

KENYA LEAVE NO ONE BEHIND INITIATIVE

POLICY BRIEF

An Overview

March 2021

Preamble

This policy brief overview summarizes the proposed policy direction to address gaps, and the root causes of marginalizing factors identified by Kenya Leave No One Behind Initiative (February-April 2021) research on disabilities. Disability itself is fraught with perceptions of unquestioned beliefs and myths underpinned by superstition, suspicion, stigma, biases, stereotypes, prejudice regarding its root causes, including the reasons behind its prevalence. Differently, it is clouded by lived experience and feelings, of shame, guilt, fear, regret, and doubt at the household and personal level.

Perceptions and notions on Disabilities

At the community level, the dominant notion points out that, disability is primarily perceived as a curse to the family, and family group where a child with a disability has been born. Disability is also perceived to occur due to sorcery and witchcraft, bad omen, or having occurred because one of the parents (usually the female) has tendencies to be or becoming a witch or sorcerer.

Regarding the person so born with or who has disabilities (disability might occur during life even when one was born without disabilities), the perception is that the person is incapable, unproductive hence, due to their dependency on other family members, they are regarded as unimportant, not valued, and not valuable to the household, family, and society as a whole. In this regard, their views, opinion, thoughts, or inputs are not sought.

As a result, these perceptions indirectly point to aspersions that persons with disabilities do not have rights, cannot access rights, do not deserve protection, dignity, and justice. The research findings indicate that majority of community and household members were aware of the concepts of rights and human rights. They are also aware of the need for inclusion, participation, and inclusion of persons with disabilities in processes of family community and society. However, the research also found that the communities and households had limited appreciation of how this would become applicable creating space for persons with disabilities.

Communities and households seem to still struggle with how to create and enforce access to rights, protection, dignity, and justice for persons with disabilities. Households and communities are divided on whether and when it is appropriate for persons with disabilities to have a say, leaders make decisions affecting others around them and the community. This perception persists even when lived experience in communities has examples of stable households headed by persons with disabilities. At the household level, often persons with disabilities were not accorded full rights, especially to inheritance.

The perceptions also affect the types and manner of relations, association, interactions, and transactions with persons with disabilities in society. This points to factors on the degree to which persons with disabilities are isolated, excluded, and some of them completely secluded from access to quality and resilient wellbeing, which results in living in undignified conditions of life.

View and lived experience

This aspect has two factors; the view and lived to experience persons with disabilities, and then the view and lived experience of the caregiver to a person with disabilities.

Persons with disabilities have views about themselves much as a society also has views about them. The aspect of dependency underlies the views of self and lived experiences as a person with disabilities. Persons with disabilities themselves pointed out that, being in that condition is frustrating and causes one to feel they carry an invisible burden. It fills them with feelings of self-doubt, stigma, and fear. Often the one experiences regret over life as they perceive themselves as a burden to others around them.

Persons with disabilities need support in more ways and aspects than persons without disabilities. Due to this, they are dependent. This seems to undermine their view of self and affects their self-esteem. Dependency as a factor they live with causes their approach to other people to be one of seeking sympathy.

Low self-esteem underlies self-confidence and the ability to affirmatively express oneself. Where self-esteem and self-confidence are low, this tends to undermine how persons with disabilities present themselves to others, and how they raise, voice, and present issues related to their experiences, needs, and priorities about themselves and their situation.

On the other hand, caregivers of persons with disabilities, whether the caregivers are parents; relatives, or hired caregivers have a particularly different life experience than other persons in the household. They are always focused and concerned about the one they care for among other important aspects of their life. This has influenced and affected their worldview. The view of themselves as family members and caregivers often encounters stigma due to their association with persons with disabilities. Part of it is shared with the foregoing view that persons with disabilities have about themselves. Due to the obligation of caregiving of another life, caregivers seem to experience stigma by association. This leaves them with similar feelings of discrimination and marginalization the persons with disabilities face.

They also view themselves as having a burden (heavy, demanding responsibility), and that weighs them down mentally and emotionally. This context cannot let caregivers live lives to the full, as would, other persons in households without persons with disabilities. Many of the caregivers spend most or all of their time taking care of persons with disabilities and are left with no time to attend to their own needs. As a result, they are not fully economically productive and in other fields, as they are unable to exploit their full potential, which possibly contributes to poverty, hence a tendency to seek assistance through handouts or quick short-term solutions to livelihood needs.

As caregivers spend most or all of their time caring for persons with disabilities appropriate types of livelihood options for caregivers are needed. The livelihood options should be of nature and type caregivers can engage to earn a decent living sustainably to be resilient, while at the same time they facilitate caregivers to persons with disabilities to be close to the person they care for.

The context of a caregiver is also limited as dependent on their level of education, livelihood competencies, and income-earning capabilities. It is also greatly influenced by the type of disabilities of the person or persons they care for. It was evident that caregivers need to plan their time and life around being available to support and care for persons with disabilities. "It is a full-time occupation", as one caregiver in Kibwezi observed.

A caregiver of persons with disabilities has perhaps more confined livelihood options in life as they might not take options that require them to be out and away from the household for long periods. "My occupation and employment in life is this person and all the time I have to be available because, I do have to know what they will need next, and do my best to provide it", remarked a caregiver in Taveta.

With better recognition that caregiving is full-time engagement, it might be useful for households and programs designed to support caregivers to include options for home-based caregiving where there is more than one member in the household giving care. Options of rehabilitation and training the persons with disability for self-care are also open as possibilities in this case.

Introduction

The Constitution of Kenya 2010 is specific with regards to the rights of groups of the population that face specific risks and have different needs throughout their life cycles such as persons with disabilities, the elderly, children, the youth, and most vulnerable members in the community, minority groups, and marginalized groups.

The Constitution of Kenya 2010 Article 43, ref. Article 43(3) avers that the State "shall provide appropriate social security to persons who are unable to support themselves and their dependents"¹.

Article 21 commits the state to work towards the progressive realization of the social and economic rights and binds the State to "observe, respect, protect, promote and fulfill the rights and fundamental freedoms in the Bill of Rights." This article mandates the state organs and public officers to address the needs of vulnerable groups within society, including women, older members of society, and persons with disabilities, children, youth, and members of minority or marginalized communities. The clause does not directly on how the vulnerable groups within society are to be identified.

¹<http://www.kenyalaw.org:8181/exist/rest/db/kenyalaw/Kenya/The%20Constitution%20of%20Kenya/docs/ConstitutionofKenya%202010.pdf>

Kenya's development blueprint, its Vision 2030², which aims at "providing a high quality of life for all its citizens by the year 2030" and further advocates in its social pillar for "a just and cohesive society with social equity in a clean and secure environment".

In line with Kenya's Social Protection Policy 2019, the government at the national and county level is committed to providing social protection in a framework of 'set of policies, programs, interventions and legislative measures aimed at cushioning all Kenyans against poverty, vulnerability, exclusion, risks, contingencies and shocks throughout their lifecycles, and promoting the realization of economic and social rights.

The foregoing premise is in line with Agenda 2030, Sustainable Development Goals, and subsumes the principle of Leave No One Behind³.

However, it is noted that Social Protection in Kenya is not a devolved function. It is coordinated by the national government through a range of government organs, departments, and agencies. At the county level, social services are delivered via departments of education; health; social services, culture, gender, and children; labour agriculture, public works, and soil and water conservation.

The devolution of policies and national frameworks to the county level to guide relevant units of government on how to deliver social protection has been useful. It is observed that the devolution of the policies provides a wide range in the variety and variance of the models of execution and cohesion in the social protection agenda. Another observation is that not one county provides social security the same way as another. This notwithstanding, Counties have different plans, programs, and budgets in place that address social protection related to disabilities. Despite this, it was also observed that budgets on disabilities tended to be generic and not targeted to types and classifications of disabilities. County budgets on disabilities also tended to be minimal and generic or got easily reduced when government finances were low.

Summary of Key Findings

1. Assessment Identification and Classification of Disabilities

The foregoing notwithstanding, disabilities are of a wide range and manifest in different forms. It is on this basis that assessments are carried out. Based on assessments, the procedures for assessment, identification, classification, and registration of persons with disabilities are done. The research found that this service normally requires more than one individual assessor to complete the process. A combined team of assessors is needed for the assessment to be done proficiently and effectively. For the most part, there aren't enough competent persons professionally and technically at the county level to sustain an ongoing process for this service. As a result, the counties do not have plans to reach out to communities where the need for this service is greatest to carry out household-based service delivery in this aspect.

Assessment, identification, and classification of disabilities have increasingly become important to provide person-centered caregiving and services. Currently, at the county level, there are very few health facilities with the capacity to offer this service that continues to meet the needs at the county level. On the other hand, the classification and registration process takes time as it is centralized nationally. As a result, the process to obtain registration cards takes a lengthy period. When the registration cards arrive at the county, often they take time to reach the due holders as the card does not identify where the holder resides.

Given the mobility challenges experienced by persons with disabilities, the mechanism for identification and registration should be varied and made shorter in terms of process as well as in terms of access points. An option to this could be to induce mechanisms of certified centres that offer services in assessment, identification, and classification located in places persons with disabilities have access as offering continuing services.

At the same time, the process for obtaining registration cards could be digitized and linked to the certified assessment, identification, and classification centres making registration cards issuable at County and Sub-county levels. The period of the validity of the registration card for disabilities should also be extended card from 5 to 10 years.

²<https://vision2030.go.ke/>

³UNDP (2019). <https://sustainabledevelopment.un.org/content/documents/21252030%20Agenda%20for%20Sustainable%20Development%20web.pdf>

It is in this backdrop that this policy brief is developed. The policy brief proposes to provide scope to address aspects of data collection on disabilities, address factors limiting caregiving, and access to the assessment, identification, classification, and registration services, and enhance the disaggregation of the types of data collected on diabetes to provide the basis for focused caregiving and service delivery to persons with disabilities and the most vulnerable in society.

Social protection of persons with disabilities and the most vulnerable in society is the focus of this Policy Overview. The policy brief is informed by a research in Kenya that sampled 4 counties to research on the status of disabilities under the theme, Sustainable Development Goals - Leave No One Behind. The research had six objectives a summarized below:

Objective 1: *Map out organizations that are planning to conduct surveys to include questions on inclusiveness and meaningful participation*

Organizations found to have plans to conduct Surveys to include inclusiveness and meaningful participation at the county level were, the National Council of People with Disabilities in Taita Taveta (collection of disaggregated disability data at household level riding on on-going vulnerability study), Makueni Department of Gender, Culture, Children, and Social Services. The Kenya National Bureau of Statistics indicated that it has the capacity at the county level to undertake and or commission specific data-related studies in collaboration with any department or actors interested in data-related needs.

In Taita Taveta, World Vision was in collaboration with the National Council of People with Disabilities. The African Medical Research Foundation, Association for the Physically Disabled of Kenya, and United Disabled Persons of Kenya, also provide some interventions nationally although not n a continuing basis. The Kibwezi Disabled Persons Organization (Mokena County focus) also provides some interventions in Kibwezi Wes Sub-county.

Objective 2: *Establish existing programs and projects, systems, and policies that allow or hinder meaningful participation of the different social groups in the implementation of SDGs through desk review.*

Aspects that hinder meaningful participation occurred due to limited dissemination and use of the Disability Mainstreaming and sensitivity approaches. Disability-sensitive planning and budgeting as an approach to inclusiveness did not always engage persons with disability as mobility inhibited them and also the forums for this process were far from the local level accessible to persons with disabilities.

There was also hindrance caused by low awareness, and lack of information among persons with disabilities on roles they can play in forums focusing on county planning budgeting. The exits a low level of engagement and participation of persons with disabilities at the household and community level, as the views and opinions of persons with disabilities seemed not to be highly valued and recognized. Caregivers were particularly excluded from forums and spaces to participate and express the conditions and situations faced by persons with disabilities they care for.

Objective 3: *Examine existing participation mechanisms for Persons with Disabilities in Voluntary National Review (VNR) reporting and county budget formulation.*

Overall in all the counties under the study, there was evidence that persons with disabilities and the majority of caregivers have a very low level of awareness and lack information on Voluntary National Review as a process, and also lack of knowledge on their roles in the process. In this regard, there was very limited participation and those who had information tended to be only a few elite persons with disabilities.

Objective 4: *Determine existing inequalities that lead to exclusion and considering intersectional disadvantages through systemic literature review.*

Most gaps identified by the research fall under this objective. The gaps are deliberated n in the below section on "Practice and Policy Gaps".

Objective 5: *Gather qualitative data/commission research to close out knowledge gaps on drivers and level of marginalization among marginalized groups.*

Knowledge gaps identified by the research and possible viable actions for further research aspects are profiled below under the relevant section

Objective 6: *Review national and county planned policies, strategies, and programs that the project can influence at the drafting stage.*

Relevant planned policies and policy gaps at the national level that could be influenced include devolution of the assessment identification, classification service to persons with disabilities; the digitalization and devolution of the registration process for persons with disabilities (to be similar to issuing of national ID). The strategies and approaches at the county level that can be influenced have been addressed below under the profile of the key gaps by the statements on "Needed Action to remedy gap". The policy aspect is addressed below under "Policy Action".

2. Practice and in Policy Gaps

The findings of the research identified some key gaps in practice and policy implementation.

- Among the key gaps in the *function and role of caregivers to persons with disabilities*. These functions and roles were not adequately addressed in policy and planned strategies, program initiatives, and budgets. The livelihoods and wellbeing of caregivers supporting persons with disabilities are in jeopardy as caregivers themselves are not directly addressed in the context of their real-life situation on livelihoods, access to resources, and income.

Needed Action to remedy gap: *At the county level, in line with citizen engagement, social inclusion, and disability mainstreaming, guidelines, include the function and roles of caregivers in the social inclusion and disability mainstreaming frameworks at the county level, and create a new policy with a clause that recognizes the function of caregiving with guidelines on quality of care, and benchmarks for tracking and monitoring of household caregiving.*

- The second key gap is *access to assessment, identification, and classification of disabilities and registration cards* for persons with disabilities for enumerating need-specific data to guide the planning (technical, budgetary, and service delivery options) for the delivery of the most relevant types of services, and registration of persons with disabilities. There is an inadequate number of competent disability assessment, identification, and classification personnel at the county, in levels where the service is most needed viz. health, education, law enforcement, protection, access to rights, and delivery of justice. Often people with disabilities wait for a long time or are denied access to protection, rights, and justice by those in position to address these aspects -local public administration, law enforcement, and the justice system.

Needed Action to remedy the gap: *Create a dedicated technical team of professionally competent personnel at the county level to strengthen the capacity of accessible facilities closer to communities to offer services continually. This team should deliver assessment, identification, classification; and registration identification cards for persons with disabilities closer at Sub-county and Ward level continually.*

- The third key gap is the *types, quality, and quantity of disaggregated disability data available at the county level* to depict the types of disabilities, classification of severity of disabilities, age locality where persons with disabilities reside, etc.

Needed Action to remedy gap: *For purposes of disability-sensitive planning, budgeting, engagement, participation, and inclusivity; collaboration with Kenya National Bureau of Statistics, National Council for Persons with Disabilities, relevant actors with a priority focus on disabilities, carry out a process that deepens disaggregation of disability data at County, Sub-county and Ward level building on current 2019 Census Data.*

- Fourthly, *County budgets did not adequately indicate effective use of disability-sensitive county planning and budgeting* interventions as the plans budgets disabilities tended to be generic on disabilities. Available documented plans and budgets were tended to be small and not specific to the classification types of the disabilities or the relevant services needed to address and support persons with disabilities as they purport to target. The budgets were also easily reduced when funds in the county were low and this limited the efficacy in providing for the professional, technical elements of disabilities and hinders continuity in service delivery thus hindering the counties from addressing specialized aspects of disabilities adequately.

Needed Action to remedy this gap: *Improve and enhance the engagement, participation, inclusion, and involvement of persons with disabilities in processes focusing on disability-sensitive county planning, budgeting, and interventions at all levels. This should be guided by disability-specific priorities, that promote continuity in service delivery on disabilities with adequate need-based budgets.*

- And fifthly, *persons with disabilities and caregivers to persons with disabilities were not engaged adequately hence did not participate appropriately in relevant forums, platforms, and levels; and they were always faced with a social situation and demand of, "burden of proof" when it came to issues of disabilities. This was noted to be the case whether it had to do with proof of disability by type or requirement in access to rights, protection, or access to justice where violations had occurred.*

Needed Action to remedy gap: *For purposes of "Leave No One Behind, social inclusion and citizen engagement, enhance the level of awareness, participation, and access to forums by persons with disabilities and caregivers in local county forums.*

3. Policy Action

The research encountered and interacted with many useful policies and frameworks promoting aspects of inclusion, participation, empowerment, a portrayal of disability, sensitivity, and mainstreaming of disabilities in Kenya. It also identified several opportunities counties have taken to address some of the gaps inherent as identified.

In Taita Taveta County, for instance, the county NCPWD Office was working with relevant county departments, other actors, and stakeholders to undertake an in-depth data collection that would be useful in identifying persons with disabilities, where they live and create a databank and baseline for use in guiding the process of guiding technical plans on the identification and assessment for classification of disabilities by type and severity in the county.

In a different setting, the Makueni County the Department of Social Services, Protection, Children, and Gender was in the process of developing a policy to complement its social protection policy draft already in place. In addition, the county had a developed tool for collecting data on disabilities to complement the KNBS data on disabilities as in the KPHC Dataset (2019)⁴. The efforts in the counties serve as an indication that counties can address the gaps, determine measures and solutions for addressing the gaps identified.

In all the counties under the research, relevant county departments work with NCPWD Office, other actors, and stakeholders to address disabilities. At the time of the research, some plans on disabilities were in specific County Integrated Development Plans, and some were included in the specific County COVID-19 response strategies. This notwithstanding, there was no evidence indicating the level of engagement persons with disabilities had in the development of the documents, plans, budgets, and strategies.

Apart from self-help groups, social cash transfers, and the intermittent distribution of assistive devices and appliances and the general health and education services, there were very few evident programs, projects, and strategies that the counties had initiated at Sub-county or Ward level. The youth and economic empowerment programmes were reported not to include persons with disabilities adequately. Part of the reasons identified for this state of affairs included exclusion, inadequate dissemination of the right information to persons with disabilities, access challenges due to inadequate mobility, and also a low level of education among persons with disabilities. In this regard, research data indicate that persons with disabilities were not aware of interventions that targeted or provided access to opportunities for engagement and participation. This would indicate the need for added effort in disseminating Disability Mainstreaming and sensitive approaches and information and knowledge sharing to promote adequately inclusive citizen engagement at all relevant levels

The research identified that the landscape and architecture of policies and key guides on how to address disabilities had an adequate provision in documents for the time being. There seem to be limitations in the impetus at the national and county level to roll out disseminate and implement a well-organized and systematically coordinated plan on disabilities in line with the policies, frameworks, and guidelines in place. At the same time, some key aspects are not covered creating gaps under the existing policy architecture and these are highlighted here to guide the policy formulation process to address the gaps.

⁴KNBS (2019). *Kenya Population and Housing Census Dataset*

It is the submission of the research team that, there is a clear need to advocate for the implementation of the policies, frameworks, and guidelines provided for disabilities to the level where persons with disabilities have adequate support. This will facilitate their full participation and access to their rights, protection, justice, and facilitate them to enjoy their dignity as full members of households, communities, society, and full citizens in the county and the County.

The research team also noted that current policies, frameworks, and guidelines in the disability sector were silent on caregivers to persons with disabilities. This is an aspect possibly for a new policy in the disability sector to complement the current situation where the caregiver is excluded by omission.

Overall Needed Action: *There is a need for a County advocacy policy that drives affirmative action at the national and at the county level to ensure persons with disabilities and caregivers have adequate access to services and support, while also promoting the to exploit their full potential in productivity, and in full inclusion and active participation as equal members of their households and communities in the counties.*

In this connection the policy should address itself to:

- The creation of a technically competent set of criteria, standards, and benchmarks by which to assess, identify and classify different types, ranges, and severities in disabilities and peg them to a person-centered classification. In addition, the policy must determinedly guide on specific multiple access localities where the services can be reached at the county level. Designing and describing these will require definitions and criteria, benchmarks, and standards of quality that affiliate the tracking and monitoring of service delivery as intended.
- Determine the types of human resource, technical, social, psychological and otherwise that must be in place at the county level for an effective professional assessment, identification, and classification process. This will also guide the determination of the set up of standards of the venues to be used for systematic assessment, identification, and classification. This will lead to the determination of tools, facilities, equipment, utilities required for an ongoing process at the county level closest to where the service is most needed.
- The policy to address itself to caregiving and caregivers, to highlight the nature of care, types of care, and attributes of effective caregiving, and propose an outreach service to support household caregivers, while at the same time monitoring the quality of life of particular persons with disability. Caregivers will be reached for orientation enhancement of awareness, knowledge, and understanding of disabilities due to the process of creating disability classifications. This will also be a measure to monitor caregiving at the household level as part of access to rights.
- Address aspects of interpersonal communication, public relations, and other relational aspects at public, private spaces, including service and support centres where persons with disabilities are not regarded or respected to provide guidelines. This will require re-orientation in line with the standards and benchmarks based on criteria and charter of caregiving, service, and support to persons living with disabilities. This will require re-orientation of personnel, the appointment of new levels that did not exist as disabilities space was not person-focused. The policy will create new slots of jobs that need competent skills in a range of new ways.