Submission in response to call for input by the OHCHR on study on statistics and data collection under article 31 of the UN Convention on the Rights of Persons with Disabilities.

29 October 2021

Submitting organisations:

The Africa Albinism Alliance, Standing Voice, The Albino Foundation, Positive Exposure- Kenya, Source of the Nile Union of Persons with Albinism welcome the opportunity to jointly submit their contribution to the OHCHR study on statistics and data collection under article 31 of the UN Convention on the Rights of Persons with Disabilities.

- **Africa Albinism Alliance,** established in February 2021 is a consortium of organizations working to promote – through human rights advocacy – the dignity, rights and welfare of persons with albinism and their family members in Africa. The Alliance aims to ensure that the African Union Plan of Action to End Attacks and other Human Rights Violations Targeting Persons with Albinism (2021-2031) is implemented at the national level, including through national action plans with multi-year budgets; and that the positive effects of these measures concretely advance the enjoyment of human rights by persons with albinism in the Africa region.
- **Standing Voice** is an international non-governmental organisation based in Tanzania, Malawi and the UK. Founded in 2013, it promotes and protects the rights of people with albinism and their families across Africa. The organisation works as a catalyst to amplify marginalised voices, enabling individuals to shape their own lives and futures
- **The Albino Foundation (TAF)** is an independent non-governmental/not-for-profit organisation incorporated with the Corporate Affairs Commission of Nigeria. Founded in 2006, TAF is principally an organisation established for persons with albinism, other disabilities and vulnerable groups. TAF is a special focus organization that advocates for the recognition and respect of the rights and socio-economic inclusion of persons with disability in Nigeria. Headquartered in Abuja – Nigeria, The Foundation bears a national spread with chapters across all 36 states of Nigeria and the FCT – Abuja.
- **Positive Exposure- Kenya** is a non-profit organization that exists to promote the well-being of persons with albinism (PWA) by providing an opportunity for PWA, their families and communities to celebrate diversity, challenge stigma and celebrate each individuals' extraordinary uniqueness. Positive Exposure was initiated by Jane Waithera (a young woman with albinism) inspired by the works

of Rick Guidotti with the main goal to challenge stigma, fear and discrimination and support positive social change in relation to albinism in Kenya and later to other African countries.

- Source of the Nile Union of Persons with Albinism (SNUPA) is a non-profit organization based in Jinja Uganda. it was formed by Persons living and those affected by albinism to advocate for access to quality services for this group.

Contact:

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Introduction:

The African Albinism Alliance and its allies appreciate the opportunity to provide the information below to OHCHR during the drafting of its report on statistics and data collection on persons with disabilities. This, submission will provide information on the situation in Kenya, Malawi, Namibia, Nigeria and Uganda.

Whilst the submission endeavours to provide some general information on disability data and statistics in the countries that the submitting organisations work the submissions primarily focus on data collection and statistics as it pertains to persons with albinism. The rationale for the focus on persons with albinism is that persons with albinism as a group are oftentimes not properly accounted for in disability statistics and data collection. Of particular concern is that the Washington Group Short Set (WG-SS) questions does not address albinism directly and so does not identify the people who have albinism as a distinct group. Recommendations have been made for a question to be added to the WG-SS that explicitly asks if the person has albinism. This recommendation is strongly supported by civil society groups working on albinism who have argued that identifying "albinism" as a distinct group allows for recognition of discrimination based not only on visual impairment but also based on colour/appearance which often leads to harmful practices including physical attacks. In addition, the inclusion of albinism as a distinctive category in the WG-SS also facilitates access to health for people with albinism given their high vulnerability to skin cancer. This element becomes invisible in government data if people with albinism are limited to the category of vision impairment alone.

Background: Albinism definition & Statistics in Africa

Albinism is a relatively rare, non-contagious, genetically inherited condition in which a person produces little to no melanin, resulting in little to no pigmentation, in the skin, hair and eyes. This lack of melanin often results in a pale or "white" appearance compared to other members of their family, community or ethnic group causing hypervisibility. In addition, the lack of melanin results in two congenital and permanent health conditions: visual impairment of varying degrees as well as high vulnerability to skin damage from ultraviolet rays, including skin cancer. Albinism affects people worldwide regardless of race, ethnicity or gender. Africa has one of the highest prevalence's of persons with albinism in the world.

In Africa, estimates on the occurrence of albinism range from 1 in every 5,000 people to 1 in every 15,000. In some populations in the region, including in Southern Africa, where

most of the contributing organizations are located, it may be as high as 1 in 1,000.[1] Up-to-date reliable statistics and data on albinism remains a challenge on the continent.

The UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism reports show that people with albinism in Africa experience multiple and intersecting discrimination on the basis of their visual impairment and colour.[2]

Response to the OHCHR call for information on statistics and data collection under article 31 of the Convention on the Rights of Persons with Disabilities pursuant to Human Rights Council resolution (A/HRC/43/l.34) concerning the rights of persons with disabilities.

Country focus: **Kenya**

Contributing Organization: **Positive Exposure**

Contact person for more information: Jane Waithera, Positive Exposure, Jane@positiveexposure-kenya.org

1(a).   Do you have information on country laws, policies, plans, strategies or guidelines at any level of government relating to statistics and data collection about persons with disabilities? In particular initiatives to:

- Collect statistical data in censuses or population registers on persons with disabilities (for example use of the Washington Group Short. Set of questions, please clarify if the questionnaire is used as recommended by the Washington City Group on Disability Statistics or a modified version);

  ➢ There has been a shift in the approach used by the government of Kenya to collect statistics on disability in the last years. The Kenya Population and Housing Census of 2009[3] contained questions on disability that sought to ascertain whether the person being interviewed and members of their household identified as having a visual, hearing, speech, physical, mental and other impairment. There was no clear recognition of albinism as a disability. The 2019 Kenya Population and Housing Census[4] used the Washington Group Short Set of questions. There was greater appreciation on the part of government of Kenya of the need to collect statistics on persons with albinism but using the WG-SS questions had its limitations. From our observations the effect of the WG-SS when not supplemented with

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[1] Preliminary Report of the United Nations High Commissioner for Human Rights, "Persons with Albinism," September 12, 2013 at para 14, http://www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session24/Documents/A_HRC_24_57_ENG.doc, and Esther S. Hong, Hajo Zabeed, Michael H. Repacholi, "Albinism in Africa as public health issue", BMC Public Health, vol. 6, No. 212 (August 2006). www.biomedcentral.com/1471-2458/6/212

[2] UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism. Albinism Worldwide. U.N. Doc. A/74/190 (July 18, 2019)
Relebohile Phatoli, Nontembeko Bila and Eleanor Ross, "Being black in a white skin: beliefs and stereotypes around albinism at a South African University", in African Journal of Disability, vol. 4, No. l, (2015).

[3] 2009 KENYA POPULATION AND HOUSING CENSUS (https://international.ipums.org/international/resources/enum_materials_pdf/enum_instruct_ke2009a.pdf)

[4] 2019 Kenya Population and Housing Census (

a specific albinism question is that it subsumes persons with albinism under the category of those who have difficulties seeing or under persons with multiple impairments or those who have difficulties in doing activities in daily life.[5] So, albinism ends up being counted as visual impairment, multiple or no impairment. This is unhelpful in planning and budgeting for the interventions and services for persons with albinism, who need not only ophthalmology services/interventions for instance but dermatological as well given their high susceptibility to the sun's rays. The unclear interpretation of questions and low awareness levels by enumerators also contributed to persons with albinism not being counted accurately in the last census.

- Collect statistical data on persons with disabilities in surveys such as household income and expenditure surveys, labour force surveys, demographic and health surveys or similar surveys (please provide details and the data collection tools);

  ➢ The Kenya National Council for Persons with Disabilities established under the Kenyan Persons with Disabilities Act 2003 regularly collects statistical and other data on persons with disabilities.[6] For instance they collect statistics and data of persons with disabilities on the Kenya Social Cash Transfer Programme and persons with disabilities receiving tax exemptions. They normally use categories of impairments in identifying persons with albinism, with albinism as a standalone category.

- Collect administrative data for the operation of government programs or services assessing persons with disabilities to access social protection or other benefits or as part of the Education Management Information System or Health Management Information System (please specify the disability assessment tools, e.g., International Classification of Functioning, Disability and Health; WHO Disability Assessment Schedule; among others)

  ➢ There is a challenge in the collection of administrative data in Kenya that disaggregates by disability including albinism. There are a number of points of entry of services that do not collect data on disability including some university admission and thus miss the opportunity to create more inclusive services. More forms use at points of entry need to be edited so include a question whether the person has a disability and how they can be supported in accessing that service. We did a disability sensitivity training in one University that claimed to have no students with disabilities enrolled and found 3 at the end of the session. The question had never been asked. So having a question on disability will also help in raising awareness about disability amongst service providers both private and public and destigmatise disability. People will begin to see disability as a normal part of human diversity.

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[5] https://devinit.org/resources/status-disability-kenya-statistics-2019-census/
[6] (https://www.un.org/development/desa/disabilities/wp-content/uploads/sites/15/2019/11/Kenya_Persons-with-Disability-Act.pdf)

- Promote a human rights-based approach to data collection[7], including research- and community-based data collection, to improve or develop policy in line with the Convention on the Rights of Persons with Disabilities.

  ➢ We have encountered a number of people who when collecting data on disability whether for government and other entities are insensitive. Their manner of asking question and tone can be degrading. Sometimes they just assume you have a disability and don't even ask. They don't even explain why the data is being collected or take time to ensure their questions are understood.

1(b).   What are the challenges to implementing the above?

  ➢ Disability is often still forgotten, then remembered when data is collected. It needs to be part and parcel of efforts to collect data and not an add on. There is no synchronisation of data collection on disability in the country. There is a lot of duplication in the data collected by different government departments, civil society organisations, development partners. Data is not shared across different sectors. The Kenya National Council for Persons with Disabilities in our view does not have a proper data management system in place. Data is still captured manually most times. So, they repeatedly come to the disability community to ask for the same information over and over again.

There are also not enough checks and balances on the collection of disability data. Criminals have taken advantage of this to impersonate government officials and con persons with disabilities. For instance, they have been reported cases of criminals impersonating Disability Council officials requesting persons with disability to pay registration fees in order to register them to access disability benefits. Some criminals get the details of persons with disabilities under false pretence and collect the cash transfers due to them.

There are civil society organisations that collect data of persons with disabilities for purposes of developing proposals for funding but the people don't benefit from these programmes. They sometimes use the data gathered for marketing, which in the case of persons with albinism can expose them to attacks where identifiers such as location where person with albinism stays. There is need for information of persons with albinism in light of attacks and killings in part of Kenya to be safeguarded.

2(a).   What legislative and policy measures are taken to address data protection and the implementation of safeguards to ensure protection of confidentiality and respect for the privacy of persons with disabilities?

  ➢ Data protection is poor in Kenya. There are not enough controls or checks and balances. The Kenya National Council for Persons with Disabilities even publishes lists of people they have given aid to. It's an infringement of the privacy of those people. The government doesn't expose similar data on Kenyan receiving other services so there is no reason for them to do so where persons

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[7] https://www.ohchr.org/en/issues/indicators/pages/documents.aspx

with disabilities are concerned. Persons with disabilities don't feel safe giving their details to the Council and some even opt out of services as a result. If you have albinism and collect sunscreen from the Council you may very well find a list posted on their board of all the people who collect sunscreen.

2(b).   In particular, please describe how the collection, administration and use of disability data complies with common principles such as:

- purpose specification and use limitation;

  ➢ It's not always clear when data is being collected what it's for. The people collecting data don't always provide sufficient explanation on how the data will be used.

- self-identification, including the option to disclose, or withhold, information about personal characteristics

  ➢ Not enough consideration is given to this. It is common for photos of people with disabilities are used without their consent.

- sensitive data administration, including in health, work and employment, and educational environments;

  ➢ The Kenyan government don't seem to fully consider the safety and security issues related to disability data collected. There is a casual approach to data sharing by the Disability Council. The data may easily end up in the wrong hands.

- data quality;

  ➢ The quality of the data is questionable sometimes. Data is collected at short notice. For instance, the Disability Council can require the disability community to furnish them with certain information with only a days' notice. There are many cases of persons without disabilities benefiting from tax exemptions meant to benefit persons with disabilities.

-data transparency and accountability, including accessibility of public and statistical data to persons with disabilities in a language and format, taking into account considerations such as disability, language, literacy levels and cultural background; and

  ➢ Public data on disability is not as accessible, getting the final reports has been a challenge for persons with disabilities and their representatives. Organisations are not always aware of the Protocol involved in accessing data from the National bureau of statistics.

- due diligence for third parties' collaboration.

  ➢ The government normally use sub chiefs and other local leaders in the collection of data without providing them with adequate disability training and does not always use persons with disabilities.

3.   Are indicators, including on the Sustainable Development Goals, COVID-19, among others; disaggregated by disability in general/non-disability-specific data processes, such as in census reports or research based on surveys and community-based data collection?

➢ No. In fact we have lost a lot of people with disability to Covid but this is not evident from the Covid statistics published. The government refused to recognise persons with disabilities as person at high risk and vaccinate them early. They were not prioritised.

4. Please provide information on the measures undertaken to share public data and ensure access to data for persons with disabilities, including dissemination of statistics, questionnaires, and metadata in accessible formats.

➢ The Kenyan National Bureau of Statistics does make the data they collect available to the public however the reports often use in infographics, and do not take into account the accessibility needs of persons with disabilities. There is also no targeted dissemination of data to the disability community who are interested in this data.

5. Please provide information on the role of persons with disabilities and their representative organisations, including children with disabilities, in the design, implementation, monitoring and evaluation of all measures relating to data collection, analysis, use and dissemination.

➢ Persons with disabilities and their representative organisations often participate in the design and other stages of data but the participation is tokenistic and not meaningful participation. The government will already have made the decisions and persons with disabilities are only there to endorse the decision. They are often called to consultation meetings last minute, leaving them with little time to consolidate inputs, some have no knowledge of data collection intricacies and need their capacity developed to more meaningfully engage.

Response to the OHCHR call for information on statistics and data collection under article 31 of the Convention on the Rights of Persons with Disabilities pursuant to Human Rights Council resolution (A/HRC/43/l.34) concerning the rights of persons with disabilities.

Country focus: *Namibia*

Contributing Organization: Disability expert; Chief Legal Officer, Law Reform and Development Commission Ministry of Justice & member of Support in Namibia of Albinism Sufferers Requiring Assistance (SINASRA)

Contact person for more information: Ruusa Ntinda, rntinda@gmail.com

1(a). Do you have information on country laws, policies, plans, strategies or guidelines at any level of government relating to statistics and data collection about persons with disabilities? In particular initiatives to:

The Namibian data and statistic laws include but not limited to the following:

➢ Statistics Act No 9 of 2011 provides for the national statistics system. It establishes the National Statistics Agency, the national spatial data infrastructure and incidental matters.

➢ Data collection, processing and dissemination policy and practice No. 20 of 2015\

- ➢ National spatial data infrastructure (NSDI) policy No. 103 of 2015

- ➢ Namibia quality assurance framework for statistics (NQAFS) No. 231 of 2020

- ➢ Determination of collection of statistics in relation to dwellings and other building structures for enumeration: Statistics Act 1976 No. 114 of 2010.

- ➢ The manner and specification for the capturing of spatial data, including any application for exemption from such manner or specifications. No. 404 of 2016.

- ➢ Namibian statistical systems standard for measuring "leave no one behind" N0. 233 of 2020.

- ➢ Code of practice: professional and ethical standards applicable to statistics producers 2014.

- ➢ Determination of collection of statistics in relation to household income and expenditure and regulations relating to collection: statistics Act 1976. N0. 162 OF 2009.

- • Collect statistical data in censuses or population registers on persons with disabilities (for example use of the Washington Group Short Set of questions, please clarify if the questionnaire is used as recommended by the Washington City Group on Disability Statistics or a modified version);

The most recent statistics on disability data collection was conducted in 2016 by the Namibia Statistics Agency. According to the **Namibia Inter-censal Demographic Survey** 2016 Report:[8]

Disability means physical, pyscho-social or sensory impairment that alone or in combination with social and environmental barriers, affects the ability of a person concerned to take part in education, vocational or recreational activities (National Disability Policy, 1997).

For the purpose of this survey, long term is defined as a condition lasting for more than six months, however, obvious disabilities such as legs and arms amputations, were recorded even if they happened within less than six months.

Seven types of disability were identified for this purpose: hearing impairment, visual impairment, speech impairment, physical impairment of lower and upper limbs, mental disability and **albinism. It is important to mention that the survey collected information on albinism in order to identify these groups of people for the formulation of special programmes and policies targeting this special group**.

Although disability is manifested in any form that can be categorised as either mild or profound (severe) it is important to note that the survey collected all the disabilities as per the definition above regardless of their seriousness.

Below is a link to the Namibia 2011 Disability Census report.[9]

Question 1 (b) What are the challenges to implementing the above?

- ➢ One of the challenges of the NIDS data collection survey was that it is a household-based survey, excluding the population that was in institutions at the time of the survey, such as school hostels, army/police barracks, hospitals wards, etc. Household

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[8] NIDS 2016 Report. Available at https://cms.my.na/assets/documents/NIDS_2016.pdf. Last accessed on the 26th of September 2021.
[9] https://d3rp5jatom3eyn.cloudfront.net/cms/assets/documents/Namibia_2011_Disability_Report.pdf

members residing in these institutions were only included if they live in private accommodation which constitute households.[10]

Question 2 (a) What legislative and policy measures are taken to address data protection and the implementation of safeguards to ensure protection of confidentiality and respect for the privacy of persons with disabilities?

> Namibia has not enacted comprehensive data privacy legislation. However, various sector-specific laws are in place to protect client information, including in the legal and banking sectors. Namibia recognizes the right to privacy as a fundamental human right under Article 13 of the Namibian Constitution. Accordingly, all persons have a right to privacy in their homes and communications. The right to privacy is limited as required by law and in the interest of protecting:[11]

- national security and public safety

- the nation's economy

- health and morals

- against disorder and crime

- the rights and freedoms of others

The Namibian Government is currently drafting a Data Protection Policy that, although not yet public, is expected to:[12]

- protect the fundamental rights and freedoms of natural persons, and in particular their right to privacy with respect to data processing

- protect Namibian citizens from abuse of their personal data, and

- harmonize Namibia's data protection policy and legal framework with regional and international standards to promote the free flow of personal data under conditions of assurance and trust

Further, the Ministry of Information and Communication Technology (MICT) is expected to finalize a draft Data Protection bill in 2019 or 2020.

Question 2 (b) In particular, please describe how the collection, administration and use of disability data complies with common principles:

> The NIDS 2016 was conducted by the Namibia Statistics Agency in accordance with the Statistics Act, 2011 (Act No.9 of 2011). The Act mandates the Agency, among others, to constitute the central statistical authority of the country and to collect, produce, analyse and disseminate official and other statistics in Namibia. By virtue of this Act, all information collected that could be linked to identified individuals or households was kept strictly confidential.

The survey was conducted in close collaboration with key stakeholders that form part of the National Statistics System (NSS). The collaboration took place in respect of the following areas:

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[10] Ibid.

[11] Data protection laws of the world: Namibia. Obtained from https://www.dlapiperdataprotection.com/index.html?t=law&c=NA. last accessed on the 24th of September 2021.

[12] Ibid.

i. Review of variables and questions asked in the 2011 census

ii. Contribution to the drafting of the questionnaire for the 2016 NIDS

iii. Sourced new questions from stakeholders

4. Please provide information on the measures undertaken to share public data and ensure access to data for persons with disabilities, including dissemination of statistics, questionnaires, and metadata in accessible formats.

➢ Currently through the Namibia Statistics Agency there aren't any alternative forms of data and statistics dissemination to persons with disabilities. This process can however be facilitated upon writing to the statistician general of the NSA.

5. Please provide information on the role of persons with disabilities and their representative organizations, including children with disabilities, in the design, implementation, monitoring and evaluation of all measures relating to data collection, analysis, use and dissemination.

➢ There are invites sent to various stakeholders which include persons with disabilities. These invites are for persons to with disabilities and relevant stakeholders to offer input in the implementation and evaluation of data collection. There has been a positive response from organizations of persons with disabilities in this process.

Response to the OHCHR call for information on statistics and data collection under article 31 of the Convention on the Rights of Persons with Disabilities pursuant to Human Rights Council resolution (A/HRC/43/l.34) concerning the rights of persons with disabilities.

Country focus: *Malawi*

Contributing Organization: STANDING VOICE | Malawi

Contact person for more information: Bonface Ophiyah Massah; Country Director; bon@standingvoice.org

1(a). Do you have information on country laws, policies, plans, strategies or guidelines at any level of government relating to statistics and data collection about persons with disabilities? In particular initiatives to:

• Collect statistical data in censuses or population registers on persons with disabilities (for example use of the Washington Group Short Set of questions, please clarify if the questionnaire is used as recommended by the Washington City Group on Disability Statistics or a modified version);

➢ The 2018 Nat Population [13] Census collected statistics on disability using the WG-SS questions. The Malawi Human Rights Commissioner following the publication of the Census results raised a number of complaints with the National Statistics Office received from the disability community about the manner in which the WG-SS questions were administered. Concerns had been raised that the numerators did not understand the new approach of collecting disability data. Some were completing the questions based on their own perceptions. The translation of questions into local languages was also a challenge, for instance making the distinctions of the different levels of difficulty in Chichewa a local language is linguistically difficult. Disabilities such as epilepsy and albinism were not fully accounted for in the Census.

The DPO's also collect their own data. Standing Voice[14] for instance collects data on albinism through its skin cancer programme in the communities it works like Mangochi. There are disparities between the data collected by DPO's and that collected by government. The population of persons with albinism in The Mangochi in the past 3 years according to Standing Voice stands at around 470. The data was collected through community mobilisation. The government's statistics show the population of persons with albinism at the district level at 3 million. Which doesn't add up.

- Collect statistical data on persons with disabilities in surveys such as household income and expenditure surveys, labour force surveys, demographic and health surveys or similar surveys (please provide details and the data collection tools);

  ➢ Haven't seen a lot of that in Malawi. Agencies such as UN Women have started collecting data on women with disabilities as part of their programme work.

- Collect statistical data on environmental barriers faced by persons with disabilities (please detail if you have country information on the use of human rights indicators in place to focus on the environmental barriers measured, e.g., access to public buildings and public access venues, access to information including public media –sign language interpretation, closed captioning, audio description–, access to justice independent living services, among others); or

  ➢ There have been collaborations between government and DPO's and other CSO's to collect data on barriers experienced by persons with disabilities. **For instance, Standing Voice & the Malawi Ministry of Health and Gender have been working together to collect data on access to healthcare goods and services by persons with albinism in 17 District and hope to have collected data throughout the country in the next 5 years reach all corners. Standing Voice also collects this data on human rights violations experienced by persons with albinism when it runs its clinics. Another organisation Association of Persons with Albinism in**

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[13]http://www.nsomalawi.mw/index.php%3Foption%3Dcom_content%26view%3Darticle%26id%3D226:2018-malawi-population-and-housing-census%26catid%E2%80%89%3D%E2%80%898:reports%26Itemid%E2%80%89%3D%E2%80%896
[14] https://www.standingvoice.org/

Malawi (APAM)[15] is collaborating with the Ministry of Education to collect data of learners with albinism in schools.

- Collect administrative data for the operation of government programs or services assessing persons with disabilities to access social protection or other benefits or as part of the Education Management Information System or Health Management Information System (please specify the disability assessment tools, e.g., International Classification of Functioning, Disability and Health; WHO Disability Assessment Schedule; among others)

  ➢ The government has argued that due to budgetary constraints it is not always able to disaggregate data according to disability. Cash transfer programmes, housing programmes where persons with disabilities are beneficiaries do have administrative data on disability. **The National Action Plan on Albinism for Malawi calls for more disaggregated administrative data according to albinism.**

- Collect administrative data including persons with disabilities, without discrimination, such as in birth registries, civil registries, voters registries, among others.

  ➢ Malawi IDs don't show that a person has a disability on the card. There was some debate as to whether this should be the case but the consensus was that it was not preferable. The National Registration Beaure does collect some data on disability.

- Promote a human rights-based approach to data collection[16], including research- and community-based data collection, to improve or develop policy in line with the Convention on the Rights of Persons with Disabilities.

  ➢ Generally good involvement of the disability movement in Malawi in the collection of data including the hiring of persons with disabilities as enumerators. The Federation of Persons with Disabilities in Malawi has had some training on data and statistics on disability and so are able to provide government with concrete recommendations.

1(b).   What are the challenges to implementing the above?

  ➢ Resource constraints is seemingly the biggest challenge, doing separate survey on disability or albinism is argued to be costly. There is also fear and hesitation amongst persons with albinism and their families in Malawi to participate in surveys and other data collection in light of reported attacks and killings against this group. Some families will not disclose they have a family member with albinism as a way of protecting their family member.

2(a).   What legislative and policy measures are taken to address data protection and the implementation of safeguards to ensure protection of confidentiality and respect for the privacy of persons with disabilities?

  ➢ Data collected by the National Statistics Office is highly guarded and not easy to access.

2(b).   In particular, please describe how the collection, administration and use of disability data complies with common principles such as:

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[15]

[16] https://www.ohchr.org/en/issues/indicators/pages/documents.aspx

- data quality;

  ➢ The national statistics on albinism in Malawi are higher that the statistics in most African countries. There is a sense amongst organisations working on albinism that the government may have overestimated the numbers under political pressure both internationally and locally to show a strong commitment towards the rights of persons with albinism in the country. Even the statistics published on attacks against persons with albinism by the Minster of Police are argued to be incorrect. There has been a national budget to support the implementation of the National Plan of Action on Albinism. Money allocated did not include money to collect data on albinism. Without sufficient resources the data collection is poor.

- data transparency and accountability, including accessibility of public and statistical data to persons with disabilities in a language and format, taking into account considerations such as disability, language, literacy levels and cultural background; and-

  ➢ It is relatively easy to get data on disability in the country. Government institutions however have a screening process to ascertain that you have a legitimate reason for requesting the data.

3.   Are indicators, including on the Sustainable Development Goals, COVID-19, among others; disaggregated by disability in general/non-disability-specific data processes, such as in census reports or research based on surveys and community-based data collection?

  ➢ Increasing the government and other stakeholders are talking about including albinism in the data they collect. Monitoring reports on disability rights implementation in Malawi can be silent about albinism. APAM and other DPO's have recommended to the President the need to disaggregate data Covid statistics based on disability.

4.   Please provide information on the measures undertaken to share public data and ensure access to data for persons with disabilities, including dissemination of statistics, questionnaires, and metadata in accessible formats.

  ➢ This is a major weakness. There are no dedicated workshops and other initiatives put in place to ensure disability data is accessible to persons with disabilities. Most reports produced are very technical in nature making the information out of reach.

5.   Please provide information on the role of persons with disabilities and their representative organisations, including children with disabilities, in the design, implementation, monitoring and evaluation of all measures relating to data collection, analysis, use and dissemination.

  ➢ During national surveys FEDOMA nominates youth with disabilities to be part of the data collection.

Other information:

  ➢ There is little data on children with albinism. Children are highly targeted for attacks, need early health intervention, subject to myths and superstitions and so getting statistics for this group is very important. Even limited to districts working, age brackets.

Response to the OHCHR call for information on statistics and data collection under article 31 of the Convention on the Rights of Persons with Disabilities pursuant to Human Rights Council resolution (A/HRC/43/l.34) concerning the rights of persons with disabilities.

Country focus: Uganda

Contributing Organization: Source of the Nile Union of Persons with Albinism

Contact person for more information: Peter Ogik; founder and chairperson of Source of the Nile Union of Persons with Albinism, a non-profit organization in Jinja; ogikpeter17@gmail.com

1(a).   Do you have information on country laws, policies, plans, strategies or guidelines at any level of government relating to statistics and data collection about persons with disabilities? In particular initiatives to:

- Collect statistical data in censuses or population registers on persons with disabilities (for example use of the Washington Group Short Set of questions, please clarify if the questionnaire is used as recommended by the Washington City Group on Disability Statistics or a modified version);

  - ➤ The government has collected statistics on the number of persons with disabilities in the country during the 2014 census.[1] The statistics collected focused on the common categories of persons with disabilities such as visual impairment and did not focus on albinism and put the number of persons with disabilities at 12% of the population. There are no figures on how many persons with albinism are in Uganda. The government says it has taken note of this issue. Statistics on other groups such as persons with psycho social disabilities are under estimated. The WG-SS questions are good but leave out other disabilities like albinism. The question will not help in identifying the needs of persons with albinism particularly in relation to sunscreen.

- Collect statistical data on persons with disabilities in surveys such as household income and expenditure surveys, labor force surveys, demographic and health surveys or similar surveys (please provide details and the data collection tools);

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[1] https://www.ubos.org/wp-content/uploads/publications/03_20182014_National_Census_Main_Report.pdf FOR Pwds page 22, 80-83 focuses on disability.

THE ALBINO FOUNDATION

Response to the OHCHR call for information on statistics and data collection under article 31 of the Convention on the Rights of Persons with Disabilities pursuant to Human Rights Council resolution (A/HRC/43/l.34) concerning the rights of persons with disabilities.

Country focus: *Nigeria*

Contributing Organization: The Albino Foundation, Nigeria

Contact person for more information: Jake Epelle, CEO/Founder of The Albino Foundation Nigeria; epellejake@gmail.com

1(a).   Do you have information on country laws, policies, plans, strategies or guidelines at any level of government relating to statistics and data collection about persons with disabilities? In particular initiatives to:

- Collect statistical data in censuses or population registers on persons with disabilities (for example use of the Washington Group Short Set of questions, please clarify if the questionnaire is used as recommended by the Washington City Group on Disability Statistics or a modified version);

- ➢ Yes, Nigeria has just started collecting data on disability and plans to collect more in the upcoming census. To date data collection has been sporadic and not holistic. Different actors both government and non are collecting pockets of data. Development partners including the World Bank and the EU have been spearheading efforts to collect data including by funding data collection. The Albino Foundation currently has a grant to help identify persons with albinism eligible for voting and encourage their inclusion and participation in political processes. It is also embarking on a baseline study on persons with albinism. The data is to be collected in 9 States. Since the WG-SS of questions doesn't focus on albinism when we use it in data collection, we must ensure that it is tailored and adapted to account for persons with albinism.

- Collect statistical data on environmental barriers faced by persons with disabilities (please detail if you have country information on the use of human rights indicators in place to focus on the environmental barriers measured, e.g., access to public buildings and public access venues, access to information including public media –sign language interpretation, closed captioning, audio description–, access to justice independent living services, among others); or

- ➢ The government not doing much, most data collection on disability is left to CSO's.

1(b).   What are the challenges to implementing the above?

➢ Ignorance on the part of officials at the National Bureau of Statistic and a lack of prioritisation of disability data. The Bureau is very effective and vibrant when it comes to collecting economic related type of data. Not as much on social related data. Disability data is not high on the political agenda. Government doesn't appreciate the need and value of this data collection. . DPO's have been lobbying for greater collection of disability data.

2(a).   What legislative and policy measures are taken to address data protection and the implementation of safeguards to ensure protection of confidentiality and respect for the privacy of persons with disabilities?

➢ The government is quite careful about the collection & usage of data. DPO's like the Albino Foundation who collect data try to be also vigilant about protecting raw data and not disclose personal information that can identify people.

2(b).   In particular, please describe how the collection, administration and use of disability data complies with common principles such as:

- self-identification, including the option to disclose, or withhold, information about personal characteristics

➢ Most data collected is done so with free and informed consent. Know of situations where persons with disabilities did not wish to participate in the data collection and their wishes were respected.

- data quality;

➢ This is an important issue to all us. Both quantitative and qualitative data must be of good quality. As DPO's we have been calling for standardised instruments for data collection.

3.   Are indicators, including on the Sustainable Development Goals, COVID-19, among others; disaggregated by disability in general/non-disability-specific data processes, such as in census reports or research based on surveys and community-based data collection?

➢ There is something going on that, still work in progress.

4.   Please provide information on the measures undertaken to share public data and ensure access to data for persons with disabilities, including dissemination of statistics, questionnaires, and metadata in accessible formats.

➢ There is some sense of accountability on part of government. They are data validation processed in place.

5.   Please provide information on the role of persons with disabilities and their representative organisations, including children with disabilities, in the design, implementation, monitoring and evaluation of all measures relating to data collection, analysis, use and dissemination.

➢ The government and DPO's designed a strategy around engagement of persons with disability as data collectors, put them in the field during national censuses and other such surveys. This is an empowering model of data collection.