The QuadPara Association of South Africa (QASA) is considered the leading agency representing persons with spinal cord injury and physical disability in South Africa. In June 1978, a group of Quadriplegics in Johannesburg decided to establish QASA as a national coordinating structure representing all Quadriplegic associations in South Africa. Since then, QASA has grown to include six regional associations (Eastern Cape, Gauteng North, Gauteng South, KwaZulu-Natal, North West and Western Cape) and a membership of more than 6500 Quadriplegics and Paraplegics. Over the years, QASA has initiated, extended and refined its services and programmes to meet the needs of its members as well as the disability sector. QASA is a NPO of Quadriplegics and Paraplegics, and strives to develop products, programmes, and services to develop capacity amongst its members and to offer opportunities for societal integration.
Website: https://qasa.co.za/

Rare Diseases South Africa (RSSA): Statistics indicate that 1 in 15 South Africans are affected by rare diseases. Despite this, the rare community are severely under-represented and remain vulnerable from a medical and policy perspective. RDSA brings together international best practice and local medical innovation, driving a collective voice and playing a

fundamental role in bridging the gap between vulnerable communities and medical advancement, working towards providing a better tomorrow for those living with rare diseases. Founded in 2013, RDSA is a non-profit organization advocating to ensure that people living with rare diseases and congenital disorders experience greater recognition, support, improved health service and better overall quality of life. Started out of personal need following the diagnosis of organization founder, Kelly du Plessis' son, it became evident that there was a lack of awareness and support for rare diseases in general in South Africa.
Website: https://www.rarediseases.co.za/

South African Federation for Mental Health (SAFMH): The South African Federation for Mental Health (SAFMH) is a national non-governmental organization and was founded in 1920, originally called The South African National Council for Mental Hygiene and the Care of the Feeble-Minded. Through the years it has changed its name several times, eventually settling on the South African Federation for Mental Health in 1990. Since its humble beginnings, SAFMH has played an important role as an advocacy body, promoting community mental health care and de-institutionalization, and fighting for the rights of persons with psychosocial and intellectual disabilities. Today, SAFMH is the largest national mental health federation in South Africa, with the national office situated in Johannesburg, and 17 constituent bodies [known as Mental Health Societies] located in all nine provinces.
Website: https://www.safmh.org/

South African National Council for the Blind: The vision of the Council is to facilitate a network of organizations that collaborate towards the prevention of blindness, and securing the full participation and inclusion of blind and partially sighted people in all aspects of a diverse South African society. The Council is overseen by the Department of Sport, Arts and Culture (DSAC). The Council's objectives are to: provide relevant services and support to South Africans with visual impairments; facilitate collaborative partnerships to serve the interests of visually impaired South Africans; advocate on behalf of people with visual impairments; develop and maintain standards for services offered to people with visual impairments; promote the education, training and rehabilitation relevant for the employment of people with visual impairments; help organizations for and of the blind to deliver effective and relevant services; gather and disseminate information on matters concerning visual impairment; initiate and implement projects beneficial to people with visual impairments; supply assistive devices and related technologies to people with visual impairments; preserve and restore sight and prevent blindness; work together with international organizations for the improvement of the quality of life of people with visual impairments; create awareness of the skills, capacities and abilities of people with visual impairments; and ensure that blind and partially sighted people of all ages enjoy all rights promised by the Constitution of South Africa.
Website: https://nationalgovernment.co.za/units/view/173/south-african-national-council-for-the-blind

South African National Deaf Association: The South African National Deaf Association is a leading independent not for profit, public benefit, national advocacy, and consumer organization registered both as a section 21 company and Non-Profit Organization (NPO). SANDA represents South Africa's more than 4 million Deaf and hard of hearing people, and is dedicated to providing quality services, ensuring public accessibility and increasing awareness of issues affecting Deaf people at all levels in South Africa. The organization was founded in 2004 (an important moment in the history of South Africa, namely, the coming into being of a decade of a democratic dispensation - ten years of post-apartheid government) and is managed by Deaf people.
Website: http://www.sanda.org.za/index.html

Appendix 2: Summary of participants roles and responsibilities

Executive leadership roles include: (a) Leadership and strategic development (e.g., delivery of the organization's philosophy, mission, vision, strategy, and its annual goals and objectives, provide executive administrative and governance support; provide informed research on key advocacy and national project matters), (b) Advocacy and engagement (e.g., ensure that there is ongoing proactive communications with government departments and other disability organizations and applicable NGO partners from the South African and International arena; Residential social worker), (c) Fundraising (e.g., fund raise, plan and implement programs, identify resource requirements, research funding sources, establish strategies to approach funders), (d) Communications and outreach (e.g. present regularly to large audiences on radio and television), and (e) Training (e.g. conduct training, and write/prepare the material).

Manager roles include: (1) Overall resource management (e.g. liaise with branches and ensure organisation's programmes are developed, promoted, and operationalized, provide supervision of services), (2) Client engagement (e.g., determine community needs, ensure timely attendance to beneficiaries needs), (3) Research and project planning/management (e.g., compile analysis reports, develop project proposals, and plan and implement new projects).

Social and/or auxiliary workers roles include: (1) Provide services to beneficiaries/clients, including family members and partners (e.g.., provide psycho-social support, education, assistance, participate in the process of improving the quality of their life) (2) Facilitate access to support services and resources (e.g., identify other agencies and funding options , develop plans of action), (3) Advocacy, engagement and empowerment (e.g., awareness campaigns at schools, private, public sector and general public, radio and TV interviews), and (4) Fundraise (e.g., income generation projects, raising funds).

Project leads/Leader roles: (1) Expertise (e.g., provide insight into disability information and regulations, write evidence-based and rights-based policy briefs, comment on national policies) (2) Communications and advocacy (e.g., public speaking, press releases, social media content), and (3) Administration (e.g., administration assistance).

Support staff: (1) Client/beneficiaries service (e.g., greet people when the come to the organisation or call, respond to emails/phone calls, maintain schedules, and other administrative tasks) (2),

Appendix 3: National Survey questionnaire

Organisation detail

- Name of organisation
- Organisation address
- Province
- Position at the organisation
- How long have you been employed at the organisation (years/months)

Data collection

- How does your organisation collect information about beneficiaries?
- How often does your organisation collect information about beneficiaries?
- At what level is the beneficiary's information being collected at?
- How often does your organisation summarise beneficiaries' information and/or prepare reports using this
- data?
- How are these reports used?
- Are there any challenges that your organisation faces when collecting and reporting on beneficiaries' data?
- What would help support your organisation to collect and report on beneficiaries' information?

Beneficiaries' profiles (last financial year - 1 April 2021-30 March 2022).

- Total number of beneficiaries for the relevant Provinces where the organisation has provided services.
- Total number of beneficiaries by race (Black, Indian/Asian, Coloured, White, Other).
- Where beneficiaries live (Formal urban settlement, Informal settlement, Formal rural, Tribal areas, Other)
- Total number of beneficiaries who have: Never attended school, Primary school (Grade 7), High school (Grade 10), High school (Grade 12) Certificate (at least one year), Diploma, Degree/Postgraduate.
- Total number of beneficiaries who fall under these categories: Unemployed with no income, Unemployed with a social grant, Casual worker, Part-time employee, Fulltime employee, Self-employed, At school, Studying at a tertiary, Institution, Retired, Dependent
- Total number of beneficiaries for these categories of disabilities: Physical, Sensory, Neurological, Psychosocial, Intellectual, Other.

Current issues that girls and women with disabilities are facing.

- What are the current issues that girls or women with disabilities are facing in our societies? Please rank the issues below from 1-8
    - Biological and Physiological Needs: (basic life needs-air, food, drink, shelter, warmth, sex and sleep)
    - Safety and Security Needs: (protection, security e.g., gender base violence and genocide, order, law e.g., access to justice for victims of gender base violence, limits, stability, and security of body).
    - Love and Belonging Needs: (family, affection, relationships, work groups and sexual intimacy)
    - Esteem Needs:(achievement, status, responsibility, and reputation)
    - Cognitive Needs:(knowledge and understanding and self–awareness)
    - Aesthetics Needs: (Beauty, balance, and form)
    - Self-Actualization: (Personal growth and self-fulfillment)
    - Transcendence:(Helping others to self-actualize)
- How do the issues that are identified above, impact on the lives of girls and women with disabilities?

Intervention Strategies

- Advocacy, Empowerment and Development: What are the key intervention strategies used to address the current issues faced by girls and women with disabilities served by your organization? Please select all that apply.
    - Advocacy and Human Rights Programmes
    - Advocacy and Lobbying with National Government
    - Awareness Campaigns and Empowerment Services
    - Child and Youth Development
    - Community Development

- Community Strengthening Initiatives
- Disability Forums
- Empowerment Workshops for Girls and Women
- Food Security Projects
- Protective Workshop
- Victim Empowerment Programmes
- Other

- Health, Education, and Work: What are the key intervention strategies used to address the current issues faced by girls and women with disabilities served by your organization?
  - Entrepreneurial Training
  - Health and Welfare Service
  - Health Education
  - Inclusive Education
  - Job Access Workshops/Work Readiness
  - Mental Health and Wellbeing
  - Orientation and Mobility Services and Employment Programmes
  - Sector Education and Training Authorities (SETAS)
  - Self-employment Initiatives and Support
  - Skills Development (Learnership Programmes, Technical Skills Training and Bursaries)
- Psychosocial Support and Counselling Services: What are the key intervention strategies used to address the
- current issues faced by girls and women with disabilities served by your organization?
  - 24 Hour Help Line
  - Braille Services
  - Child Protection
  - Day Care Facilities and Stimulation Groups
  - Family Therapy
  - Gender Based Violence Prevention Programmes
  - Legal Counselling and Support Services
  - Parent Support
  - Physiotherapy
  - Research Focusing on Girls and Women
  - Residential Care Facilities
  - Shelters
  - Substance Abuse
  - Support Groups
  - Other
  - Which of these intervention strategies that you selected in Questions 3.1, 3.2, and 3.3 do you think has made the biggest difference to the women and girls you support
  - Which of these intervention strategies that you selected in Questions 3.1, 3.2, and 3.3 has made the least difference?
  - In what ways do you determine the effectiveness of an intervention?
  - Are there gaps with the interventions strategies that need to be addressed?

Referral System, and Monitoring and Evaluation

- Do you refer girls or women with disabilities, facing problems that cannot be addressed by your organization, to other organizations?
- Please indicate the total number of referrals made to other organizations.
- Please list the names of the organizations and reason for the referral (within the last two months).
- Please tell us the total number and percentage of follow-up referrals that you made.
- Please tell us the total number and percentage of client's that report satisfaction with the referral process.

COVID-19 Issues

- In 2021, how did Covid-19 affect your clientele and your organization?
- In 2021, what impact did the Covid-19 pandemic have on your service delivery to girls and women with disabilities?

Optional questions to help with future survey development.

- Did you feel excluded from the survey at any point? For example, did you feel that there were key issues, interests, or groups of importance to you that were overlooked in the survey? Was the language difficult to understand? Were there ways in which the technology being used made it difficult to complete?
- If you did not complete the survey, please tell us why?
- Is there anything else that you would like to share with us that could help make the survey better?
- Are there any other questions that you think would be helpful to include in this type of project?

Appendix 4: Age and gender with additional details

	MDFSA	SANDA	SANCB	Epilepsy SA	Sub-totals	%	Category-age	age %	Female/male	Female/male%
Urban-Child-female	30	13			43	0.40				
Informal-Child-female	20	8			28	0.26				
Rural-Child-female		2			2	0.02				
Tribal areas-Child-female					0	0.00				
Urban-Child-male	26	12			38	0.36				
Informal-Child-male	13	7			20	0.19				
Rural-Child-male		5			5	0.05			73	Female: 53.68
Tribal areas-Child-male					0	0.00	136	1.28	63	Male: 46.32
Urban-Adolescent-female	36	28		239	303	2.85				
Informal-Adolescent-female		9		679	688	6.47				
Rural-Adolescent-female	3	8		76	87	0.82				
Tribal areas-Adolescent-female		4		1071	1075	10.12				
Urban-Adolescent-male	61	22		280	363	3.42				
Informal - Adolescent-male	34	10		649	693	6.52				
Rural-Adolescent-male	3	7		124	134	1.26			2153	Female: 52.47
Tribal areas-Adolescent-male		1		759	760	7.15	4103	38.61	1950	Male: 47.53
Urban-Young adulthood-female	52	20			72	0.68				
Informal - Young adulthood-female	5	16			21	0.20				
Rural-Young adulthood-female		5			5	0.05				
Tribal areas - Young adulthood-female					0	0.00				
Urban-Young adulthood-male	63	33			96	0.90				
Informal -YA-Young adulthood-male	10	17			27	0.25				
Rural-Young adulthood-male		6			6	0.06			98	Female: 42.79
Tribal areas - Young adulthood-male		2			2	0.02	229	2.16	131	Male: 57.21
Urban-Middle adulthood-female	40	12		869	921	8.67				
Informal-Middle adulthood-female	3	16		1058	1077	10.14				
Rural-Middle adulthood-female		5		88	93	0.88				
Tribal areas-Middle adulthood-female		4		586	590	5.55				
Urban-Middle adulthood-male	22	14		651	687	6.47				
Informal-Middle adulthood-male	5	13		1004	1022	9.62				
Rural-Middle adulthood-male		3	1100	34	1137	10.70			2681	Female: 46.03

Tribal areas-Middle adulthood-male		6	78	213	297	2.80	5824	54.81	3143	Male: 53.97

	MDFSA	SANDA	SANCB	Epilepsy SA	Sub-totals	%	Category-age	age %	Female/male	Female/male%
Urban-Matured-female	26	2			28	0.26				
Informal - Matured-female		5			5	0.05				
Rural-Matured-female		4			4	0.04				
Tribal areas-Matured-female		6			6	0.06				
Urban-Matured-male	7	2			9	0.08				
Informal - Matured-male		2			2	0.02				
Rural-Matured-male		3			3	0.03			43	Female: 72.88
Tribal areas-Matured-male		2			2	0.02	59	0.56	16	Male: 27.12
Urban-Other	70			42	112	1.05				
Informal - Other	32			2	34	0.32				
Rural-Other	26			19	45	0.42				
Tribal areas-Other				84	84	0.79	275	2.59		
Total					10626		10626			

Appendix 5: Education status

Education status	MDFSA	SANCB	SANDA	Epilepsy SA	Totals	%
Primary-Ado-male	32	58		787	877	10.66
Primary-Ado-female	10			855	865	10.51
HighG10-Ado-female	16		41	589	646	7.85
HighG10-Ado-male	33		30	576	639	7.77
No school-MA-female		248	2	367	617	7.50
Primary-MA-female	2	120		492	614	7.46
No school-Ado-female			2	606	608	7.39
HighG10-MA-female	13	280	12	272	577	7.01
No school-ado-male			3	417	420	5.10
No school-MA-male	1	130	2	211	344	4.18
Primary-MA-male	1	60		216	277	3.37
HighG10-MA-male	3	70	11	152	236	2.87
HighG12-MA-female	18		11	159	188	2.28
HighG12-MA-male	10		12	80	102	1.24
HighG12-Ado-male	31		5	61	97	1.18
HighG10-YA-male	4	80	12		96	1.17
HighG12-YA-male	48	20	16		84	1.02
Primary-Child-female	49		23		72	0.88
HighG12-Ado-female	13		6	52	71	0.86
HighG10-MAT-female	10	43	15		68	0.83
Cert-YA-male	20	20	23		63	0.77
HighG12-YA-female	50		12		62	0.75
Primary-Child-male	35		24		59	0.72
No school-MAT-male		48	1		49	0.60
Other	47				47	0.57
Cert-MA-male	10		8	22	40	0.49
No school-MAT-female	2	38			40	0.49
Primary-MAT-male		34			34	0.41
Cert-MA-female	4		8	21	33	0.40
Other	32				32	0.39
HighG10-YA-female	6		21		27	0.33
Primary-MAT-female	5	21			26	0.32
Other	25				25	0.30
HighG10-MAT-male	2	17	5		24	0.29
Diploma-MA-female	6		2	12	20	0.24
Diploma-YA-male	1	15	3		19	0.23
Cert-Ado-male			2	16	18	0.22
Degree/PG-MA-female			2	14	16	0.19
Diploma-MA-male	2		2	7	11	0.13
Degree/PG-MA-male	3		1	6	10	0.12
Other	10				10	0.12
Cert-Ado-female				9	9	0.11
HighG12-MAT-female	7		1		8	0.10
Degree/PG-YA-male		5	2		7	0.09
Cert-YA-female			6		6	0.07
Other	6				6	0.07

HighG12-MAT-male	3		2		5	0.06
Other	5				5	0.06
No school-Child-male	4				4	0.05
Other	3				3	0.04
No school-YA-female			2		2	0.02
No school-YA-male			2		2	0.02
Diploma-MAT-female	2				2	0.02
No school-Child-female	1				1	0.01
Diploma-YA-female	1				1	0.01
Cert-MAT-female			1		1	0.01
Cert-MAT-male			1		1	0.01
Diploma-MAT-male	1				1	0.01
Degree/PG-MAT-male	1				1	0.01
Total					**8228**	

Education status

- Never attended school.
- Primary school (Grade 7)
- High school (Grade 10)
- High school (Grade 12)
- Certificate (at least one year)
- Diploma Degree/Postgraduate

Age categories

- Child 0-11yrs, female/male
- Adolescence 12-18yrs, female/male
- Young adulthood 19-40yrs, female/male
- Middle adulthood 41-65yrs, female/male
- Maturity 66+yrs, female/male

Appendix 6: Employment status

Employment status	SANDA	SANCB	Epilepsy SA	Totals	%
USG-Ado-Male	37		1644	1681	19.12
USG-Ado-Female	44		1602	1646	18.72
USG-MA-Female	14	680	404	1098	12.49
USG-MA-Male	33	560	409	1002	11.39
At school -Ado-Female	42		726	768	8.73
At school-Ado-Male	36		505	541	6.15
Dependent-MA-Female			403	403	4.58
UNI-MA-Male	8		308	316	3.59
UNI-MA-Female	7		113	120	1.36
Retired-MA-Female	4		100	104	1.18
USG-YA-Female	23	80		103	1.17
USG-YA-Male	29	70		99	1.13
USG-MAT-Female	14	80		94	1.07
CW-MA-Female	22		45	67	0.76
CW-MA-Male	13		51	64	0.73
Selfemp-Ado-Female		58		58	0.66
USG-MAT-Male	7	50		57	0.65
Dependent-MA-Male	3		50	53	0.60
PTE-MA-Male	9		32	41	0.47
Dependent -Ado-Female	34			34	0.39
PTE-MA-Female	7		26	33	0.38
CW-Ado-Female	4		28	32	0.36
SelfEmp-MA-Female	4		23	27	0.31
At school - Child-Male	24			24	0.27
Dependent -Child-Male	24			24	0.27
At school - Child-Female	23			23	0.26
Dependent -Child-Female	23			23	0.26
SelfEmp-MA-Male	3		19	22	0.25
CW-Ado-Male	5		15	20	0.23
FTE-MA-Female	9		9	18	0.20
UNI-YA-Male	16			16	0.18
FTE-MA-Male	12		3	15	0.17
Retired-MAT-Female	14			14	0.16
FTE-YA-Female	13			13	0.15
CW-YA-Male	13			13	0.15
TI-YA-Male	13			13	0.15
TI-YA-Female	9			9	0.10
Retired-MAT-Male	9			9	0.10
UNI-YA-Female	8			8	0.09
FTE-YA-Male	8			8	0.09
TI-MA-Male			7	7	0.08
Dependent -Ado-Male	4		2	6	0.07

PTE-YA-Female	6			6	0.07
At school-YA-Male	6			6	0.07
TI-Ado-Female	3		2	5	0.06
CW-YA-Female	5			5	0.06
PTE-YA-Male	5			5	0.06
Dependent-MAT-Male	5			5	0.06
TI-Ado-Male	4			4	0.05
Dependent-YA-Female	4			4	0.05
TI-MA-Female			4	4	0.05
Retired -MA-Male	4			4	0.05
PTE-Ado-Male	3			3	0.03
UNI-MAT-Female	3			3	0.03
At school-YA-Female	2			2	0.02
SelfEmp-YA-Male	2			2	0.02
Dependent-YA-Male	2			2	0.02
SelfEmp-MAT-Female	2			2	0.02
Dependent-MAT-Female	2			2	0.02
UNI-MAT-Male	2			2	0.02
PTE-Ado-Female	1			1	0.01
SelfEmp-YA-Female	1			1	0.01
Total				8794	

Legend

Employment status

- Unemployed with no income (UNI)
- Unemployed with a social grant (USG)
- Casual worker (CW)
- Part-time employee (PTE)
- Full-time employee (FTE)
- Self employed (SelfEmp)
- At school
- Studying at a tertiary institution (TI)
- Retired
- Dependent

Age categories

- Child 0-11yrs, female/male
- Adolescence 12-18yrs, female/male
- Young adulthood 19-40yrs, female/male
- Middle adulthood 41-65yrs, female/male
- Maturity 66+yrs, female/male

Appendix 7: Protection of Personal Information Act (POPIA)

POPIA gives substance to the constitutional right to privacy and therefore seeks to protect persons from having their personal information used to cause harm. Personal information is broadly defined and includes:
information relating to an identifiable, living, natural person, and where it is applicable, an identifiable, existing juristic person, including, but not limited to:

1. *information relating to the race, gender, sex, pregnancy, marital status, national, ethnic or social origin, colour, sexual orientation, age, physical or mental health, well-being, disability, religion, conscience, belief, culture, language and birth of the person;*
2. *information relating to the education or the medical, financial, criminal or employment history of the person;*
3. *any identifying number, symbol, e-mail address, physical address, telephone number, location information, online identifier or other particular assignment to the person;*
4. *the biometric information of the person;*
5. *the personal opinions, views or preferences of the person;*
6. *correspondence sent by the person that is implicitly or explicitly of a private or confidential nature or further correspondence that would reveal the contents of the original correspondence;*
7. *the views or opinions of another individual about the person; and*
8. *the name of the person if it appears with other personal information relating to the person or if the disclosure of the name itself would reveal information* about the person;

In order to achieve the objective of protecting personal information, POPIA regulates the processing of personal data. "Processing" of personal data is defined in section 1 of the act as:
any operation or activity or any set of operations, whether or not by automatic means, concerning personal information, including—

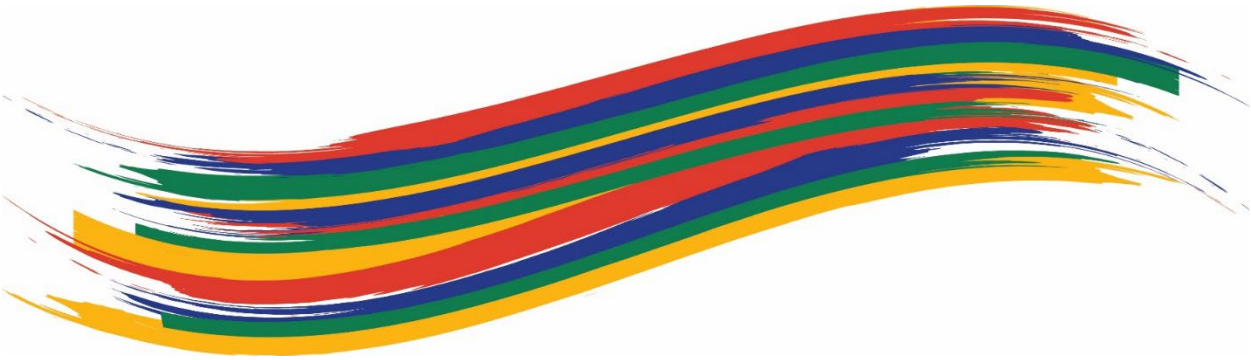
(a) the collection, receipt, recording, organization, collation, storage, updating or modification, retrieval, alteration, consultation or use;
(b) dissemination by means of transmission, distribution or making available in any other form; or
(c) merging, linking, as well as restriction, degradation, erasure or destruction of information;

Processing is similarly broadly defined and therefore it is imperative to understand that personal information can only be legally processed when certain conditions are met. There are eight conditions set out in section 4 of POPIA, namely: accountability; processing limitation; notification of collection and collection for specific purpose; further processing limitation; information quality; openness; security safeguards; and data subject participation.
Consequently, it is clear that processing of personal information is strictly regulated and that all requirements as stipulated in POPIA for processing information should be met to avoid the prescribed penalties for contraventions.

EDID-GHDI

We acknowledge our presence and work on Indigenous Territories. We respectfully recognize the persistent and unequal effects of colonization on Indigenous peoples and all Canadians.

We gratefully acknowledge funding from the Social Sciences and Humanities Research Council of Canada for this project.



Live Work Well Research Centre
University of Guelph
Attention: EDID-GHDI
501 MacKinnon Building
50 Stone Rd E
Guelph, Ontario, Canada
N1G 2W1
Email: edid-ghdi@uoguelph.ca
Website: www.edid-ghdi.ca

Social Sciences and Humanities Research Council of Canada
Conseil de recherches en sciences humaines du Canada
Canada