About the book

This groundbreaking work, *Disability Rights Movement in Nigeria: The Beginning, The Now and The Future,* chronicles the three-decade evolution of disability activism in Nigeria. Using experiential evidence and a witness-based storytelling approach, the book documents the struggles, achievements and key milestones of our movement, culminating in the landmark Discrimination against Persons with Disabilities (Prohibition) Act of 2018.

The book reminds readers of the urgent need to end the perpetual discrimination and exclusion faced by Nigeria's estimated 36 million persons with disabilities. It amplifies the voices of activists and leaders, shifting the narrative from charity and misfortune to human rights and inclusion.

As the first chronicle of JONAPWD's evolution and journey, it is a significant contribution to disability inclusion in Nigeria, launching an institutional memory for the future of the movement. Readers will gain a deep understanding of disability rights issues, the mechanisms for promoting full participation, and effective ways to remove societal barriers. It provides guidance for policymakers, development partners, the media, and the rest of the population (the public) in working towards an equitable and accessible Nigerian society.

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DISABILITY RIGHTS MOVEMENT IN NIGERIA
The Beginning, the Now and the Future

JONAPWD

DISABILITY RIGHTS MOVEMENT IN NIGERIA

The Beginning, the Now and the Future

MacArthur
Foundation

Disability Rights Movement in Nigeria

The Beginning, the Now and the Future

Abdullahi Usman Aliyu
Ekaete Judith Umoh
Olumide Olaniyan

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FOREWORD

It is with profound pride and hope that I write this foreword to a book that so beautifully captures the heartbeat of our movement, ***the Nigerian disability rights struggle***. For decades, those of us who have walked this road know that it has never been an easy one. It has been a journey of persistence, of resilience, of voices refusing to be silenced, and of people insisting on visibility, dignity, and equality.

This book is not just a documentation of our past; it is a living testimony to how far we have come—from the days when disability was viewed through the lens of charity and pity to this era of rights, inclusion, and active citizenship. Each chapter carefully unfolds a layer of our collective experience as persons with disabilities, as advocates, as dreamers, and as nation-builders.

In the opening chapter, the *Evolution of Disability Discourse in Nigeria* brings to life our shared history from obscurity to recognition. It charts the transformation of ideas, language, and activism that shaped how the Nigerian state and society perceive disability today. The deeply personal accounts of *Abdullahi Usman Aliyu* and *Ekaete Umoh*, two distinguished national presidents of JONAPWD, that follow, remind us that leadership within the disability community has always been born of lived experience, courage, and love for our people. Their voices humanize our policies, turning statistics into stories and advocacy into passion.

Next is a charge to burst entrenched myths, redefine what disability truly means, and compel the reader to see that disability is not a lack but a form of diversity, a dimension of human experience that enriches our collective existence and challenges ableism. The narrative unfolds into our organizational history, tracing the uncharted routes that led to the birth and sustenance of JONAPWD, our national umbrella body. I find this particularly moving because it tells the truth: our progress was never linear, but our resolve was unbroken towards an inclusive, lateral future.

The aspects of reflection on inclusion, gender equity, and representation are reminders that disability rights cannot exist in isolation from other struggles for justice. The emphasis on gender equity, social inclusion, and leaving no one behind resonates deeply with our continuing work at the MacArthur Foundation and beyond to ensure that all voices, particularly those of women, youth, and children within intersectional contexts, find equal space at the table of impact.

I am intrigued by the examination of Nigeria's journey with the *UN Convention on the Rights of Persons with Disabilities (UNCRPD).* We are reminded that treaties alone do not bring change; people do. Yet, the work celebrates, as it should, the monumental step of our nation's ratification and its translation of the convention into the *Discrimination Against Persons with Disabilities (Prohibition) Act of 2018*, a victory we all share. The concluding part of this work is particularly impressive as it brings a perfect blend of reflection and vision, interrogating the present challenges of JONAPWD, the achievements that give us hope, and the partnerships that promise a more inclusive tomorrow. Most inspiring, the book closes with a call to sustain passion and purpose —the twin forces that have carried our movement through decades of advocacy.

The reader must not miss the Supplementary part of this book, which offers a practical guide, a gift to the next generation of disability organisations and advocates. It embodies the spirit of continuity, mentorship, and shared responsibility that is at the core of our movement.

This book is more than a chronicle; it is a mirror and a map. It mirrors our struggles and triumphs, and it maps the road ahead for those who will continue this work when we are gone. For policymakers, it offers insight. For allies, it offers understanding. For young persons with disabilities, it offers hope, proof that their dreams are valid and their voices powerful.

As one who has stood shoulder to shoulder with many of the pioneers of the disability rights movement in Nigeria, I am filled with gratitude and pride. May this work inspire renewed commitment to build a Nigeria where every person with a disability is not only seen but valued, not only included but empowered.

This book is a celebration of resilience, of identity, and of the unstoppable spirit of persons with disabilities in Nigeria. Let this foreword serve as both a salute and a promise, a salute to those who have paved the way, and a promise to those who will carry the torch forward.

Amina Salihu, PhD.

PREFACE

This book documents the evolution of the disability rights movement in Nigeria. It highlights the movement's origins, growth, and significant milestones that culminated in the enactment of the Discrimination Against Persons with Disabilities (Prohibition) Act of 2018. It also includes stories about how our community mobilised to ensure the effective implementation of the Act. The work captures real stories from individuals involved in the disability rights movement in Nigeria, though largely at the national level, and to some extent at the sub-national level.

The Joint National Association of Persons with Disabilities (JONAPWD) is an umbrella body with subdivisions across the thirty-six states and the Federal Capital Territory (FCT). The book offers a detailed account of JONAPWD's struggles and achievements. It also captures key lessons and aspirations for the future.

Using historical narrative methods, the book tracks the origins and development of disability rights movements in Nigeria. It highlights key accomplishments of JONAPWD, as the umbrella body and national organisation of persons with disabilities in Nigeria. It focuses on its core actions, events, and roles in the significant events for the passage of the Discrimination Against Persons with Disabilities (Prohibition) Act 2018 at the national level. This came after several failed attempts since Nigeria's return to democracy in 1999.

The book amplifies voices of persons with disabilities, activists, leaders, and organisations of persons with disabilities. It is a call for disability inclusion throughout society. This helps society better understand the importance of, and mechanisms to be used in, promoting the rights of disability community in Nigeria. This is not a formal research report, but a narrative account by the current and immediate past presidents of JONAPWD, Abdullahi Usman Aliyu and Ekaete Judith Umoh respectively. Other persons were consulted to provide testimonial evidence and validate aspects of the record. Nonetheless, this remains largely an account of JONAPWD's journey as narrated by its current president, and his immediate predecessor mentioned above.

The work explores witness-based storytelling and personal testimony approach. This is experiential and evidence-based information sharing. It helps readers follow JONAPWD's tale. While disability issues and discourse have been in existence in Nigeria prior to the emergence of JONAPWD, we have been co-travellers on the journey as the current and immediate past presidents of the association.

From its inception, JONAPWD has had five presidents. Ekaete Judith Umoh, my immediate predecessor, and I, Abdullahi Usman Aliyu, the current president, are the two surviving presidents. Three former presidents—Barrister Philip Ibrahim, Prince Paul Adelabu, and Barrister Danlami Basharu—have passed on. May their souls continue to rest in peace. To ensure that this book becomes a key tool for advocacy, additional materials were sought to enrich the work from JONAPWD's records and other sources.

This helps capture an overview of the relationship between the disability rights movement, disability inclusion, and the perception of the rest of the population regarding disability discourse. It includes responses to disability generally in Nigeria. For those that might not be familiar with disability terminology, 'the rest of the population' means people without disabilities. It is not 'normal people', 'healthy people', or 'able-bodied' people. Persons with disabilities are also normal, able-bodied, and healthy. Everyone experiences ill health at some point in their life—whether they are persons with disabilities or not. We will discuss this at length as we progress with this work.

Now, back to our discussion. The book tracks the cultural, social, and political roles of JONAPWD in promoting disability rights in Nigeria. The background was broadened through secondary analysis of the impact of disability laws and actions in Nigeria. This uses the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) articles to guide the process. The UNCRPD was adopted by the UN General Assembly on 13 December 2006; it was opened for signature on 30 March 2007.

This book will benefit disability rights activists, disability inclusion researchers and students, Organisations of Persons with Disabilities (OPDs), Organisations for Persons with Disabilities (OfPDs), donors, national and international civil society organisations, academic community, policymakers, legislature, ministries, departments and agencies (MDAs), disability community members, and the media. It will guide these stakeholders in their work with persons with disabilities and the rest of the population. Moreover, individuals within the rest of the population could read the book to improve their knowledge of disability rights issues in Nigeria and beyond.

The manuscript was further peer-reviewed by the JONAPWD secretariat team, and selected persons with disabilities involved directly in JONAPWD's formation, especially during the early days of the movement.

This book is part of a whole, as no single book could contain the story or history of an important association such as JONAPWD. This is especially true when capturing its evolution, successes, challenges, and lessons. Moreover, JONAPWD exists across the thirty-six states of the federation and in the FCT, with its national headquarters in Abuja. The story is co-authored by Abdullahi Usman Aliyu, the current president of JONAPWD, Ekaete Judith Umoh, the immediate past president of JONAPWD, and Olumide Olaniyan, a governance and disability inclusion expert of over two decades.

Disability inclusion issues are grassroots issues. The majority of persons with disabilities in Nigeria, and across many developing countries, reside in grassroots locations and other hard-to-reach communities. Due to the prevalence of discrimination against our people across different spectrums, we do not have access to quality education when compared with the rest of the population. JONAPWD will, in the not-too-distant future, work towards reproducing this book as a short audiovisual documentary in Pidgin English and a few other Nigerian languages to be systematically selected.

The short audiovisual narration, not exceeding ten minutes, will be produced and disseminated through new media, such as, WhatsApp, to reach people in hard-to-reach communities. This will reach the digital generation and other audiences who could have been excluded. Other assistive devices will be used to ensure no person with disabilities is left behind. Disability inclusion stakeholders may build on this work using various methods in collaboration with JONAPWD secretariat or independently.

Notwithstanding any identified gaps, this book is an important synopsis of central events and activities that have contributed to reducing discrimination against our community in Nigeria.

While there are books on disability issues out there, there is hardly any book about JONAPWD, nor is there any about disability movements in Nigeria. So, yes, this is a very important project aimed at sharing the stories of the disability rights movement in Nigeria. This will help promote disability rights movement's projects and advocacy. It will also educate both decision-makers and the rest of the population.

ACKNOWLEDGEMENTS

We are deeply grateful to our friends, colleagues, and associates within the disability community and beyond for their contributions in one way or another to making this mission a reality. When we sketched out and agreed on the book outlines, we asked ourselves: how do we tell the right story of the disability rights movement in Nigeria? The shortage of records, coupled with the limited knowledge of both the theory and practice of disability inclusion, is daunting. Moreover, this is a storytelling task that spans three decades, tracing the rise of disability activism and the call for an inclusive society by persons with disabilities in Nigeria since the early 1990s.

It is on this basis that we wish to acknowledge the contributions of the following persons. First, we appreciate the sharing of experiential and evidentiary information on JONAPWD's formation during interviews and the validation session by Rilwan Mohammed Abdullahi, who has served in several positions within the association at both national and state levels, including as the current National President of the National Association of Persons with Physical Disabilities. Dandeson N. Hart, a former National Secretary of JONAPWD (2008–2012), and currently the Executive Director of the Foundation for Persons with Disability in the Niger Delta, played a significant role in recognising and validating the achievements of some of the pioneering leaders of the disability rights movement in Nigeria. Mike Maikumo Gideon, the North Central Zonal Coordinator of JONAPWD, and Jide Ojo, a Public Affairs Analyst, and others made useful suggestions on how to improve the manuscript during the validation session.

The comments on the draft and the administrative support provided by the JONAPWD National Secretariat team—led by Adetunde Ademefun, Head of Secretariat/Director of Programmes; Usman Umoru, Programme & Impact Manager; Gibson Abidemi, Programme Finance Officer (PFO); and other staff members—helped us finish the task in record time. Alex Byanyiko, a writer and filmmaker, transcribed and analysed the audiovisual interviews conducted during the drafting of the manuscript.

We would like to extend special thanks to our editors, Mike Ekunno and Amina Aboje, for their invaluable editorial contributions and support throughout the preparation of the manuscript. This acknowledgement would be incomplete without mentioning the MacArthur Foundation's Africa Office team, led by Dr Kole Shettima, the African Director, and Amina Salihu, PhD., Deputy Director, who supervised JONAPWD's implementation of the project awarded by the MacArthur Foundation, entitled 'Strengthening Accountability and Transparency Framework on the Post-Moratorium Cycle of Discrimination Against Persons with Disabilities (Prohibition) Act in Nigeria. Amina Salihu's, PhD. insightful comments helped us address several structural gaps during the internal review of the manuscript. The credit for all pictures and images used in this book belongs to JONAPWD National Secretariat, Abuja, Nigeria.

ACRONYMS

Acronym	**Meaning**
ADF	African Disability Forum
ADHD	Attention Deficit/Hyperactivity Disorder
AI	Artificial Intelligence
ARPWD	Affirmation of the Rights of Persons with Disabilities
AWID	Association for Women's Rights in Development
CAC	Corporate Affairs Commission
CCD	Centre for Citizens with Disabilities
CDPF	Commonwealth Disabled People's Forum
CoE	Colleges of Education
CVR	Continuous Voter Registration
C4C	Coalitions for Change
DFID	United Kingdom Department for International Development
DGD	Democratic Governance Development
DPI	Disabled People International
DRF	Disability Rights Fund
FACICP	Family Centred Initiative for Challenged Persons
FCDO	United Kingdom Foreign, Commonwealth and Development Office
FCT	Federal Capital Territory
FIA	Fight Inequality Alliance
FMWASD	Federal Ministry of Women Affairs and Social Development
FRN	Federal Republic of Nigeria

IBP	Issue-Based Project
IDA	International Disability Alliance
IDD	Intellectual and Developmental Disabilities
IDEA	Integration, Dignity and Economic Advancement
IDPs	Internally Displaced Persons
INEC	Independent National Electoral Commission
IRI	International Republican Institute
JAMB	Joint Admissions and Matriculation Board
JONAPWD	Joint National Association of Persons with Disabilities
MDA	Ministry, Department or Agency
MDAs	Ministries, Departments, and Agencies
NAB	National Association of the Blind
NCPWD	National Commission for Persons with Disabilities
NITDA	National Information Technology Development Agency
NNAD	Nigerian National Association of the Deaf
NSCDC	Nigeria Security and Civil Defence Corps
NTA	Nigerian Television Authority
NUC	National Universities Commission
NPC	National Planning Commission
NYSC	National Youth Service Corps
OfPDs	Organisations for Persons with Disabilities
OPD	Organisation of Persons with Disabilities
OPDs	Organisations of Persons with Disabilities
PACT	An International NGO in Nigeria

PLAC	Policy and Legal Advocacy Centre
PLS	Post-Legislative Scrutiny
PRO	Public Relations Officer
SCIAN	Spinal Cord Injuries Association of Nigeria
SGBV	Sexual and Gender-Based Violence
TMG	Transition Monitoring Group
UAF	Urgent Action Fund - Africa
U.I	University of Ibadan
UN	United Nations
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UNDP	United Nations Development Programme
WAFOD	West African Federation of Persons with Disabilities
WILD	Women's Institute on Leadership and Disability
YALI	Young African Leaders Initiative

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CHAPTER ONE

Evolution of Disability Discourse in Nigeria

The story of the disability rights movement in Nigeria is too important to be left untold. While persons with disabilities are excluded across many walks of life, their story remains one of the least told in the history of Nigeria's human rights movement. This stands in contrast to the plethora of books on youth and women's rights in Nigeria—and perhaps across the continent of Africa and the globe. The exclusion of persons with disabilities is a concern among disability rights activists and organisations, including JONAPWD, especially considering that we constitute approximately 15% of the population of the community or nation-state where we live, including in Nigeria using the United Nations matrix. (World Health Organisation's 2023 factsheet estimate is 16%). 'The use of disability to disparage a person has no place in progressive, democratic society, although it happens at present all the time.' (Siebers, T. 2011:4).

The Scale of Exclusion

The current population of Nigeria is approximately 238 million people (2025 estimate), according to Worldometer. This translates to approximately 36 million people in Nigeria being persons with disabilities as at 2025. This population of persons with disabilities in Nigeria exceeds that of at least forty other African countries, including Côte d'Ivoire, Republic of the Niger, Tunisia, Mali, Cameroon, Zambia, Malawi, Chad, Zimbabwe, Sierra Leone, and Guinea.

Furthermore, of the forty-four countries in Europe, only nine—Russia, Turkey, Germany, the United Kingdom, France, Italy, Spain, Ukraine, and Poland—have a greater population than the number of persons with disabilities in Nigeria. The remaining thirty-five countries each have a population of less than 36 million people. In fact, when considering the 193 United Nations member states as of June 2025 (plus the two observer states, Vatican City and Palestine), 148 of these entities each have a population smaller than our projected 36 million Nigerians with disabilities.

This means the ‘nation’ of persons with disabilities in Nigeria has a larger population than about 150 separate countries across the globe. The fundamental question is: how can such a large group be excluded from our everyday affairs and journey towards nation-building? It means that in our country, Nigeria, about 36 million people face perpetual discrimination from the rest of the population through attitudes, social engagement, law-making and implementation, environmental designs, and across all spectrums.

This projected population cannot be further disaggregated into specific disability clusters in Nigeria, as an actual census has not been carried out to determine the percentages of the Blind, the Deaf, persons with physical disabilities, persons with albinism, persons of short stature, persons affected by leprosy, or persons with intellectual and/or psychosocial disabilities, among others. Nonetheless, this staggering number necessitates urgent and concrete action from all of Nigerian society to end discrimination against persons with disabilities.

Discrimination against persons with disabilities is not peculiar to Nigeria alone. We face discrimination everywhere, in every society—developed, developing, and underdeveloped nation-states. The level of response and state action, however, differs. This difference is largely determined by the level of disability awareness among leaders, the nature of legislation, and the actions and roles played by persons with disabilities and the rest of the population in those countries.

Global Context of Disability

The World Health Organisation, for instance, estimates the global population of persons with disabilities at 1.3 billion out of 8.2 billion in the world as of mid-2025 being 16% of the world population. The number of persons with disabilities is ever-increasing due to everyday human conditions: congenital conditions or health differences at birth, diseases, accidents, age-related disabilities, and depression, among other factors that can cause impairments, such as damages, losses, or injuries. Disability is an enduring part of human existence, interaction, and society, and it cannot be wished away or its importance de-emphasised.

The Need for Storytelling

The story of the disability rights movement is vast; it cannot fit into a single narration or a book, and no one individual is perfectly positioned to tell the entire story. Yet, it is a story that must be told in its various forms. As individuals who have been part of this journey and have been elected to stay in the front row—as leaders within disability community—we will use this medium to make further contributions to efforts at addressing discrimination against persons with disabilities through storytelling.

Additionally, as this is the first time the journey of JONAPWD is being chronicled, it is important to ensure that the roles and contributions of our first three elected presidents, who have since passed, are not ignored or forgotten in the building of the disability movement. Having passed on to glory, these three former presidents would have otherwise been part of the authorship of this book, which is a narration from JONAPWD presidents' perspectives.

Disability is not an aberration. It is not a disease, bad luck, or a misfortune, as some individuals who lack sufficient knowledge about disability inclusion may wrongly believe. This is precisely why it is crucial that the story of the disability rights movement, as well as the journey of JONAPWD, be brought to life. The story is too important to exist only in our minds; it belongs in institutional memory. This record will provide strong stepping stones for those coming after us to move JONAPWD to greater heights.

For a book of this nature, which aims to discuss the disability rights movement in Nigeria, it is important to begin by addressing critical questions such as: What is disability? and Who is a person with disabilities? The rest of the population (persons without disabilities), as well as a sizeable number of persons with disabilities, do not have a comprehensive understanding of the disability concept. Consequently, these not fully informed persons with disabilities are often unable to engage and demand their rights in line with national and international disability and human rights laws. Furthermore, the rest of the population is often unaware of how to properly engage with us, frequently viewing us through a 'wrong prism'.

This lack of understanding has escalated the discrimination, oppression, and disempowerment of persons with disabilities to what James Charlton terms a 'human rights tragedy of epic proportions'.

> 'Human life confronts the overwhelming reality of sickness, injury, disfigurement, enfeeblement, old age, and death. Natural disasters, accidents, warfare and violence, starvation, disease, and pollution of the natural environment attack human life on all fronts, and there are no survivors. Whatever our destiny as a species, we are as individuals feeble and finite' (Siebers. T, *Disability Theory*, p. 7).

CHAPTER TWO

The Disability Experience: Stories from JONAPWD's Current and Immediate Past National Presidents

Abdullahi Usman Aliyu's Story: National President

Persons with disabilities are not special people. They are everyday people and part of human history like anyone else. However, a few decades ago, society's understanding of disability was primarily as an illness or misfortune resulting from birth, accident, or old age. The rest of the population, who see themselves as sympathetic, usually focus on trying to help or give us hope. They view persons with disabilities as those who are unable to meet the demands of a productive life, focusing on their impairments—blindness, albinism, deafness, Hansen's disease (leprosy), physical disabilities, Down syndrome, spinal cord injury, and so on. The individuals, with or without disabilities, see the impairments and not the human being created by God.

As JONAPWD's president and a person with physical disabilities, sometimes when I approach a well-to-do person, a 'big man' as we say in Nigerian parlance, on my crutches, the first thing that would come to his mind is, 'Ah, this one is here to beg for alms.' Before I even reach him, he is trying to put his hand in his pocket to see if he has ₦500.00 or even ₦2,000.00 to give me so that I would go away. To such a 'big man,' this charity is his own reaction to disability.

In some other instances, some other persons without disabilities see me and they become unnecessarily sympathetic, 'Ah, oh, sorry, sorry, God help you. Sorry Sir, sorry.'

This becomes the default instead of looking at disability on the basis of fundamental human rights or thinking of how to empathise and support my cause to fully enjoy the same rights as everyone else. Several times, people tell me ‘sorry’ because they see me on crutches; or want to give me ₦200.00 thinking that I need it to go and buy 'akara'!

The rest of the population sympathise with us all the time. They feel sorry for us as persons with disabilities. They see us as disadvantaged, different, alienated people. This is because the system in place, as well as the programmes, policies, and the environment, has isolated us and injuriously entrenched a false difference between a person with disabilities and a person without disabilities. What is appropriate is to show empathy—the rest of the population need to put themselves in our shoes and feel what we feel. This helps them to look away from the impairment and to see that we are just as human, and it is our right to have full access to all benefits and not be deprived of full participation in society, as the situation is at the moment.

Disability is not due to sin or wrongdoing in anyone’s previous life, as some are said to believe. Everyone is God’s creation, whether they are persons with or without disabilities. Perhaps, it is a way through which God tests our resilience as individuals. How do we react to our conditions as persons with disabilities? How do we react to other challenges we might face as individuals, whether we are persons with disabilities or not? How do persons with disabilities relate amongst themselves—do they compare their disabilities and say, 'Oh, I am better off?' How do people without disabilities relate with fellow human beings with disabilities? Why should society or the rest of the population put barriers in place that limit us from working with other citizens towards the progress of the society?

Answering these questions and many more will help us to deepen our knowledge of disability inclusion and address the ubiquitous discrimination against persons with disabilities.

My predecessor, Ekaete Umoh, had similar experiences over and over again. Of course, this is the experience of many. As persons with disabilities, we are not addressed by our potentials, but by our impairments.

*****

Ekaete Umoh's Story: Immediate Past National President

Long before I grew in disability activism, the urge to correct this aberration of oppression of individuals because they are persons with disabilities started at the University of Ibadan (U.I). A few decades ago, I was given accommodation with other students who had one form of impairment or the other because I have an impairment, as a survivor of polio, but I could walk without crutches or a walking stick. The accommodation was actually quite thoughtful—we were housed two students per room in executive-style quarters with good single beds, centre tables, comfortable furnishings, and kitchenettes. The school was constantly thinking about how best to ensure our comfort. They even allowed us to choose our roommates. Looking back, I can see that the University of Ibadan was genuinely trying to provide what they believed was the best possible accommodation for us.

However, even with these good intentions and considerable efforts, I found myself questioning the approach. Why were we being separated from other students and quartered in a particular block? I wondered why we couldn't stay together with fellow female students without disabilities in the general halls of residence. I was already fighting for inclusion, though I didn't have a name for it at the time. Are we really different from the rest of the students and the larger society because of our impairments? When I raised questions about this as a budding disability activist, they gave me an excuse for what I would now regard as accessibility related, that is, putting us together in a particular block makes it easy for us to access our rooms, especially those who are wheelchairs users given the structural barrier they would face navigating other blocks of hostels.

For me then, that wasn't all about accessibility, because we had both the Deaf and Blind students including those with various medical conditions quartered in the same block of hostel. Besides, I was still taking my lectures three or four floors upstairs with other students without disabilities. So, what was the reason for quartering students with disabilities in a particular block? I thought, maybe they just wanted the best comfort for us as persons with impairments. We could have been mixed on the ground floor of any of the same block where other students were quartered, and not isolated in a particular block alone which could lead to profiling or labelling, even though that was not the intention of the school.

However, I really struggled with the school policy of segregating female student with disabilities into a separate hostel block; it felt very strange to me.

Did we have impairments? Yes.

Did those impairments make us different from other students? No.

Did those impairments make us less efficient? No.

Anyway, I challenged the system. I protested against that accommodation. So, I went to the Student Affairs Office. I thanked the man very much and said to him, 'Sir, this accommodation is a fantastic arrangement, the room are executive and really nice but I am feeling like I'm in a rehabilitation centre. Please Sir, I want you to change my accommodation.'

It is worth pointing out here that the city of Ibadan is well known for all types of rehabilitation centres for persons with disabilities, the early missionaries played their part, trying to care for persons with disabilities and building lots of charity homes, including schools for the Handicapped which was a progressive idea then and did serve their purpose; but as we moved into the human rights phase for persons with disabilities, these concepts are being rethought.

Anyway, in response, the Student Affairs Officer explained that it was the practice of the school to quarter students with disabilities together. Of course, I wasn't swayed by his explanation but listened carefully, wondering why the school authorities made such a decision.

But, looking back now, I understand that the management of the University of Ibadan was quite ahead of their peers with regards to the welfare of persons with disabilities. They recognised the presence of persons with disabilities in the school community and were working in the best interest of these students by providing very comfortable accommodation for them, based on their level of disability awareness then. However, considering that I was coming from a background where I had never been treated differently from others on account of my disability, the fact that we were placed in a hall separate from those of other students was disagreeable to me. I saw this segregation as discrimination. So I challenged it because I felt it was stigmatising. But honestly, I must appreciate the University of Ibadan for being ahead of other universities at that time by giving priority to the wellbeing of persons with disabilities and providing them with convenient accommodation for the whole length of their study, given that were fewer accommodation compare to students' population.

Decision-makers across the country, then and till date, still don't have adequate knowledge of what disability is and how to ensure they are not unintentionally discriminating against us. Nigeria as a country, and several public and private institutions, are still struggling to fully understand and identify processes for disability inclusion. What we have in place at the moment could best be described as attempts at disability integration, which is a process that ensures conditions for us to participate are put in place. Meanwhile, what we want, which is a human rights issue, is the removal of all barriers, an accessible environment, and full participation like other citizens in the Nigerian society. That is disability inclusion.

To continue my story, the Student Affairs Officer said, 'You should be grateful we got you enough space...' He tried to explain further why we, the students with disabilities, should be quartered together so we could relate together more. I allowed him to finish his explanation, then I left. But every time I had a free period, I went to his office to repeat my request to be quartered with other students, and not be separated from them because of my impairment.

Each time he saw me, he said, 'You have come again?!'

'Yes, Sir. I'm not going to stay in that accommodation until you convince me of why I should be on that floor.' I responded.

I disturbed him for almost half a semester.

One day he called me and said, 'Let's discuss further.'

'Okay.'

'Looking at you right now, I think they need you on that floor.'

By this he meant other students with disabilities, perhaps those with more severe disabilities.

I guess he was struck by my resilience, the clarity and justification of my request. Maybe he also saw the confidence and boldness with which I pushed … Anyway, I am not too sure, but I know he was taken aback.

'How?' I asked.

'You know,' he continued, 'no one has ever raised these questions with us in this university the way you have. Most students appreciate the special accommodation we provide, but you're challenging us to think about it differently. I see it from a different perspective now.' He concluded. 'Tell you what—there is this place called Agbowo, just opposite U.I (University of Ibadan).' He said.

I listened as he went on, curious to know what he would propose.

'Look,' he said, 'I have students (without disabilities) who stay in some accommodation in Agbowo. If at the end of first semester, let's say by second semester, you still feel strongly about this, I promise you, I will give you accommodation there. Then you have the kind of accommodation you're calling for. Is that okay? Deal?'

'Deal.'

From that day, I felt heard and respected.

After that encounter, I was no longer persistent in my clamour for inclusive accommodation, knowing that I had the choice of going to Agbowo if I didn't want my current accommodation. But I'm really thankful for the initial resistance he put up. It was my association with other students with disabilities in that block that truly opened my eyes to the huge challenges we face. As students with disabilities, we shared experiences of what we faced with one another. That was when I heard some horrible stories. Some people's parents got divorced because they had a child with disabilities. Some children with disabilities were taken to homes led by people who saw disabilities as evil, a problem, or a disease, and maltreated the children.

My family treated me like a queen and my opinion mattered. My immediate family didn't relate with me based on my disabilities. Being the first in a family of six children, my father was very proud to show me off. Whenever he was going to play lawn tennis, as soon as he picked his kits, the next thing was me. He showed me to anybody who wanted to see me, and proudly so. I never knew that children with disabilities were being discriminated against or being hidden by their own parents and family members. A child with disability should not be hidden from friends and relatives by the parents, or denied quality education and other privileges provided for the siblings without disabilities. Parents should not segregate a child with disabilities for any reason.

So, there I was hearing about people who were locked away because they had certain disabilities, or their parents getting divorced because of that. You can imagine how gloomy that block was. There were carryovers of experiences of pains, isolation and discrimination and marginalisation by majority of the female students from various home/families into the space. I really felt bad, but most times I went out of my way intentionally socialising and encouraging sisters as much as I could.

The floor was almost always quiet. No vibes. No music. Limited laughter. I'm a noisemaker; a very cheery person. So, at first, I didn't understand why people wore such gloomy faces. I later understood. This was how the seed of activism sparked up within me and I started challenging all sorts of stereotypes, faulty generalisation/negative narratives about persons with disabilities, because that was not my story.

Where I was born and lived, precisely Sapele in the Niger Delta, we don't have the word ‘disabled’ in our lexicon. There, you could only hear people say, in Pidgin English, ‘eye dey pain am,’ or ‘hand dey pain am,’ that is, the person has an eye or a hand ailment or condition. And this was not perceived as being derogatory or belittling.

So I became more familiar with the term, ‘Ọmọ disabled’ (disabled people) and several other labels associated with disability for the first time while in school at Ibadan. This was how my awareness of disability activism became more prominent. It also explains how and why I became fully involved in disability advocacy and how I came into this space and sustained my drive in my call for justice and an end to discrimination of persons with disabilities. I haven't been in this space only. I have dared so many other spaces, too. I started with the women's movement. And I made it my business to ask for my place anywhere, everywhere. Whenever I showed up, they would be like: ‘Hey, Ekaete, we know what you want to say.’

So, each time things happened, and I couldn't find my space, I would ask them, ‘OK, so I'm here. Why am I here now? You people didn't even talk about me, my participation and effective representation, that is, how this affects me as a woman with disabilities.’ I would remind them and show them the gaps in the programming and the activities being designed or being implemented without disability inclusion, thereby ensuring I make an effort to improve disability inclusion awareness in everything I do. Sometimes people realise the disability gap but do not know what to do about it.

‘Okay we see the point,’ they would say. ‘Now that you are here, what do we do?’

It was very difficult. People didn't know how to include disability conversation in the general discourse that was happening.

This still happens today in several meetings and events. My disability awareness and advocacy were further energised through further education and training in the United States and other locations across the globe. I knew I had to connect and work with others to address the continual discrimination against us across the board. After my leadership training and further schooling, I started looking for disability groups in the country. I learnt about the existence of JONAPWD. In those early days, with my experience, I knew it could be better. Our leaders then tried their best within the confines of the knowledge available to them at that time. I was coming with fresh ideas, having gained more practical knowledge on disability theory and practice. So, I thought I could change my world overnight.

One day, I had the opportunity to meet with Danlami Basharu, one of the pioneer leaders of the disability movement in Nigeria. We discussed the issue of disability exclusion and the need for more advocacy. It was at that point I informed him that I was going to attend a session at the United Nations in New York, and requested if he had leaflets on disability issues in Nigeria that I could share with participants at the meeting. Each time I travelled to Europe or the US, I always saw people talking about movements and bigger organisations but Nigeria was missing.

Anyway, Barrister Danlami, (as we fondly used to call him) and I struck a professional relationship and I started volunteering for JONAPWD as Technical Assistant to the National President (Danlami Basharu). I had a wealth of experience on programming and was able to speak frequently the language of the development agencies while supporting them to design and implement programmes from the disability lens. I introduced the Twin-Tracked Approach to disability Inclusion to most development agencies, meaning in development work disability could be treated as a standalone thematic issue as well as cross-cutting issue and that was the strategy JONAPWD had used to engage all development partners we worked with.

JONAPWD gained significant visibility at the beginning largely due to the charming and intellectual presence of Danlami Basharu as one of the early leader of the movement. Armed with a Bachelor of Laws, a Master of Laws from Cambridge, a degree in Education/History from University of Wales, and several other academic qualifications, Danlami's transition into disability advocacy was seamless and impactful. As a barrister, he skillfully used his legal expertise to articulate and champion the crucial shift from viewing disability issues through the charity model to embracing a human rights approach. His compelling arguments and presentations won widespread admiration and respect within and beyond the movement. Under his influence, JONAPWD began to be recognised not merely as a charitable cause but as a powerful movement led by sharp minds and strong intellectual conviction, dedicated to advancing the rights and dignity of persons with disabilities in Nigeria.

CHAPTER THREE

Unpacking Disability: Beyond Myths and Realities

Disability is a question with no straightforward answer. Disability studies is a field that is relatively new and still evolving. It cannot be reduced to a simple, fixed definition. What was known about disability yesterday may be obsolete today in the context of development.

For instance, there was a time when academics and disability stakeholders used the acronym PWD (Persons with Disabilities), much like they would use UN for the United Nations. Recently, PWD has been removed from the disability lexicon, abbreviations, discourse, and scholarly writing. Disability activists are now determined to prioritise disability, mentioning and explaining it everywhere to raise greater awareness. We are not ashamed of our disabilities, so the word should not be replaced with an acronym or other euphemisms often based on pity or sympathy from the rest of society.

Many changes are taking place daily within disability theory and practice. New lessons are emerging from the intersectionality of disability, marginality, and disempowerment based on social construction.

> ‘People with disabilities want to be able to function: to live with their disability, to come to know their body, to accept what it can do, and to keep doing what they can for as long as they can. They do not want to feel dominated by the people on whom they depend for help, and they want to be able to imagine themselves in the world without feeling ashamed’ (Siebers, T. 2011:68–69).

The Evolution of the Disability Concept

One approach used to explain disability is tracking its conceptual evolution across ages and different schools of thought. We could safely start by saying that disability is a social concept or creation. It's like asking, 'What is gender?' or 'What is democracy?' There can be as many definitions as there are schools of thought. This is why we began this book with our personal tales of disability experiences. Let us, therefore, start the discourse on how disability has evolved over time, though it is still evolving.

Many years ago, issues around disability were viewed through the lens of sickness or impairment—people who were unwell or people who were deformed. Society saw individuals with physical signs of impairment: eyes that did not open, hands or legs that did not move well, and so on. Consequently, the rest of society understood disability from the perspective of a group of people who were sick and needed help.

For a very long time, the focus was on fixing them. People without disabilities sought a medical solution to disability. The narrative was centred on negatives: they can't see, can't hear, can't walk, can't do. Disability was explained in this context, and we were situated in this position. Sadly, this remains a major issue in the developing world, especially in countries with low awareness of disability inclusion.

For a very long time, the majority continued to see people with impairments as a group of sick people who needed medical attention. Any potential they might have had was ignored. In the eyes of the public, the prevailing thought was, 'You're not normal. I want to make you normal,' or 'You are not feeling well.'

The Medical and Charity Models

Beyond the medical aspect, some felt pity and wanted to help. However, worse than the medical-only focus were the horrible stereotypes and primitive beliefs attached to disability. People would say, 'You're unwell; it is probably a curse. Perhaps it's due to something you did, or because your parents were horrible, or because you were so horrible in your first life, and now you're getting the punishment in your second life.' As a result, we encountered all kinds of abuse, cruelty, and insensitive treatment that are better imagined than experienced.

This is not to condemn support, treatment, or the provision of assistive devices such as mobility aids, hearing aids, or medication for ailments. However, for the most part, society was not looking beyond treatment. The approach was: you don't have legs, so let's give you a prosthetic, and then you're fine; you are blind, so let's give you a white cane; you have a spinal cord injury, so let's give you a wheelchair; you have psychosocial disabilities, so it's best to lock you up for your own good and for societal good—at least you are eating and not roaming the streets. This approach became known as the medical model by disability theorists.

Then, a group of people challenged this view, saying, 'Wait a minute, it's much more than that.' They argued that these individuals were not simply a bunch of sick people. Even if they had an illness (impairment), that was only one aspect of their lives. Some religious bodies and other good-hearted people began to ask, 'For how long will you be sick?' They also asked the treating institutions, 'Now that you couldn't fix it; now that it seems like, 'Okay, this is how you are, as it were, for now,' what do we do?'

However, a new perception entered the discourse: helplessness. We were seen as helpless because we had issues with our legs, amputated hands, or could not see or hear. Our senses were incomplete. Our heads were considered bigger than others' and empty. These do-gooder groups decided: what can we do? Let's simply feel sorry for them and give them food. Everyone deserves to eat; they didn't create themselves. This gave rise to the charity model of disability.

It was a case of society being sympathetic without understanding that what we actually needed was empathy—for the rest of the population to place themselves in our shoes and genuinely feel what we felt. This would allow them to respond appropriately and not profile, pity, or disempower us with their attitudes.

Institutionalisation and Exclusion

At that time, they also started institutionalising persons with disabilities. They built 'funny homes' for the Blind, for persons with physical disabilities, and for autistic children. Society began erecting walls to place persons with disabilities in segregated locations where they could feed them and give them used clothes, shoes, toiletries, bags of rice, and generally meet their basic daily needs. In essence, the charity model is based on the assumption that there are some weak people who need help at all times. They are sick. They are weak. We need to give them food.

Therefore, during that era, society treated us as recipients of charity, not as people who could contribute to society. Keeping with the mindset of the charity model, we were not considered for employment, business ownership, participation in sports, development programmes, or other such endeavours. We were simply regarded as helpless people.

This also played out within the family setting. In a family of six, with one or two children with disabilities, those children would most likely be treated differently because the family head might consider any developmental support for them an unprofitable investment. This meant such a child might not be sent to school, as that would be considered a waste of resources. That was the perspective held for a very long time: society erecting walls to contain us. For example, the rich might dump their children with disabilities in a special school or home devoid of love and care.

It was believed that children with disabilities were better cared for in such segregated schools or homes; that they were better off if lumped together with fellow disabled children. Was that wrong? It's tough to judge the parents, as that was the prevalent practice according to the knowledge available to them at the time. That was the most they thought they could do. There were all kinds of homes, like homes for the handicapped, homes for the sick, and so on. They believed there was nothing else they could do but dump them somewhere and feed them, which made them look like very good people in the eyes of the world.

Survivors of leprosy were kept far away in the forest or some other out-of-the-way location, stripped completely of their humanity. Even within our associations and clusters, some still consider leprosy-related impairments only as a medical condition and keep away from persons affected by Hansen's disease. The pervasive discrimination meant that, at the initial stage, leprosy survivors struggled to be recognised even by other clusters within the disability community. Initially, the cluster was more known by its global name—IDEA (Integration, Dignity and Economic Advancement). JONAPWD worked assiduously in disability discourse with other human rights organisations and organisations for persons with disabilities in Nigeria to address the issues of exclusion and stigmatisation of this cluster, IDEA, before they were fully registered and integrated into the disability community. The process that led to their integration is discussed more in other chapters of this book.

The charity model wrecked the potential of persons with disabilities. Unfortunately, it has not been discarded;

many individuals and national and international institutions fixated on impairments still relate with us from the position of wanting to help us through charity support because they simply cannot see beyond those impairments. This has continued for a long time. The charity model gave rise to much institutionalisation, segregation, and all kinds of stereotypes, labelling, and dehumanisation. Persons with disabilities were not considered as productive forces collectively or as productive citizens individually. There was widespread exclusion, as we were viewed either as recipients of charity or as burdens on our families and the government.

The Rise of the Social Model

As time passed, persons with disabilities started becoming assertive. They began to question the prevailing faulty mindsets and kick against society's limiting beliefs about them. It was like, 'Excuse me, what do you mean I cannot do this?' Consequently, it dawned on the rest of the population, as well as activists within the disability community, that disability inclusion was not just an act of charity, and that persons with disabilities could actually use their hands and intellect. This win came from the people themselves—the people with disabilities. It got to the point where persons with disabilities and other advocates challenged the system. They said, 'Excuse me, I can't sit here and keep getting all these handouts from you. I can do much better than that.'

It was at this point that the global disability movement started pushing back, saying:

> 'We are much more than this. We are not a bunch of sick people. We are not people who need this kind of charity. What we see is that even if we have these impairments, they are not enough to exclude us from

society. We could go to school, we could read, we could write.'

Note that while persons with disabilities were being institutionalised, they were also given education—schools for the handicapped, schools for the Deaf, schools for the Blind, and so on. Some of these schools were created because of the gaps. For example, the school for the Blind was established to give them a space to learn according to their pace and the speed their impairment would allow. The Deaf, DeafBlind, and hard of hearing learnt sign language at the elementary levels. As a result, many of them could continue their education at mainstream schools with adequate provision of assistive devices and reasonable accommodation, especially in societies with high levels of disability inclusion awareness. This increased the number of persons with disabilities who had some form of education.

Image 01: Persons with disabilities, as the rest of the population, can participate in social life, including sporting activities with right assistive devices. (www.jonapwd.org)

With this, they began to realise that it was not true that they were helpless and should always be perceived as persons with caps in their hands begging for alms. They realised that being a person with physical disabilities does not make them handicapped; that being deaf does not make them dumb; that being blind is not an indication that they lack vision; and that being a wheelchair user isn't an indication that they cannot participate in physical or sporting activities, move to a podium, or enter a storeyed building.

Within society, these more enlightened persons with disabilities started challenging the systems, and the disability movement globally began to say:

> ‘No! Excuse me, you are misjudging us! Within this institution, we can read and write. We can be productive. So why are you keeping us in this space?’

They started fighting against the institution, which prompted the campaign for deinstitutionalisation. All those schools for the Blind, the Deaf, and persons with physical disabilities, and similar institutions, have begun to be dismantled.

Defining the Problem: Society, Not the Individual

What’s most interesting is that the disability movement reached another phase where they sat together and said:

> ‘Excuse me, I think society is really not treating us well. They have been misjudging us. And based on their narrow view, we are being called what we are not.’

They then realised that the real problem was not disability but the way society was structured. Environmental construction–roads, buildings, markets, sporting arenas, offices, homes, motor parks, airports, lifts, walkways, religious centres, schools, and libraries–were all constructed without having us in mind. Additionally, various forms of equipment and gadgets were also not designed to be inclusive. Even laws, policies, websites, programmes, conferences, workshops, and all forms of human gathering were not designed to accommodate persons with disabilities.

So, it became clear why they encounter barriers to participation. Persons with disabilities realised that even if you have impairments, those impairments are not strong enough to stop you from participating in society. Then they asked themselves, 'What are those things that are actually stopping us?'

Therefore, it became a reversal. It was not a problem with the persons with disabilities, but a problem with society. But if that is the case, what are the problems with society? Again, they uncovered the problem themselves and said:

'I think we're experiencing some kinds of barriers here, and that's why we cannot participate. I think there's an institutional barrier. Maybe when your policies and laws are crafted, you never thought of us, so we can't even fit into how you implement those laws and policies.'

Persons with disabilities, therefore, saw that even an attitudinal barrier is a big issue: the way people look at and treat us; the negative assumptions, perceptions, and beliefs that persons with disabilities are not capable. For instance, many persons with disabilities have taken exams online and passed with 100% at one time or another. But when they showed up for a physical interview, they got responses like:

'Oh, sorry. Oh, really? You'll hear from us.'

This is one of the attitudinal barriers persons with disabilities frequently face. Disability activists also identified environmental barriers concerning the buildings, roads, staircases, and all of that. They recalled:

'I've done all these exams, I'm showing up now, and your interview room is on the fourth floor, and I'm a person on a wheelchair; therefore, I can't get up there.' Or, 'I am a lawyer and polio survivor. Your court room has staircases but no ramp or any provision to enable me to access it.'

These are built-environment – environmental barriers. There were also identified communication barriers in terms of the Deaf not hearing and the Blind not being able to see information on non-interactive platforms or websites. Finally, the disability movement considered social barriers: how, in the name of religion, traditions, and beliefs, persons with disabilities are relegated to the background in society. They used their voice and demanded accountability. They confronted society, saying:

'Even though I am blind, I can see and read!
'Even though I am deaf, I can speak and hear!
'Even though my legs are amputated, I can walk!'

Persons with disabilities could, of course, use assistive devices – braille, white cane, hearing aids, sign language, prosthetics, a wheelchair, crutches. They explained further:

'Yes, it is your fault, because you're not taking diversity into account. And you're doing a lot of things; you never thought of us. Your policies, your programmes, and the way you design everything. It is your fault. Actually, it is you, society, that has erected those barriers that have caused this disabling condition for us.'

So, that model became the social model. The social model was birthed, and it became a way to address the social and environmental barriers. The disability movement started shouting out at society:

'Society, don't you get it?! Take off those barriers and see if I will not participate. You're not getting it; you're not thinking right. It's your fault. You have been using a one-size-fits-all approach, which is not working.'

This further fuelled the campaign for inclusion. It gave practical approaches to addressing disability inclusion. Society now took note and concurred, ‘Yeah, it's our fault.’ Decision-makers started talking about how to remove the barriers, such as disabling discrimination. Legal prohibition of discrimination is one of those steps.

‘We're pulling down institutional barriers. So, okay, we agree. Now, part of it is to make ramps, make this, make that, and provide needed assistive devices.’

The Rights and Human Rights Approaches

However, it is far beyond that. There are other aspects that have to do with human respect, dignity, and integrity; these are also critical values indicative of our collective humanity. So, following the positive integration of the social model, persons with disabilities started talking about the importance of the human dignity and rights approach. It is beyond attending to the social needs of persons with disabilities; it is also about their rights as human beings. When that happened, the disability evolution train moved to the rights approach in addressing discrimination against persons with disabilities. We are, first of all, human beings and are entitled to whatever rights anybody has. And I, as a person with disabilities, must have my space within those essential rights.

While this looks like a victory, it isn't *uhuru* yet. There were still problems. The sets of rights and the Universal Declaration of Human Rights and treaties and conventions in place are, interestingly, not fully disability-rights inclined nationally and at the international level. Yes, nobody stopped us from having our rights, but society had already built or constructed structures that would not allow us to access our full potential within the universal human rights declaration. Nonetheless, the impact of the rights approach is that it further deinstitutionalised disability theories and practices. From this approach, persons with disabilities could say to anyone, ‘I don't even care what it is. I'm a human being first of all; whatever right you have, I have.’

Then, we climbed another step by merging the social approach and the rights approach. This brought in the human rights approach. And then there was a design for the UN Convention on the Rights of Persons with Disabilities. It was this disability rights development that guided the United Nations into forming the UN Convention on the Rights of Persons with Disabilities (UNCRPD) in 2006. This convention has not come to give new sets of rights. It has only come to enable persons with disabilities to enjoy their full rights and achieve their full potential.

It is in this context that one may directly attempt to define what disability is, and that has been made easy. Let's look at Article 1 of the UN Convention on the Rights of Persons with Disabilities, with the purpose to:

> ‘… promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.’

Image 02: Abdullahi Usman Aliyu (JONAPWD National President) and

Adetunde Ademefun (Head of National Secretariat, JONAPWD) joined other delegates at the 2025 UNCRPD Committee Session in Geneva, Switzerland

The Article elaborates further that persons with disabilities:

> ‘… include those who have long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.’

This definition is expressive, expansive, and, of course, inclusive of all clusters of disability. Its originality and depth are demonstrated in its reliance on the evolution and historicity of the disability rights movement. The UNCRPD was adopted on 13 December 2006 and ratified on 30 March 2007.

According to the International Disability Alliance (IDA), 177 countries have ratified the UNCRPD, and 92 have signed its optional protocol as of mid-2025. The UN did not rest on its oars after observing that several countries that are already signatories to the disability treaty are yet to mainstream a disability approach into their systems, let alone achieve disability inclusion. The UN, therefore, in 2019 came up with the 'UNCRPD Implementation Strategy' document to assist nation-states in effectively domesticating and implementing disability discrimination prohibition laws.

Modern Disability Theory

On his part, Tobin Siebers in *Disability Theory* (2011:3), describes disability as:

> ‘… a minority identity that must be addressed not
> as personal misfortune or individual defect but as

> the product of a disabling social and built environment.’

He explains further that in modern times, disability is not:

> ‘… an individual defect but as the product of social injustice, one that requires not the cure or elimination of the defective person but significant changes in the social and built environment’ (ibid., p. 3).

Furthermore, Siebers expatiates:

> ‘Disability studies does not treat disease or disability, hoping to cure or avoid them; it studies the social meanings, symbols, and stigmas attached to disability identity and asks how they relate to enforced systems of exclusion and oppression, attacking the widespread belief that having an able body and mind determines whether one is a quality human being … Disability is not a physical or mental defect but a cultural and minority identity’ (ibid., p. 4).

This is why the Nigerian disability community is engaging with global disability groups—to share lessons, learn from their experiences, and help ensure Nigeria becomes a more disability-aware nation-state. The aim is not just to have the laws in place, but to ensure they are actually implemented.

In 2018, a former JONAPWD president, Danlami Basharu, was appointed to the UN Committee on the Rights of Persons with Disabilities, during which he shared his experience of Nigeria's struggles with disability inclusion with his peers and also brought home practical lessons to promote disability inclusion as practiced in other nations. It was during this period that Nigeria eventually enacted the Discrimination Against Persons with Disabilities [Prohibition] Act (2018).

My predecessor, Ekaete Judith Umoh, is the first and only female National President of JONAPWD to date. Until recently, she was the Inclusion Coordinator at the United Nations Resident Coordinator's Office in Nigeria. She pioneered the implementation of the United Nations Disability Inclusion, providing system-wide support in Disability Inclusion to all agencies of the UN Office in Abuja, Nigeria.

I also joined other leaders in the disability community as JONAPWD President at the Global Disability Summit 2025. The summit addressed issues of accessibility, equal opportunities, and the promotion of participation of persons with disabilities in socio-economic and political life. It was another opportunity for JONAPWD to network, share, and learn lessons on disability inclusion with a global audience.

CHAPTER FOUR

Who Counts? Defining Persons with Disabilities in Our Stories

Are You a Person with Disabilities? Some of you who are not currently identifying as persons with disabilities reading this book now might scream, 'God forbid!' This is due to your socialisation. You are still seeing impairments, such as physical disabilities, long- or short-term ill health that causes permanent injuries, as an untoward state of being. Being a person with disabilities does not mean you are not a person. This is why a school of thought amongst disability theorists recommends the term 'persons with disabilities' as appropriate, putting the person first before the disability. That is why we are clamouring for disability inclusion. Many people are persons with disabilities and they don't realise it, or don't want to admit it.

If we run a disability matrix, we may find out that some of you have psychosocial disabilities that you don't consider as an impairment. Those long- or short-term conditions, such as injuries that have caused mental or physical damage to your mind or body, chronic and protracted depression. Others include lingering diabetes, glaucoma that has significantly impaired or damaged your vision, albinism, and such impairments that require that you use an assistive device, qualify you as a person with disabilities. If you are unable to function in your workplace, for instance, due to chronic fatigue conditions, and you constantly need your reasonable accommodation to relax for five or ten minutes, you are a person with disabilities.

This condition, often termed energy-limited disability, is a chronic fatigue disorder, distinct from exhaustion caused by overworking. The impairment leads to constantly reduced energy and a persistent lack of stamina, which significantly affects your daily functioning. This condition manifests whether you are overwhelmed with work or not, and it is an example of an invisible disability—of which there are several others. Reasonable accommodation refers to the necessary modifications and adjustments required for you to function as a person with disabilities in your workplace. Remember the simple equation: Impairment + Barrier = Disability, only a few years ago did the rest of society start noticing concepts like invisible disabilities.

Prior to this, people were often ashamed to identify as persons with disabilities due to the derogatory labelling and offensive language associated with it. Consider chronic illness: if you refer to our definition or Article One of the UN Convention, it states, 'If you're experiencing long-term impairment...' A chronic illness can create an impact severe enough to cause an impairment, making it difficult for you to navigate the barriers in society. Your chronic illness, in itself, is not the issue. It is the interaction of your chronic illness with those societal barriers—the institutional and social barriers we mentioned—that makes it count. This interaction is what produces disability. We require functional limitations related to health for it to be counted as a disability.

In Nigeria, the concept of disability is still evolving. In our quest for inclusion, the disability community has continually broadened its acceptance of the varying spectrums of impairments. For instance, two decades ago, persons with albinism were not recognised as persons with disabilities in Nigeria. Neither were persons with mental and psychosocial conditions. Today, they are strongly recognised as such. Similarly, persons with short stature were not recognised, but now they are. Even parents of children with disabilities were not formerly recognised as part of the disability ecosystem. However, discussions are now strongly emerging on the need to integrate long-term caregivers—such as parents of children with disabilities, formal caregivers, and sign language interpreters—as essential allies within the disability movement. This is the progressive state of the Nigerian disability movement, a stage already reached in countries with progressive disability inclusion policies.

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My Personal Journey: Abdullahi Usman Aliyu

There are also persons with disabilities who do not wish to associate with the disability community, sometimes due to a simple unawareness that such a community exists. Others actively avoid association because they equate disability with disempowerment, discrimination, dependency, and neediness. That was the mindset I had decades ago when I was a young man in my hometown in Kebbi State. I did not associate with persons with disabilities, despite being affected by polio from a very young age.

Previously, particularly in Northern Nigeria where I originate, many persons with disabilities were unfortunately seen as street beggars. As a university graduate and a member of a royal family, I saw no connection between myself and those street beggars. Although some fellow students in school used to call me *gurgu* (a cripple), it did not enrage me, nor did I feel that I was a person with physical disabilities. I attended a mainstream school and did not see myself as being different from the other students.

There were two primary reasons for this perception: first, I was an active student; second, I come from a royal family. A *gurgu* is socially perceived as a poor, lame person who is expected to beg for alms. Since I was not doing that, why would I be categorised as a person with disabilities alongside a *gurgu* begging for alms? My disability is visible, yet throughout my childhood years—from primary school up to university, and even during my National Youth Service Corps (NYSC) year—I acknowledged my impairment but never associated myself with people with disabilities. I was integrated into mainstream schools with the rest of the population.

Of course, this mindset eventually changed. One day during my postgraduate studies in Kano, I was on my way to visit a colleague near the Aminu Kano Airport. I frequently used Katsina Road to get there. On one such visit, I came across some persons with disabilities who were not begging, but were using their hands to manufacture tricycles. I was astonished. It was the first time I had seen persons with disabilities productively engaged, and I remember thinking:

'These people—they are not beggars! They are actively working to benefit themselves and even some of their community members.'

So, I met and spoke with them, learning that they belonged to an association that encouraged and supported members to be productive rather than beg. That was the first time I heard of the existence of the Joint National Association of Persons with Disabilities (JONAPWD). Having learned this, I was inspired, thinking that this practice should be replicated in my home state of Kebbi—there should be an association that encourages persons with disabilities to be productive there, too. When I completed my schooling, I returned to Kebbi and began reaching out to people with disabilities. In part, that is where my personal struggles and activism began.

I formally joined JONAPWD in Kebbi State around 2004. Being the only person with disabilities in my family, I felt guided to connect with people outside my immediate relatives. Persons with disabilities became another family for me, and this is why I advocate so strongly for whatever can improve our general wellbeing. Twenty years later, in 2024, my advocacy and commitment to disability inclusion—particularly in Kebbi State and in Nigeria as a whole—were recognised when the Governor of Kebbi State, Comrade Dr Nasir Idris, appointed me as the pioneer Executive Secretary of the Kebbi State Commission for Persons with Disabilities.

CHAPTER FIVE

What Disability is Not: Moving beyond the Label

If we are already agreed on what disability is, are you surprised that we are also asking what disability is not? This is important in order to repeat the truth often until it is known, understood, and accepted by everyday people and decision-makers. As for me—Ekaete Umoh—I have never seen myself as a person with disabilities in the situation of being helpless, destitute, diseased, a sufferer, handicapped, a victim, or a receiver of handouts. These are what disability is not.

Furthermore, disability is also not those funny, belittling names and phrases that the rest of society calls or associates persons with disabilities with, such as albino, handicapped, afflicted with, sufferer of, brain damaged, invalid, leper, cripple, wheelchair-bound, deaf and dumb, deformed, mentally deranged, downie, dwarf, imbecile, midget, moron, blind or deaf (when used with negative inferences, as a derogatory proverb, or in order to discriminate against the Blind or the Deaf), and several other such derogatory names and phrases that abound in our indigenous languages. Disability is not those names.

Additionally, using disability as a derogatory label or in a discriminatory stance is unacceptable. For instance, if persons with disabilities assertively demand their rights at an event, and you comment, 'These disability people are something else,' that bias is fundamentally wrong. Crucially, disability is also not a temporary illness, like a fever or malaria, that can be cured with medication. We must return to the social model of disability: impairment plus barrier equals disability.

These labels reflect a global history of dehumanisation. James I. Charlton, in explaining the connection between language and disability, provides stark examples of how people with disabilities are imagined in the minds of others. For instance, in China, people with disabilities were historically called *canfei*, meaning ‘crippled and useless' (Charlton 1998: 68). Charlton further notes how this linguistic process assigns meaning:

‘Consider, for example, 'cripple,' 'invalid,' 'retard.' In Zimbabwe, the term is *chirema*, which literally translates as 'useless.' In Brazil, the term is *pena*, which is slang for an affliction that comes as punishment. These terms are evidence of how persons with disabilities are dehumanised. The process of assigning 'meaning' through language, signs, and symbols is relentless and takes place most significantly in families, religious institutions, communities, and schools’ (ibid., p. 52).

While there are communities in Nigeria where this toxic labelling is less common, the core truth remains: everyone needs support at one point in their life or another.

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For example, as a woman with disabilities, if I were on an outing and young girls were walking too quickly, I would stop them and say with confidence, ‘What's going on? You're leaving me behind. Can't you see I'm walking slowly?’ I would ask them to wait for me without apology. Persons with disabilities must engage with confidence and demand to be treated with respect. We don't have to fit into the straitjacket of conformity or accept what society expects of us. This is undoubtedly harder for those who are poor, but as students of politics remind us: power is taken, it is not given. The 2006 UN Convention on the Rights of Persons with Disabilities (UNCRPD) exists because activists didn't wait for a sympathetic society to help them—they demanded it. We must continue to demand our rights, just as everyone else does.

In the various communities I've lived in, people often found me too assertive. They had rigid expectations for how persons with disabilities, particularly women, should conduct themselves. Perhaps I was expected to be browbeaten, to say 'Thank you, Sir' to every injustice. Instead, I found myself shouting at the top of my voice, rejecting what was wrong.

Many people were simply not used to seeing someone like me behave this way, leading to confusion: 'Which one is this one?' Yet, my boldness in engaging them ultimately shifted their perspective: 'Oh, this one is a different person.'

I had polio as a child—so what? Is that supposed to make me less than a human being?

This experience echoes James I. Charlton's own encounter with pity:

'Every day, somebody will stop me and tell me I should find God and be happy. I tell them I'm already happy. They say no one can be happy in a wheelchair. I just laugh at them...' (ibid., p. 61–66).

CHAPTER SIX

Disability is Not the Opposite of Ability

It is important to clarify that disability is not the opposite of ability. Both concepts are social constructions rooted in society's flaws. Tobin Siebers provides an excellent explanation for this, which he itemised in his book, *Disability Theory*. Citing and paraphrasing some of his arguments reveals that, due to our limited knowledge of disability theory as a society, we have positioned ability as the 'ideological baseline by which humanness is determined… [T]he lesser the ability, the lesser the human being.' Based on this flawed premise, society uses disability as a yardstick to prevent persons with disabilities from fully participating in large societal affairs, unless their inclusion is based on pity from the rest of the population. Human actions, conditions, thoughts, and desires are, therefore, judged based on where they originate—from persons with disabilities or from the rest of the population.

Disability is consequently not considered a feature of humanity, despite the fact that it can arise from birth or other human conditions throughout life. Ability, however, is considered a feature of humanity. We assume that if you are not a person with disabilities, you are able-bodied and, therefore, able to live life fully. This assumption leads us to design environments that primarily ease things for the rest of society.

We provide staircases in storey buildings for persons without disabilities, yet leave the wheelchair user behind. We provide glasses for people with long or short sightedness to read effectively, but no Braille for the Blind. We provide a microphone so that the rest of the population in a large hall can talk and listen to one another with ease, but no sign language interpreters for the Deaf and the hard of hearing to participate equally. We construct high podiums with steps at ceremonial or official gatherings for the rest of the population to climb and sit on an elevated stage, but no ramps for persons with physical disabilities or wheelchair users. The implicit message is that we don't expect them to be part of the process. Persons with disabilities are never considered when designing revolving doors. Toilets, bus stations, and train stations are routinely designed to be inaccessible for persons with disabilities.

Our imagination is fixed: disability is inability; ability is capability. Due to our socialisation and acquired attitudes, we sometimes even think—and say out loud—that death is better than (severe) disabilities, including mental illness and multiple disabilities. We are surprised when we see women with disabilities become pregnant. We scream that demeaning question: 'Disabled and pregnant?!' When men or women with disabilities achieve great feats, we are shocked; we expect that only from the rest of the population. We ask: 'How did he or she perform excellently despite his or her disabilities?' We are well aware of the barriers we have created to impede, limit, or stunt the growth of persons with disabilities. Therefore, we perceive strangeness—we see something special—simply because a human being performed what other humans are performing!

The general societal mindset is that such achievement is extraordinary—it should not be a person with a disability making a public presentation, leading an office, training others, playing musical instruments, or being a professional—a lawyer, a professor, a medical doctor, an athlete; being elected to parliament, being a judge, an artist, or simply being somebody. Siebers (*op cit.* p. 10) stresses that, for the rest of the population:

‘The value of a human life arises as a question only when a person is disabled. Disabled people are worth less than nondisabled people, and the difference is counted in dollars and cents.’

Since the rest of the population continues to see only the impairments, Siebers observes that we cause persons with disabilities to be: ‘...bitter, angry, self-pitying, or selfish. Because they cannot see beyond their own pain, they lose the ability to consider the feelings of other people. Disability makes narcissists of us all.’

The injustice and oppression must be reversed. Disability is not the opposite of ability. Persons with disabilities will at no time transform into persons without disabilities. Everyone will perform to the best of their abilities if barriers are removed. Persons with disabilities want us to recognise their oppression and end it by changing attitudes and restructuring policies and all social tools that have been used to oppress them.

CHAPTER SEVEN

Diverse Experiences: Exploring Types of Disabilities Through Stories

A few years ago, people with mild polio who were not wheelchair users were not recognised as persons with disabilities—but they are. My predecessor, Ekaete Judith Umoh, was at one point perceived by some within the movement as a person without disabilities because her impairment from polio was considered mild. Yet a person who has an impairment that interacts with the environment and encounters barriers is, indeed, a person with disabilities. Through her commitment, Ekaete Judith Umoh became the first national women coordinator of JONAPWD in Nigeria and ultimately rose to become the first female national president of our association.

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Ekaete Umoh explains this further. At an early age, many people—including some persons with disabilities themselves—think disability is purely physical. They expect you to be in a wheelchair or walk on crutches, to use a white cane, or to be deaf rather than hard of hearing. If someone could scream and you could hear and respond to noise, you were not recognised as a person with disabilities. The rest of the population wanted to see severe impairment and pity you. Now, this is changing. Disability categorisation in Nigeria is expanding in tune with countries that have moved from disability mainstreaming or integration to disability inclusion, as recommended by the United Nations in its 2019 UN Disability Inclusion Strategy.

From Integration to Inclusion

Disability integration is a process that ensures conditions for persons with disabilities to participate are put in place. It mainstreams or ensures persons with disabilities are physically present or 'added' to the system. However, it does not erase attitudinal barriers or other barriers that persons with disabilities face, so their needs are not yet fully met. It does not involve complete participation in, or acceptance of, persons with disabilities by the rest of the population.

Inclusion, by contrast, goes beyond the provision of needs such as assistive devices or technology and the promulgation of policies that promote integration. Rather than simply making the environment accessible, inclusion emphasises full participation in society by persons with disabilities on equal terms with others through respect for the human rights of all persons—irrespective of whether they are persons with disabilities or not—awareness of human diversity, active involvement, and removal of all barriers against persons with impairments. The importance of disability inclusion is better explained in the diagramme below (culled from UN Implementation Strategy on Convention on Rights of Persons with Disabilities).

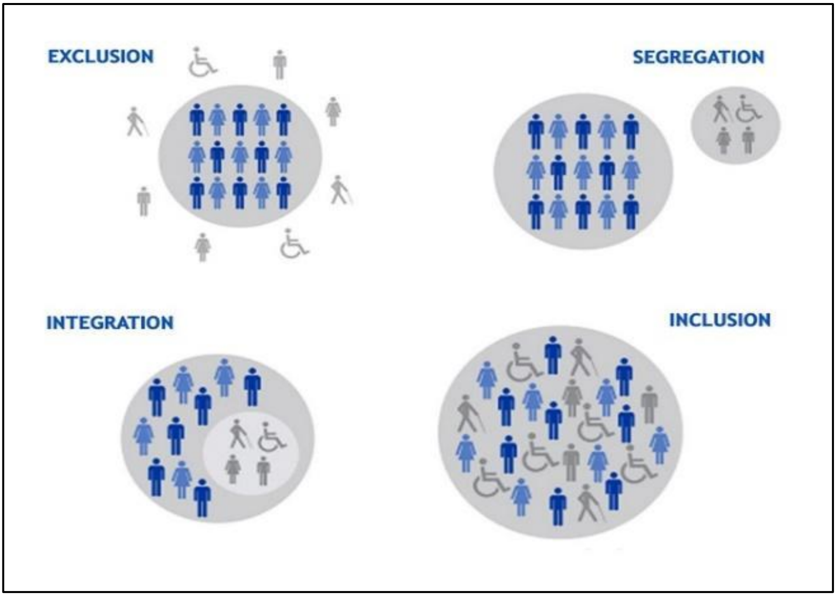

Figure 1 Source: United Nations. (2019). United Nations Disability Inclusion Strategy. New York: United Nations. Available at: https://www.un.org/en/content/disabilitystrategy/assets/documentation/UN_Disability_Inclusion_Strategy_english.pdf

Let us paraphrase James I. Charlton as he cites Chicago psychologist Carol Gill and British singer Johnny Crescendo, who reframe the issue of integrating persons with disabilities into society rather than allowing them to be included with power to decide as others do. Charlton states:

> ‘The struggle shouldn't be for integration, but for power. Once we have power, we can integrate whenever we want.’

Crescendo adds: ‘We're looking for interdependence, not independence. We're looking for power, not integration. If we have power, we can integrate with who we want’ (Brown, S.E. 1995: P. 126–127, 150.)

Permanent and Temporary Disabilities

We have permanent disabilities and temporary disabilities. If you fall into either of these two categories, whether you agree with it or not, you are a person with disabilities. It is simply another social classification of humans based on gender, race, age, and so on. Persons who are hard of hearing are now accepted as persons with disabilities, and they are gradually working towards being de-clustered from the Nigerian National Association of the Deaf (NNAD) to receive appropriate, reasonable accommodation instead of a one-size-fits-all approach.

Invisible Disabilities

We have people with invisible disabilities who are hardly recognised. For instance, a person with psychosocial disability is not seen walking on crutches or displaying certain physical evidence of their disability, but they are persons with disabilities all the same. Additionally, some diabetic persons can be categorised as persons with disabilities because, at advanced stages, diabetes affects vision, causes severe fatigue, or impacts the patient's brain until they become psychosocially affected. Sickle cell disease is also a disability because such persons need substantial assistance to function. In fact, some can be observed to be persons with physical disabilities. People whose interaction with the environment is affected by long-term depression in a way that does not affect the rest of the population become persons with disabilities.

Now, there are many kinds of disabilities. I still use that word because, over time, people have come to realise: ‘I have this chronic illness that prevents me from gaining employment; therefore, I am a person with disabilities.’ People are beginning to accept it from that lens now. The window is widening. What we know as disability is evolving, and we now have different classes of disabilities. In some countries, diabetes and sickle cell anaemia count as disabilities. In the early 2000s, persons affected by these ailments—sickle cell anaemia and diabetes, which impaired their full function in society—would protest: ‘Don't call me a person with disabilities! We are not persons with disabilities.’

Today, that has changed with greater knowledge and understanding that disability is not the impairments or the ailments themselves, but the discrimination faced by people with impairments.

Disability can also be invisible. This could be physical (hearing or vision loss that is not obvious) or mental and neurological conditions that interact with the environment and limit the persons with invisible disabilities, though these limitations are not usually visible to others. Examples of mental and neurological conditions include diabetes, multiple sclerosis, and other ailments that could limit a person with disabilities over a long period. Additionally, dyslexia and ADHD (Attention Deficit Hyperactivity Disorder), which are invisible, are considered learning disabilities.

Distinguishing Illness from Disability

It should be noted, however, that sickness or disease is not necessarily a disability. Illness is a state of ill health resulting from injury, infection, or other medical conditions over the short term. It is usually curable or manageable when proper treatment is applied. It could bring temporary discomfort but will not impair the person's health for long or permanently affect their work or everyday life. It might not result in attitudinal barriers since the person will recover and rejoin the rest of the population. However, when ill health results in an impairment that interacts with quality of life because of barriers, that is when it produces a disability.

Expanding the Movement: The Case of Leprosy Survivors

About two decades ago, it was very difficult to admit some clusters into the movement. We had six clusters across the board then. One cluster I would like to highlight here, because of the challenges they faced in gaining acceptance, is the survivors of leprosy—also known as IDEA (Integration, Dignity and Economic Advancement). They needed to form IDEA because of the stigmatisation that comes with leprosy. My goodness, it was a battle. If I had not stood firm and said, 'Listen, let me assure you, we will get through this one,' they would not have been accepted then. Can you see the layered stigmatisation here, considering the movement itself is already stigmatised? The cultural view—even the religious view—of a survivor of leprosy involves confining them in the bush.

In the past, the stigmatisation of survivors of leprosy was a significant issue. It remains so in some communities today. You should have witnessed the resistance when they wanted to join the movement! The whole saga reflected society's attitudes, even within the movement itself. May the soul of Shehu Fada, the then-president of the Survivors of Leprosy cluster, rest in peace. He passed recently. That man said to me, 'Ekaete, don't worry. Don't mind them…'

And I replied, 'Fada, sit here. You are part of us.'

We fought and brought them in. But even after we succeeded in bringing them in, keeping them as part of the movement was another challenge.

A Progressive Movement

However, I believe it is a progressive movement. Now we have people who are beginning to find their places. People are now saying, 'You didn't include me?' They want to identify with the movement. The question is: what is making them identify themselves as persons with disabilities now? People are hurrying to identify with the movement. Twenty years ago, you dared not point to someone as a person with disabilities; now they are willing to be part of the movement. This is one area requiring further research. We can all see that the movement is very open and willing to accommodate more clusters.

Women with postpartum (postnatal) issues are now finding themselves within the disability clusters, especially those with very prolong mental health challenges that have long term effect on the women's ability to carry out their day-to-day activities. However, the politics around mental health issues is that it is too elitist, too academic. Therefore, you see psychiatrists and others disagreeing with one another. There are two schools of thought about this today. Concerning psychosocial disabilities, one school believes that medicine is not the answer. They maintain that a patient needs love, support, and understanding, which would allow the affected person to evolve. Meanwhile, some psychiatrists believe that institutionalisation (confinement for medical attention) and medication are necessary. Consequently, there is a divide. That is why you cannot even have that group coming together under one umbrella. This is a key area of disability inclusion requiring expert opinion and research.

Some describe themselves as having psychosocial issues and leave it at that. Others describe themselves as having acute mental health issues and leave it at that. When you engage with those involved with mental health issues, you find professors, lecturers, and psychiatric doctors. But when you encounter those who call it a psychosocial issue, you see movements—people who have refused to be institutionalised. If there is anybody who is worse off in terms of being confined, it is those with psychosocial disabilities. You should witness the dehumanising treatment they receive—being restrained in some unlicensed mental health facilities, and all of that. These two concepts are not even the same. We will also leave it for other experts to discuss.

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The Current Clusters

Today, I am the only person with a disability in my family, and I have been the National President of JONAPWD since 2023. I understand that helping people in denial recognise themselves as persons with disabilities is a gradual process. JONAPWD stands as the umbrella organisation that recognises all clusters of persons with disabilities. Earlier, only six fully registered clusters of persons with disabilities were associated with JONAPWD. Now, we have ten clusters, namely:

Initial Six Clusters

1. National Association of the Blind (NAB)
2. Nigerian National Association of the Deaf (NNAD)
3. Spinal Cord Injuries Association of Nigeria (SCIAN)
4. Integration, Dignity and Economic Advancement (IDEA)–Survivors of leprosy
5. National Association of Persons with Physical Disabilities. (Broad cluster for polio survivors, amputees, and other physical disabilities)
6. Intellectual and Development Disabilities (IDD)

Four Additional Clusters Registered in the Last Two Years:

7. People of Short Stature
8. Persons with Albinism
9. Persons with Multiple Disabilities (such as DeafBlind Cluster) and;
10. Persons with Mental and Psychosocial disabilities.

Looking Forward

The movement is a process. We are not there yet, but we are learning very rapidly from good practices around the world. The idea for us is to create universal designs. In advocating for universal designs, it does not matter who you are or what kind of impairments you have or have acquired—persons with disabilities are either born with impairments or acquire them later in life. Once you begin to identify yourself as a person with disabilities, you can easily find your space without facing attitudinal barriers. With more evolutionary frameworks and strategic planning, more clusters will be recognised as time progresses.

CHAPTER EIGHT

The Journey on an Uncharted Route

How It Started

Disability is as old as humanity. Persons with disabilities have always been treated differently by others—often poorly and with contempt—because society perceives impairment as a limitation. At one time in history, rehabilitation homes started emerging, and citizens with disabilities were kept in these institutions. Society assumes that impairments limit citizens with disabilities from productive activities, unaware that it is the barriers constructed by the rest of the population that are the real problems, not the impairments themselves.

Persons with disabilities were perceived as birds of a feather that should flock together in their rehabilitation homes. In Nigeria, disability discourse hit the headlines at the national level in 1993 when the then military government of General Ibrahim Babangida promulgated a disability decree with the purpose of protecting and enforcing the rights of Nigerians with disabilities. Prior to this period, there had been a number of special schools for persons with disabilities and rehabilitation homes, some established before independence in 1960.

Some of these schools include the Gindiri School for the Blind in Plateau State (1953), the Pacelli School for the Blind in Lagos State (1962), and another in Obudu (Florence Banku Obi, *et al*, 2007). Today, there are over twenty schools for the Blind scattered across the country. There was a school for the Deaf in Lagos (1958), the Oji River Rehabilitation Centre in Enugu (1960), and several such special schools aimed at mainstreaming disability in education. In recent times, persons with disabilities and other activists have been calling for inclusive education and accessibility beyond education in Nigerian society to ensure that persons with disabilities fully participate in all spheres of life.

A routine challenge in developing democracies is poor documentation. Nigeria is not an exception, even with institutions of government that one would expect to be structured and funded. One can then imagine the case of the then nascent association like JONAPWD—a group of individuals with temporary or permanent impairments with which they were profiled, burdened, and obstructed. Thus, records of past JONAPWD activities are scanty and not stored in a retrievable manner.

As mentioned above, to write this book we relied extensively on our personal experiences as former and current national presidents of persons with disabilities, validated by other colleagues in the disability community known to have participated in JONAPWD's formation and growth. Since its emergence in the 1990s, JONAPWD has had five national presidents, three of whom are late. The surviving two—the immediate past national president Ekaete Judith Umoh and I, Abdullahi Usman Aliyu, the current national president—have journeyed through uncharted routes to narrate the tale of JONAPWD's evolution based on information we could piece together, as recounted below.

There are so many stories around the evolution of JONAPWD under different names. One verified narration states that the Joint National Association of Persons with Disabilities came to stay during President Olusegun Obasanjo's era. Though persons with disabilities, mobilising themselves, had also congregated under different names such as Joint Disabled People and Handicapped Disabled People—all manner of names were suggested and tested. Finally, at the point of registration with the Corporate Affairs Commission (CAC), the name JONAPWD was coined and registered.

Though there was no documented evidence, oral history has it that the seed of the disability rights movement was planted in special education departments of university campuses. Though it had no real structure, it was established in response to apparent unintended discrimination faced by students with disabilities on these campuses. A few universities mentioned as being in the limelight included the University of Jos, University of Ibadan, and University of Calabar, amongst others. These universities were said to have had more students with disabilities in their respective special education departments than other universities. Part of the students' complaints was that no matter how good their results were; they would be pushed into special education because they had a disability.

It seemed that the thinking then was that they would understand you better in such a department, so please go there. It is only in recent times that persons with disabilities have begun to study law and other courses to which they aspire. These students reached a point when they discovered that they were being treated as though they were less than other students. They were not getting the same rights as other students. They had inaccessible accommodation issues amongst several other problems. In addition, these institutions didn't seem to realise that they were persons with disabilities and therefore needed some understanding regarding reasonable accommodation. So, a time came when they grew tired of the discrimination and started agitating through direct action and advocacy. This drew attention to their plights and forced a discourse on how the campus could be more accessible.

That was where the conversation started and movements began organising. We just started with one, two, three people organising. That was how the movement started forming. I think that during that time the former president, Prince Paul Adelabu (may his soul rest in peace), and a few other forerunners got into that conversation. He made contact with the students and supported their call for more responsiveness by the universities. Before we knew it, student movements around disability issues began to evolve on different campuses. So Jos would do theirs, Calabar would do theirs, and others followed suit. This common issue became a rallying point for everyone and culminated in the establishment of the movement. That decision started on campus and was finally brought to the public sphere.

Using the movement as a platform, they started challenging systems and structures. I remember that Kaduna was also a very strategic town where students and other disability activists were convening and holding many meetings. Kaduna then was associated with one National Handicapped Association. There were all kinds of groups, such as the Disabled People Association—many names evolved. In 1999, when President Olusegun Obasanjo came to power, there were so many persons with disabilities groups showing up to see him as separate bodies representing different disability groups and not as one united front representing every cluster. According to oral accounts of one such visit, he voiced his dissatisfaction and said, 'Excuse me, I'm tired of seeing different groups coming to see me.' He then charged the movement and said, 'If you must see me, this is what must happen—go and organise yourselves together.' Then he sent all of them to a ministry.

First, they took them to the Ministry of Youth and Sports. From there they went to the Ministry of Women Affairs, and then to the Ministry of Information. Later he asked, 'Which ministry will be handling these people? I'm tired of different groups of people who should actually be together coming to shake hands with me.'

Eventually, they were returned to the Ministry of Women Affairs. The ministry put them under the rehabilitation department because at that time they saw the needs of persons with disabilities as rehabilitation. So it was at that point that they came together because the President said, 'All these different groups, put yourselves together. That is when I can talk to you.'

Therefore, the then Ministry of Women Affairs and Social Development became the mother ministry, having oversight of our activities and serving as the bridge between the organisation of persons with disabilities and the federal government.

From there the early leaders started to institutionalise the organisation. At that time, they made an attempt to register with the Corporate Affairs Commission (CAC) with a more encompassing name: Joint, meaning everybody's association of persons with disabilities, but it did not pass through. The few clusters that were active then – mainly those with visible disabilities – agreed to have an umbrella association open to all persons with disabilities in Nigeria irrespective of their cluster. So I can tell you that finally it was during President Obasanjo's tenure that we hit the ground running as a national movement recognised by the federal government. That was about the time we started putting the paperwork together.

JONAPWD as a movement began in the early 1990s, though it had yet to fashion an agreed name then. Some persons with disabilities who were considered as mentors then, having met with stakeholders in and out of government, agreed that a coordinated and collective approach, rather than individual associations or clusters, would help the movement operate more efficiently and better protect the rights of persons with disabilities. Our mentors understood that having each organisation of persons with disabilities (OPD) operating separately would not be to our advantage. Rather, it would make it easy for policymakers, and even society as a whole, to take advantage of that fragmentation to deprive us of our human rights.

Some of our mentors who pushed for the collective approach and mobilised others when it became clear to us that we needed to come together and have a stronger voice were the likes of Prince Paul Adelabu, Ms. Omotunde Ellen Thompson, Sule Makarfi, Rilwan Abdullahi, Dandeson Hart, Evangelist James Olukayode, and several others. In the end, the mentors came up with the umbrella body, and with that development, many people bought into the idea. And JONAPWD was born.

The Turbulent Years

With the formation of JONAPWD came the struggle for leadership. At that point, according to oral accounts, Prince Paul Adelabu acted as the pioneer and interim leader, though there had been no election. Adelabu came to limelight, firstly as the Principal of Rehabilitation Centre, Moniya in Ibadan, Oyo State. The leaders at the time were juggling their collective efforts to make the new joint association effective—through united engagements with state actors—with their individual ambitions and competition for control of the soul of JONAPWD. Despite this, progress was made. Eventually, they started moving around to establish some state chapters. Some people bought into this idea whilst others did not. But at the end of the day, many people across the states accepted the movement. As time went on, the first convention of JONAPWD took place in Kaduna State in 1997. The campaigns came under fire with much interest and contention. But at the end of the day, an election took place, with Barrister

Philip Ibrahim emerging as the first elected president of JONAPWD.

The First Elections and Factional Split

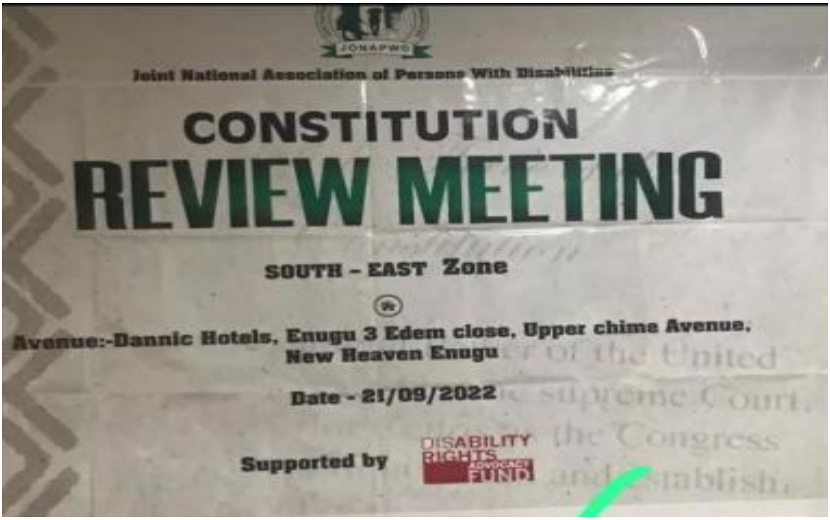
It was the first time that persons with disabilities were forming an umbrella association. It was a period of learning which also exposed the challenges of the new coalition—JONAPWD. The winner-takes-all elections did not help the situation. There was no office or secretariat then as we have today; elected officials also relied on the use of their personal funds and whatever support they could get for travel and related administrative action. There was schism, accusations and counter-accusations amongst members, depending on their pre-election lineage. Philip Ibrahim, the then national president, a civil servant with the Kano State Ministry of Justice, returned to his base and operated from there, as did other elected officials.

The new joint association was eventually divided due to the unresolved internal disputes. Some members—Prince Paul Adelabu, Rilwan Abdullahi, and Godson Amadi, amongst others—alleged that the then national president was not up and running and they started a factional movement.

As a result, sometime between 2000 and 2001, Prince Paul Adelabu, Rilwan Abdullahi and some other leaders made a move to organise another convention in Ibadan. A fresh election was conducted during which Prince Paul Adelabu emerged as president. Danlami Basharu became his vice-president. Adamu Bako from Kaduna emerged as the secretary, amongst others. However, the factional body could not progress as it did not have nationwide support. It was supported by representatives from a few states who came up to organise that convention to counter that of Kaduna. Despite the fiasco of the election by the factional groups, the schism within the movement continued. The result was that we now had a divided movement, with members divided between the two groups.

Reconciliation and Constitutional Development

At some point, one faction of JONAPWD went to pay a courtesy call on the then President Olusegun Obasanjo, then another faction went with the same request. This led to more confusion as to why two different individuals would come to represent the same organisation and request an audience with the President. It also externalised the crisis within JONAPWD. Following the directive of the President, the Ministry of Women Affairs and Social Development investigated and understood that there was a faction in the movement.



JONAPWD

Joint National Association of Persons With Disabilities

CONSTITUTION

REVIEW MEETING

SOUTH - EAST Zone

@

Avenue:-Dannic Hotels, Enugu 3 Edem close, Upper chime Avenue, New Heaven Enugu

Date - 21/09/2022

Supported by DISABILITY RIGHTS ADVOCACY FUND

Image 03: A Constitutional Review Session in 2022: As a growing association, JONAPWD is committed to change

The ministry constituted an eleven-person committee to oversee the issue. The outcome was a recommendation for the drafting of a constitution to guide the affairs of JONAPWD and help it conduct a more acceptable convention.

Following this development, Danlami Basharu tendered his resignation, withdrawing from the previous convention that took place in Ibadan. The Ministry of Women Affairs and Social Development also brokered a peace meeting attended by some of the warring factions' leaders in order to find a way forward.

The committee supported JONAPWD to draft its first constitution, which was used in organising a second convention in 2004 in Minna, Niger State. The election for the national president position was contested between Danlami Basharu and Prince Paul Adelabu. Danlami Basharu emerged as the president. The composition of that electoral committee was made up of very good people such as Gbenga Oso, Ms. Omotunde Ellen Thompson, Abdullahi Akilu who was in Kaduna, and representatives of the Federal Ministry of Women Affairs and Social Development, amongst others.

Registration and Development Partners

It was from that convention that JONAPWD started to gain traction again, as it had almost gone moribund before the convention. The new executive met and agreed to address all grievances and called for members' support and cooperation. The then newly elected president, Danlami Basharu, tried to hit the ground running and started engaging development partners. He realised the need to partner with other stakeholders to make the organisation vibrant and functional rather than rely totally on the government. It was such development partners' engagement that made us realise that we needed to be registered as a legal entity before they could work with us.

Consequently, we revived our interest in the process of registration. It took Danlami Basharu until 2008 before he finally registered JONAPWD with the Corporate Affairs Commission. This was after sixteen years of struggle and activism for disability inclusion. The disability movement gained momentum around 1992 when persons with disabilities started demanding their rights from the rest of the population, especially from decision-makers. This was after the third convention that took place in Abuja. The first was in Kaduna State, the second was in Niger State, and the third was in Abuja.

After the registration, international development partners' support started trickling in, as well as that of Nigerian-led civil society organisations partnering with JONAPWD towards making life better for persons with disabilities. Subsequently, we focused on establishing functional state chapters of JONAPWD. All through these processes, Rilwan Abdullahi, the then national auditor, and other executive members worked assiduously with the national president. It was the settling-in stage for JONAPWD—peace, effective planning, and teamwork helped in producing results. With time, some of the state chapters began functioning more effectively, engaging state and non-state actors in their respective states.

Some Key Moments in Electoral Politics

In 2008, Rilwan Abdullahi challenged Danlami Basharu for the position of national president. However, they reached a consensus whereby Rilwan emerged as the first national vice-president whilst Danlami was re-elected for a second tenure. In his second tenure, the Danlami Basharu-led executive paid more attention to advocacy, enlightenment, and calls for laws to address discrimination against persons with disabilities. It was shortly before this second tenure that JONAPWD opened its first office at the National Centre for Women Development in 2007. When we started, we didn't have an office anywhere. The JONAPWD office was anywhere we could gather and make decisions. We operated an agile work environment, not by design, but by circumstances.

In 2012, when Danlami's second tenure elapsed, there was an attempt at conducting another convention in Abuja. This did not work as there were divergent interests amongst some members. This led to the 'doctrine of necessity', that is, in order to prevent constitutional crisis, members decided to extend the tenure of the then leadership to 2013, during which an election was held in Abuja. However, this election was inconclusive.

In 2014, in order to address the political impasse already created due to the inconclusive election, JONAPWD held a fresh convention, considered as its fourth convention, in Lokoja, Kogi State. My predecessor, Ekaete Judith Umoh, emerged as the national president after she contested against eight men, including Dandeson Hart, Suraju Aminu, James Lalu, Daniel Amaechi Onwe, Rilwan Abdullahi, and three others. This was unprecedented and unexpected, as it affirmed the intensity and interest of the association's leaders in addressing the exclusion of women from politics and governance within the disability community and in wider society. The barriers and odds against the candidacy of Ekaete Judith Umoh were huge and not dissimilar to the challenges faced by women in associational and national elections in Nigeria. Some male members considered it an aberration that JONAPWD would be led by a female president at the national level.

During the 2014 election, the majority of the delegates came from the North, with several contestants from the North as well, who were men and Muslims. Some of these people from the North campaigned on ethnic, religious, and gender bases. Ordinarily, these factors were against Ekaete Judith Umoh in Nigeria's political configuration, but she still scaled through.

Image 04: Women with Disability calling for Inclusion: Commitment to Social and Gender Inclusion during a JONAPWD organised programme

I recall Danlami Basharu telling me, ‘Abdullahi, I want you to support Ekaete's candidacy because of her experience and commitment.’ However, it was her résumé which convinced me more to do so. As her campaign coordinator, I was able to sell her candidacy to the community and persuade delegates to vote for her because of her résumé, which clearly chronicled her various achievements and contributions to the community. I even tried to persuade some of the male candidates to step down for her based on the résumé, though none agreed.

A number of other factors have been attributed as responsible for Ekaete's victory, amongst which are her exposure, knowledge, educational background, network, and experience of disability inclusion nationally and at international level. Also, the fact that eight other men were contesting thinned out the votes for all the male candidates, especially those who anchored their campaign on religion, gender and ethnicity.

Nonetheless, we went into the elections. The voting process was observed by a renowned civil society group—Transition Monitoring Group (TMG)—and was broadcast live by the Nigerian Television Authority (NTA) for transparency and credibility. The Nigeria Security and Civil Defence Corps (NSCDC) provided security. Voting lasted until about 3 a.m. Immediately after, the results were declared and winners announced. Thereafter, a national press conference was held, putting the tension to rest. The 2014 election in Lokoja was the first time more than three persons would be contesting for the position of national president. Also, it produced the first and only female president of JONAPWD to date.

Ekaete Judith Umoh continued the mobilisation, strengthening of state chapters, and advocacy to decision-makers to push for disability inclusion in public and private sectors. Being a female, she also paid attention to strengthening women's participation and representation in JONAPWD. Ekaete deepened her engagements with development actors, bringing in more funding to improve disability inclusion across the board.

In 2018, another convention was held in Abuja. This would be the fifth convention. Ekaete Judith Umoh was re-elected president. However, she did not finish her second tenure. Because of an appointment as the pioneer Country Director of an international organisation of persons with disabilities–CBM Global Disability Inclusion. It was an intense assignment which would have made it difficult to perform her responsibilities as national president effectively, in 2021 she stepped aside, and I, as the then vice-president, took over as the acting president to complete the Umoh/Aliyu tenure. At the sixth convention, which was held in Abuja in 2023, I leveraged the social capital of Ekaete and I had already garnered to campaign and was voted in as the fifth national president of JONAPWD.

An Umbrella for Persons with Disabilities in Nigeria

JONAPWD is the umbrella body for all other organisations of persons with disabilities that champion inclusion across the country. For instance, there are organisations of persons with disabilities working around the inclusion of persons with disabilities in politics. Some are working around inclusive health. Some are working around inclusive education. Some are working around climate change and gender inclusion. There are some NGOs or organisations which are headed and formed by persons with disabilities working around their various areas of interest. One of the reasons for our coming together was to form a larger, stronger association that could work towards the passage of bills on the rights of persons with disabilities at the National Assembly. We felt that it was important for us to speak with one voice if we were to be listened to.

Today, JONAPWD's vision is of a society where '… equality, social justice, and rights of persons with disabilities are guaranteed,' whilst the mission is to '… attain a society where equity, social justice and rights of persons with disabilities are guaranteed through specific projects, advocacy, and partnership with relevant stakeholders.'

Its core goals remain to:

i. promote the human rights of Nigerians with disabilities
ii. promote economic and social integration of persons with disabilities
iii. provide technical support to grassroots' organisations of persons with disabilities
iv. provide a national platform for disability discourse
v. serve as a national clearing house on disability and development

In order for us to continue to speak with one voice, there is a need for continuous collaboration; use of problem-solving approaches; opening up spaces for more clusters of persons with disabilities to be part of the process; and sustenance of our core values of accountability and transparency, commitment, inclusion, and partnership.

CHAPTER NINE

Advancing Inclusion: Gender Equity and Cluster Representation

Gender Inclusion

Gender equality and women's participation in politics have been matters of concern in Nigeria's sociopolitical ecosystem. Women are left behind in political leadership participation across the political spectrum in the country. In the 10th National Assembly, for instance, the number of elected women in the Senate is four out of 109, and 16 out of 360 in the House of Representatives. This constitutes only 4% of elected women in the national parliament.

Prior to 2007, there was not much discourse on gender inclusion in JONAPWD. The association used to have an adviser to the national president on women's issues. In the disability community, the situation is not different. Patriarchy was deep-rooted. The general perception among the male membership was that women were not designed to lead.

In 2008, I told myself, ‘Go, Ekaete! Go! It is about time to lead from the front.’ So I contested for the position of Secretary General. Surprisingly, I lost. I thought that with my robust campaigns, open endorsements by supporters, assurances from different clusters, my volunteering and work with the then leadership of JONAPWD, victory was sure. Alas, when the result was declared, Honourable Dandeson Hart, a male candidate, emerged as the winner. Then, I said to myself:

> ‘Now I can understand that they are not ready for a female leader. That's a way of telling me, “Excuse me, that position is not for females. Are you okay?'

It dawned on me then that Dandeson Hart's campaign slogan—Danlami for Dandeson—was not just a jingle, but a behind-the-door arranged plot by the all-male leadership to uphold the status quo of a 100% male executive. I concluded that persons with disabilities in Nigeria, like the rest of the population, were not ready for female leadership.

And I told them,

'Thank you for giving me this opportunity to contest. This is where I end my activism with you guys. I'm done.'

'Yes,' I said to them, 'If this is the way elections are conducted, it's over, so let me move on.'

But they came back to me and said, 'you can't go like that. We can't let you go.'

Because of my exposure, I was involved in providing technical support such as drafting proposals and engaging with donor agencies, among others. I had volunteered over a long period of time, providing support to the leadership of JONAPWD. So, to placate me, I was offered the position of adviser to the president, which I rejected. I asked:

'Who am I advising? A man on women's matters? I'm not advising any man on women's matters!'

They said to me, 'okay, what do you want?'

Because there were no women in the executive, I said,

'I want a substantive role for women in the executive. You people have to institutionalise this position for women. I can't find them here. Create that space. I will only listen to you if you create it. Otherwise, I'm done with you guys.'

So, we negotiated and negotiated until we ended up with the position of Women's Coordinator. In order to validate this agreement, I said to them again, 'Okay, write it down, sign it, give me an appointment letter, stamp it. Distribute this letter to all donor agencies. Let them know that I'm the Women's Coordinator.'

But I was still not satisfied with this concession. I knew this was politics. I told them I would only accept the position if we put it in the constitution. That was how the position of Women's Coordinator, now Women's Leader came to be enshrined in JONAPWD's constitution to this date. At that time, women were so invisible in the movement. You would not see them anywhere. You could only see men bringing themselves forward. So my attempt to contest for the position of Secretary General was very odd. As is the practice in associational elections in Nigeria, the only position they reserved for women, which men have also taken over now, was treasurer. They felt that women were better managers of resources. In the past, women hardly participated in meetings. I pushed for at least two women to participate in every meeting. Now women attend meetings.

Later on, JONAPWD leadership and other critical stakeholders were supported to hold a convention in Lafia, the capital of Nasarawa State, with the support of the then Governor, Alhaji Tanko Al-Makura. Also, the Department for International Development (DFID)-supported project entitled Coalitions for Change (C4C) provided additional support to make the convention a success. (DFID is now known as United Kingdom Foreign, Commonwealth and Development Office [FCDO].) The C4C project supported us to go to Lafia for the convention to adopt a new constitution. From the time we adopted the constitution till date, it became the practice—as some kind of affirmative action—that for every congress or convention, there must be at least two women from the then six clusters. That marked the beginning of a gradual increase in visibility for women with disabilities within the movement.

At that time, disability inclusion was one of the critical issues of focus for C4C. Others were constitutional reforms, climate change, gender, accountability, water resources governance, and extractive industry justice. The C4C project was led by an amazon, a leading gender and social inclusion activist, Amina Salihu PhD., who was the programme manager. The co-author of this book, Olumide Olaniyan, was also part of the C4C team.

After the inclusion of women's representation in the constitution, which is still in force, it became compulsory for women to be part of the process. From then on, if we were going to any congress, we must bring at least two women. This singular move encouraged women to start showing up gradually. Before then, they just didn't show up; it was purely a men's affair. When JONAPWD started working more with donor agencies, of course, gender inclusion became a big issue. It was also expected of us (JONAPWD) to ensure that women and girls with disabilities had space to express themselves.

In 2014, efforts towards gender integration in JONAPWD paid off. I emerged as the first female candidate to be elected as national president within the short history of JONAPWD's existence, and it wasn't based on affirmative action. Women with disabilities and other male supporters mobilised and voted for me. It wasn't without some drama, as some women with disabilities came to me privately to ask if I was sure of winning, considering the lopsided political contestation in Nigeria.

One came to me and said, ‘you have the guts o.’

I said, ‘What?’

‘So you want to be president?’ she wondered.

‘What is wrong with that?’ I asked.

‘You didn't see the position of treasurer; it's the seat of the president that you're going for?’ she enquired. She told me she was afraid for me.

‘Afraid for what now?’ I asked. Obviously, women have been socialised to accept certain gender roles.

‘No, I'm not afraid,’ I answered.

After my emergence, using the platform of JONAPWD, I started collaborating with women's movements to push for inclusion and visibility for women with disabilities, and for them to be given spaces to thrive. Hopefully, the audacity to contest for the highest position, and my victory thereafter, would inspire more women with disabilities to contest for more executive positions in JONAPWD in the future and more positions in general elections in Nigeria. However, sometimes women who get these spaces are neither properly equipped nor confident enough to utilise them. So, there's a need to provide them with the requisite knowledge to enable them to do so.

Concerning my engagements on the international scene: at the sub-regional level, I became the Vice Chair of the West African Federation of Persons with Disabilities (WAFOD). I could contest that sub-regional election because I was the National President of JONAPWD. At the regional level, I also contested at the African Disability Forum (ADF) and was elected to the Board to represent women with disabilities across the whole of Africa. Four years after that, I contested again and was elected to be the Secretary of the African Disability Forum. I was also elected as the African Director of Disabled People International (DPI). The election was held in New Delhi, India. After that, I became the global Vice Chair for Disabled People International.

Before then, in 2012, I was elected Vice Chair, African Region, of Rehabilitation International. Rehabilitation International is over one hundred years old and is one of the oldest global disability organisations. Though, this was before becoming the National President of JONAPWD, I must add that I had access to some of those spaces because I was the National President of JONAPWD, and that gave me the platform to contest sub-regional and regional elections of the disability movement. I must also add that most of these spaces were male-dominated. But being the first female national president of JONAPWD gave me the courage to challenge at international spaces. So, I was the first female to occupy most of those international positions as a result of the experience I got from JONAPWD. Women with disabilities need not be discouraged when they face obstacles in their quest to lead. Challenging patriarchy is a continuum. It is a process, not a trophy, and it involves everyone—women with disabilities, men with disabilities, young persons with disabilities, and the rest of the population.

It's important to acknowledge the role men play in bringing women to power, and the need for women to work hard to earn the positions they aspire to. For instance, it was Danlami Basharu, the then president, who asked Mallam Abdullahi Usman Aliyu, our current national president, to work for my emergence as national president because of my contributions to the movement. So, it is not about women with disabilities versus men with disabilities. It is about space for everyone—women, men, and young people—to participate and have equal opportunities to represent the association, but you must be bringing something to the table in term of capability. What have you got?

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As a male gender justice champion and Ekaete's campaign coordinator, let me add that the support from some of my fellow gender-sensitive male leaders eased the path for Ekaete Umoh's candidacy to emerge as the winner. Thereafter, I emerged as her Vice President I, as mentioned earlier. This is one lesson the gender and women's movements can learn from JONAPWD: championing and promoting women's participation and representation in politics through male collaboration and endorsement. Political representation is not male versus female; it is cooperation and coordination for equal participation irrespective of gender, ethnicity, and disability status.

Image 05: Inaugural National Conference of Heads of Disability Commissions held in September 2025, under the leadership of Abdullahi Usman Aliyu

Ekaete Judith Umoh's victory at the polls at the highest level in JONAPWD also dismissed the usual excuse that religion, culture, and tradition are the reasons why women are not being elected into political offices. These perceived hurdles were raised but eventually set aside, as persons with disabilities demonstrated that Nigeria can navigate the current chaotic space of marginalising women – including women with disabilities – get it right, and create an amiable space for women to be elected into offices like their male counterparts, based on inclusive premises and a change of attitudes.

After the 2023 elections, in order to further strengthen women's and young persons' representation and participation, we created loose platforms for women leaders. One such platform is for general women leaders from the groups in thirty-six states and the Federal Capital Territory. We also created another platform for the young women leaders' group, also across the thirty-six states. We want women to participate fully. We will refine our strategy for this as time progresses. We are working to address the issue of low self-esteem among women with disabilities. We realise that encouraging women to participate in decision-making processes is key to disability inclusion, and we are working to achieve that.

Addressing discrimination within the disability movement, we are also making efforts towards ensuring wider space for women through the office of the women leader. We want to have vibrant women leaders across all states. We want the women to participate fully in this movement. Some of the women leaders who are not above 35 years of age are also part of the female youth group.

The government should be more responsive and responsible to citizens with disabilities. The way we are having conversations regarding gender and children is the same way we should discuss children with disabilities, women with disabilities, young women with disabilities, men with disabilities, and elderly persons with disabilities. Therefore, the government has to be more responsive.

Representation, Participation and Inclusion of Clusters of Persons with Disabilities

Some observers have noted that the persons with physical disabilities' cluster is more noticeable in the leadership of JONAPWD. This is evident if you look at the leadership since the first election that brought in Philip Ibrahim. Three of the five previous national presidents belong to the persons with physical disabilities cluster – Prince Paul Adelabu (2nd), Ekaete Judith Umoh (4th), and I, Abdullahi Usman Aliyu (5th) – while Philip Ibrahim belonged to the Spinal Cord Injuries

Association of Nigeria (SCIAN) cluster. Danlami was from the National Association of the Blind cluster.

It's not just a Nigerian case. Let's go back to how the global disability movement evolved. You remember veterans who went to war. In fact, the disability rights movement started at the end of the Second World War. We had veterans who had returned from war with injuries—that was how the movement started. These were very active and strong people. But because they now had injuries, they just kept them somewhere and gave them food and assistive devices.

However, they failed to address the overt and subtle discrimination against them from the rest of the population. Of course, they revolted. That was how the movement started building up.

Some argue that physical impairment, depending on its level of severity, is more manageable. The persons with physical disabilities are more likely to attend mainstream school from primary level to tertiary. This gives them more access to education compared to other clusters of persons with disabilities. This perceived advantage could have an adverse impact and create a gulf among different clusters of persons with disabilities. In line with JONAPWD's vision to build '…a society where equality, social justice, and rights of persons with disabilities are guaranteed,' JONAPWD is focusing on ensuring that the rest of society removes barriers for all clusters of persons with disabilities. Being the umbrella body for all persons with disabilities, JONAPWD will, therefore, continue to intensify its campaign for equity, equality, and effective participation by all persons with disabilities, irrespective of their type of disability.

Leaving No Cluster Behind

From the composition of JONAPWD, initially, we had persons with physical disabilities, the Deaf, the Blind, and the spinal cord-injured. That was how the movement began. Later on, during or after the 2004 convention, the survivors of leprosy and persons with intellectual and developmental disabilities were brought into JONAPWD, bringing the various clusters to six. At the last convention in Abuja, persons with albinism were also brought in. So, once any group of persons with certain disabilities is legally recognised and registered, JONAPWD will bring them on board. However, JONAPWD does not stop any cluster from pursuing their individual goals.

JONAPWD's constitution envisages this when it makes provisions for the leader of each cluster to be part of the executive. Article 7(B) states inter alia that:

> '…the heads of the six cluster disability groups and six Zonal coordinators, one of whom shall come from each of the six geopolitical zones of the country.'

All clusters are also encouraged and supported to participate fully in the congresses and conventions. Article 8(2) of the constitution addresses this further. This is paraphrased below:

> '…National Electoral Committee for the National Congress should be set up three (3) months prior to election to receive nominations; the Committee shall ensure that all members have adequate opportunity to make nominations and to know the names of nominees before the elections;

'…the Committee shall ensure that the spirit of disability group representation is maintained in the elections; clusters must nominate or adopt a candidate for national offices; the Committee shall allocate five minutes to each of the following candidates to convince members of their suitability for the post: President, Secretary-General, Treasurer, Financial Secretary, Social Welfare Secretary, Publicity Secretary, Planning and Organising Secretary, Sports Secretary, and Chief Whip.'

Aside from the legal provisions, in practice, every cluster is directed to bring one representative from their state chapters to every election. If such affirmative action procedures are not used, some clusters might not be represented in state and national elections. We have continued to adapt to the extent that the constitution allows us, and based on lessons we are learning from other disability communities across the globe.

Disability experts have counselled against 'impairment ranking.' This creation of ranking based on type of disability is what Tobin Siebers terms the 'hierarchy of oppression,' depending on the perception of varying types of disability among persons with disabilities and the rest of the population. Siebers. T (ibid, p. 29) disapproved of disability simulation in the name of empathy. The intersectionality theorist argues,

> '…simulations tempt students (the rest of the population) to play the game of "What is Worse?"' as they experiment with different simulations. Is it worse to be blind or deaf, worse to lose a leg or an arm, worse to be paralysed or deaf, mute, and blind? The result is a thoroughly negative and unrealistic impression of disability' (ibid, p. 29).

Full and effective participation of all clusters is one area where JONAPWD will evolve more strategies to address. Removal of barriers against all persons with disabilities is important in achieving this. JONAPWD will continue its advocacy to various agencies of government and others to ensure that discrimination against persons with disabilities ends, even if this will take a gradual process. It will especially work more with the National Commission for Persons with Disabilities (NCPWD) to ensure more effectiveness in the implementation of the Discrimination Against Persons with Disabilities [Prohibition] Act (2018). Already, the five-year moratorium given to institutions to familiarise themselves with the act and make amendments to facilities, as well as implement sections of the law as it concerns individual private and public institutions, has expired.

CHAPTER TEN

From Signature to Action: Nigeria and the UNCRPD

Nigeria is applying the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) politically. Nigeria has signed the law prohibiting discrimination against persons with disabilities, but it appeared to be a mere political move at the time it was signed. I remember in 2018, just a few months before the general election, President Muhammadu Buhari and his vice were answering questions from journalists and civil society actors when David Anyaele, the Executive Director and founder of the Centre for Citizens with Disabilities (CCD), asked a question about what the Buhari administration was going to say about the disability rights bill and how and when they were going to sign it into law. President Buhari did not respond directly or positively on the status of the bill. Instead, he had a quick tête-à-tête with the Vice President, Professor Yemi Osinbajo, who affirmed that the disability bill was at the National Assembly. At that point, it became obvious that the government did not prioritise the signing of the bill. The information in public space then was that the bill has been transmitted to the Presidency for assent.

Fortunately, at that time, JONAPWD had a running grant from the Disability Rights Fund (DRF). Having understood what had happened at the press conference, we mobilised the disability community—all the stakeholders—to come to Abuja for a press conference. We went to the Police Officers' Mess and held a global press conference there. We invited all the media houses, both print and electronic media in the country, and tagged the social media handles of the international development agencies working on disability rights.

Image 06: Abdullahi Usman Aliyu, JONAPWD National President sharing knowledge on Disability Inclusion strategy at the international level, at the UNCRPD 2025 session in Geneva, Switzerland)

Leaders in the disability community were well represented at this crucial gathering. These included Alhaji Dabo Suleiman, Chairman of the Heads of Disability Clusters; Jake Epelle, CEO/Founder of TAFAfrica (then known as the Albino Foundation); Abdullahi Usman Aliyu, then Vice President of JONAPWD; and Ekaete Judith Umoh, then National President of JONAPWD. The presence of such diverse leadership and many more demonstrated the unity and seriousness of our cause.

Our message was clear and unequivocal: 'Where is the Disability Bill?' The National President of JONAPWD presented our position on the missing Disability Bill before the global audience, articulating the concerns and frustrations of the entire disability community. We reminded the government of our collective numerical strength and the electoral value that we possess as persons with disabilities. This was not merely a symbolic gesture; it was a pointed reminder that the disability community represents a significant voting bloc that could not be ignored.

Everyone across the table spoke from a position of strength. This time, we were extremely united regarding finding the missing Disability Bill, and we were more than ready to use our numerical strength at the ballot to demonstrate our collective displeasure at its disappearance. The message to government was unmistakable: the disability community was watching, organised, and prepared to act. Guess what? In less than 24 hours, President Muhammadu Buhari signed the bill into law.

There are other stories and perspectives about what informed the president's decision to assent to the bill at that point in time. Some stakeholders attributed it to 'political pressure' as general national elections were few weeks ahead. What is important to the disability community is that the bill was eventually signed into law. We have and will continue to join hands with the commission if they want to sensitise the people on the law and the policies concerning disability rights in Nigeria. We will also put pressure on and scrutinise them, as a supply-side actor, if we notice that our rights are not being protected.

There was also external pressure on the government from donor agencies, international development partners, friends and allies of persons with disabilities in Nigeria, which eventually led to the inauguration of the board and establishment of the commission. This has also been marred by politicisation, as the National Commission for Persons with Disabilities does not have the full mandate to implement what they are supposed to be doing. Moreover, the commission should be well-funded to perform optimally. Disability inclusion is not a side event in governance; it is a key issue.

All the same, we are grateful to President Muhammadu Buhari for signing the bill into law because it was stuck for about 17 years.

However, we need to start considering its effective implementation. We need to look at what experts call post-legislative scrutiny (PLS) or legislative impact assessment of the law, to measure practically whether it is benefiting and safeguarding the rights of persons with disabilities as intended. So, to my colleagues, honestly, having a piece of legislation to protect our rights does not translate to enjoying our rights. The rest of the population still finds it difficult to obey the law. Some organisations even give the insensitive excuse of financial cost, ignoring the social cost and violation of the fundamental human rights of persons with disabilities. For them, it is business as usual; they are not empathetic because they do not face the barriers faced by fellow citizens with disabilities. They close their eyes to discrimination and oppression. This should not be allowed.

Disability inclusion, including accessibility, has to be deliberate. It is about the rights of citizens; it is capital investment. Sadly, a lot of people are standing in the way of the full implementation of the law. It is a long walk to freedom, to quote the former president of South Africa, Nelson Mandela. It is a whole lot of work. At times, it's so overwhelming and tiring. But as the national president, I would like to ask my colleagues not to be discouraged. Change does not happen overnight; it is one step at a time. Just be satisfied that you have the opportunity to contribute your bit to the growth of the community.

The implementation of legislation, policies, and treaties, both local and international, is an important issue we should be concerned with. There is a need to periodically measure our country's performance on the international treaties to which we are committed and which we have domesticated. As mentioned earlier, I tell anyone who cares to listen that the fact that you have a piece of legislation does not automatically translate to rights. That's just a little paper. And a single piece of paper is not enough to automatically guarantee access to your fundamental and related rights. That is not possible. But unfortunately, the momentum has dropped. All the activism that led to the bill being signed into law has declined. However, this is where the real work starts. And this is where knowledge will come into play. Disability inclusion is a very big issue.

Earlier, I gave an overview of how disability models have evolved over time, from the charity model, medical model, social model, rights model, and human rights model. However, people have still refused to unlearn all the negative reactions towards persons with disabilities. In fact, some of the states that have a law in place still look at disability inclusion from the lens of charity—'we are helping you!' But how is that so? For instance, as undergraduates, we (persons with disabilities) sat and wrote examinations at the same time as every other student. Nobody gave us an extra minute. So, how are we individually less of a human being than other people? As James I. Charlton (1998:93) rightly put it, 'the role of charities is to help us by controlling us, not liberating us from all that holds us down.' As a people, we need to stop viewing disability as a charity cause. We need to move the conversation forward.

Across states, disability inclusion will remain an illusion if we don't have an effective implementation strategy to fully make use of the laws. The rest of the population has been socialised into seeing persons with disabilities as people 'they need to help,' and that helping mentality cannot translate into anything meaningful. They can't use such a mentality to implement a law that they don't understand. So there's a gap now, a disconnection between the law and the people who are supposed to implement it.

The movement also needs to wake up. There's more work to do because the momentum was so strong that it felt as if, once we secured the law today, our conditions would be better tomorrow. This is now where the work starts. The zeal is dying, and there is a knowledge gap. So even though the bill has been signed into law, it is as if nothing has happened. We only have a tool that we can use. At least we now have a law, which is an instrument we can deploy. But it's not enough to scare anybody. And look at the penalties—in some cases, a person who violates the law only has to pay a penalty of ₦1 million. People with criminal tendencies would rather violate your rights and pay ₦1 million; what will you do?

In spite of the challenges, it was significant that we got it. Remember the bill was said to be missing at some point? We campaigned against that and tagged the whole world and said, 'Give us our bill!' They didn't tell us when they found the bill; we just heard that they were passing it into law. Clearly, the content had been tampered with, but we said, 'Just give it to us first,' because we realised that, even as it is, there are some articles that we can still run with. The foot soldiers are awake. The National Commission for Persons with Disabilities also needs to do more.

CHAPTER ELEVEN

Everyday Barriers and Bold Responses: JONAPWD's Current Challenges

Nigeria has been a signatory to the UNCRPD since 30 March 2007, yet its implementation remains ineffective. Although we now have a commission and the law, the commission is poorly funded. Therefore, they are unable to provide disability appliances as they should. Like several development sector organisations, JONAPWD confronts inadequate resources. More critical than financial aid are technical staff members. To some extent, the national secretariat has addressed this challenge with funding support to hire skilled staff members to drive the process. In the past, there was skeletal staffing, with most activities being carried out by JONAPWD executives themselves. This scenario persists at some of our state secretariats, where state executive members drive the process with minimal staff complement. Moreover, having technical staff members on board improves accountability and transparency, so we need technical staff in all thirty-six states and the FCT.

We have also started changing the mindsets of the rest of the population. We make it clear to everyone that disability inclusion involves everyone. Persons with disabilities and the rest of the population need to work collectively to ensure Nigeria as a country becomes disability-inclusive—that everyone in our country understands what disability is; that everyone promotes the rights of persons with disabilities; that everyone understands disability is not the impairments we see daily when we encounter persons with disabilities, but the discrimination arising from the interaction between the environment and the impaired, which oppresses, limits, discriminates against, or even stagnates persons with disabilities. There was a time when many, including some persons with disabilities, interpreted 'Nothing about us, without us' to mean the exclusion of the rest of the population.

Citing Diane Driedger (1989:28), James I. Charlton (1992:5) said:

> 'If we have learnt one thing from the civil rights movement in the U.S., it's that when others speak for you, you lose.'

This is why the insightful motto of JONAPWD—'Nothing about us, without us'—which has its roots in Diane Driedger (1989:28) and James I. Charlton (1992:5), means we should always ensure that persons with disabilities are not just add-ons in our everyday life. When decisions involve disability matters, persons with disabilities should take the lead, working with the rest of the population to drive the process. This is why the boards and commissions for persons with disabilities, at both national and state levels, are led by persons with disabilities working alongside persons without disabilities who are committed to the cause of disability inclusion. Disability is a human rights issue. Anyone could become a person with disabilities. Every citizen should be part of efforts to end discrimination against persons with disabilities in Nigeria and beyond. Let us repeat: disability is not a concern of persons with disabilities alone; however, persons with disabilities should take the lead and work with the rest of the population.

Budgeting for Disability: Driving Inclusive Change

One way to ensure that state actors walk their talk is to ensure that commitment translates into annual budget lines. JONAPWD has engaged the National Assembly through the House Committee on Disability Matters to ensure that the national budget is disability-inclusive. Citizens with disabilities in their various states and at the national level need to be involved in budgetary processes, from planning to implementation and evaluation. After a law has been passed, there will be a need for legislated budgetary allocations. If you don't have money to fund it, it will amount to nothing. Advocacy yields little or no results if we do not collectively walk the talk.

Going forward, JONAPWD will therefore work with state actors and other NGOs to track and demand budgetary accountability from ministries at federal and state levels. We want to know about the components of annual budgets of government institutions. How disability-sensitive and responsive are the budgets? This is not about adding a line or two on disability training or sensitisation. It is about mainstreaming disability into various segments of the budget. We will also follow the money and follow through to ensure that things move from budgeting to effective implementation. This is the only way we can progress as a people and as a nation—not just as a people and nation of persons with disabilities, but as a nation-state with genuine commitment to disability inclusion.

Our collective voice must be loud. With a loud voice, we have achieved the legislation against discrimination targeting persons with disabilities. It is time to move forward. The law must be translated into actual rights, into actual access, into removal of barriers that have been created and protected over the ages. Opening up access for persons with disabilities means that the legislation must be supported by actual funding. Without funding, there can be no access. If we continue advocacy to various government institutions to modify their buildings and make them accessible to persons with disabilities, unless these institutions have the budgetary appropriation to modify the buildings, nothing will happen. We understand that adjustments must be funded.

So, our next priority is to follow up with all ministries and parastatals at the federal and state levels regarding disability-related, sensitive, and responsive budget lines. At that point, we will run another level of advocacy. We will say to those concerned:

‘Okay, now that you have mainstreamed disability into the budget line, don't forget our motto: Nothing About Us, Without Us. Where is our space in this? What percentage of persons with disabilities are recruited into your MDAs? Is it in line with the law or act requirement? Are persons with disabilities being empowered through reasonable accommodation and support with assistive devices to ensure they perform their duties like others? Are you educating the rest of the staff members without disabilities on attitudes that constitute barriers to persons with disabilities?’

Image 07: JONAPWD during the protest at the National Assembly to give a 7 Day ultimatum for the Signing of the Disability Bill into law in 2018.

As persons with disabilities and organisations supporting the ecosystem of disability inclusion in Nigeria, we need to continue the advocacy. We need to continue to protest peacefully through engagement with decision-makers. There should be zero tolerance for discrimination, oppression, and marginalisation of anyone because of impairments.

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The Importance of Data and Demographics

As an association, we work with the global standard that the population of persons with disabilities in any community, location, or nation-state is 15% of the whole population. JONAPWD intends to establish comprehensive demographics of persons with disabilities in Nigeria. It is important to know the percentage of each disability cluster, their age, gender, location, level of education, skill set, and several other demographics. That way, we can structure and ascertain how many professionals we have within clusters. How many children do we have across the impairments and across the population?

Equipped with that kind of data, if I go to the Ministry of Communications or to the National Information Technology Development Agency (NITDA) or any agency for that matter, and they tell me:

> 'We are an equal opportunity ministry or agency. No persons with disabilities applied for XYZ positions. We would have given them the opportunity to compete with others. Moreover, this kind of assignment might only be executed by others, or the rest of the population.'

I will engage them with data-driven evidence, and I will say to them:

> ‘Excuse me, I have a hundred young persons with disabilities who are ICT-savvy. You can't tell me they don't have a space here. They are willing and ready to work. How did you advertise the position? Is your website inclusive—that is, interactive, disability-friendly, and accessible to all clusters of persons with disabilities: the Deaf, the Blind, and others who may face barriers accessing a generic website without the assistance of others?’

The use of technology for persons with disabilities has improved. At least we now have hearing aids, walking aids, electronic wheelchairs, artificial limbs, and so forth. So, as an MDA, are you organising an empowerment programme for young people? Are you holding an Artificial Intelligence (AI) conference or certain digital programmes without space for our people? When we look at your list, I will say:

> ‘Excuse me, we have qualified persons with disabilities who can fit into what you're doing. Look at the evidence. Like every other beneficiary or participant, all they need is the space to be included.’

If I observe that our people do not have the necessary professional skills or education, I will approach the federal and state ministries of education, National Universities Commission (NUC), and other institutions, and ask them:

> ‘Why are you giving my children special needs education? This means that you are creating another barrier for the future.’

Nevertheless, if JONAPWD does not have a database, it will be another root cause of discrimination against persons with disabilities. Having a database of persons with disabilities helps ensure that their inalienable human rights are guaranteed like those of others. It is a major factor in ensuring that persons with disabilities are not left behind and that they have equal opportunities like all other citizens of Nigeria. We have a plan for the JONAPWD database. We have instituted it, and we will expand it by working with others. Like any other association, data is a very critical tool for us. It helps us to be transparent and to hold ourselves and others accountable in all facets of life. Without data, our demands, advocacy, collaboration, and other interventions risk being based on guesswork, which could be counterproductive or even harmful in some instances.

Education, Skills, and Economic Empowerment

We are also engaging with different clusters of persons with disabilities, especially educated ones who want white-collar jobs. Our people, like anyone else, should not be denied any opportunity. Or do you think that persons with disabilities should be restricted to work in the blue-collar job sectors because of barriers created by society? This is notwithstanding that it is commonplace for others to choose the career paths they want themselves. We told educated people in our community:

'At the very least, you must have a basic understanding of computers. You must be computer literate. So, if I have a list or data on our people's skill sets, I can easily present it to various institutions that might request it. But not having such a list will defeat my advocacy and my demands as the national president of JONAPWD.'

Having a database of persons with disabilities will also help us respond appropriately when the rest of the population asks us as leaders:

‘Where are they? Where are persons with disabilities with the required skill sets for XYZ positions?’

When such questions come up, instead of trying to explain our challenges, we will simply present the list to them, email it to them, or direct them to check a designated and controlled website or database. However, just as you wouldn't ask just anybody to perform surgery or deliver a baby, we also understand that no one should be given a job they are not qualified for simply because we are advocating for equal opportunity for everyone. At JONAPWD, we are against that. We are against the rest of society pitying us because we have impairments. We know we have the capacity to engage in various spaces.

We are only saying: give us reasonable accommodation; give us the necessary assistive devices. That is all we are saying. We are saying: make it a level playing field for all citizens. As Bodil Ravneberg and Sylvia Söderström (2017:7) note, ‘ATs [Assistive Technology] are devices, big or small, that make everyday life easier for people. Such technologies are prerequisites for living an independent life for many and are also connected to universal design.’ While ATs are important, they could be counterproductive as they immediately draw attention to the impairments of persons with disabilities. Sometimes, the designs are universal, and this leaves out categories of persons with disabilities (ibid., p. 8).

However, do not be the barrier for us. Rather, address the root causes of our marginalisation. So, it is about education and the pathway to educating young people with disabilities. Therefore, let's address it together. Let the relevant institutions—the universities, the polytechnics, the National Universities Commission (NUC), the Joint Admissions and Matriculation Board (JAMB), Colleges of Education (CoE), and others—be more deliberate about giving us access and placing us in disciplines that are relevant to Nigeria's development goals. Do not just flood us with special needs education! Remove the barriers that make it challenging for us to be admitted into other courses and faculties. We want to anticipate future needs and see exactly how persons with disabilities, irrespective of demographics or intersecting elements, can be rightly placed.

We understand that by taking advantage of AI, we can solve many barriers because it means someone can sit in their house and do many things to earn money. As we tell people, are there any wheelchair users who are billionaires that people can look at and say, 'Don't come here!' Nobody will try that. So, if I'm a wheelchair user, or I have some sort of severe disability, and I'm flying in my helicopter, who will tell me not to land? We understand very well that sometimes the problem of attitudinal barriers can easily be solved with economic empowerment. That's why education is very important to us. Economic empowerment is very important to us. If we're able to establish systems, structures, and frameworks to expand our access to these very critical, life-changing elements, I believe we will do very well.

CHAPTER TWELVE

Inclusion of Persons with Disabilities in Nigeria: Achievements, Future Directions, and Partnerships.

What We've Done and Where We're Going

Initially, persons with disabilities were seen as people who depended on charity, as many believed they could not be productive because of their disability. However, this perception has drastically changed over time. One major achievement is the reorientation of persons with disabilities themselves, who now see themselves as competent, productive members of society, given the right environment in which to function.

Today, thanks to JONAPWD, it is almost impossible to discuss major national issues without mentioning or including persons with disabilities and their concerns. JONAPWD was established to advocate for a disability-inclusive society—that is, to ensure that the individual and collective rights of persons with disabilities are protected in Nigeria. Today, we are pushing for a reasonable percentage to be reserved for persons with disabilities in whatever the government is doing. Some states are implementing that now, as is the case at the national level. They are doing the same even across some local government areas.

JONAPWD has inspired various disability groups who are championing or advocating for the inclusion and rights of persons with disabilities. JONAPWD, like other development partners, has been at the forefront to ensure that there is a law on disability rights. Before the formation of JONAPWD, nobody talked about such things. But today, we have a national disability law, which also led to the founding of a National Commission for Persons with Disabilities.

As at November 2025, twenty-eight states across the federation have laws prohibiting discrimination against persons with disabilities. Whilst legislation is not enough in changing the tide of discrimination and oppression of persons with disabilities, it is a major milestone for the disability communities, disability-friendly states, and the Nigerian federation as a whole.

However, every government would like to be politically correct, meaning: 'Yes, just get the Discrimination Against Persons with Disabilities (Prohibition) bill signed and let me rest.'

Image 08: Press Conference in 2019 after the signing of the Disability Act into law, under the leadership of Ekaete Judith Umoh

As the face and the voice of persons with disabilities in this country, we are also not sleeping or resting on our oars. We are leading the advocacy from the front. Between October 2023 and March 2024, with the support of the United Kingdom Foreign, Commonwealth and Development Office (FCDO), JONAPWD implemented a project to advance the Post-Moratorium Agenda of the Discrimination against Persons with Disabilities (Prohibition) Act 2018. The Disability Prohibition Act gave a five-year transitory period from the commencement of the Act within which all public buildings should be modified or adjusted to ensure there is access to public places for persons with disabilities. The five-year moratorium expired in January 2024. Whilst some public buildings–hotels, shopping complexes, schools, government offices, and so on–have complied partly or fully, there are several others that are yet to make any adjustment at all.

A number of institutions have built ramps for wheelchair users. However, some of these ramps are not professionally constructed. Some are too steep, some are without the required railings, some are very slippery such that a wheelchair user might be at very high risk using the ramps.

Some institutions do not have disability-friendly toilets or car parks reserved for persons with disabilities. So, despite the legislation and establishment of a National Commission for Persons with Disabilities (NCPWD), we are not yet there as a country in terms of accessibility. There is ample evidence that several other sections of the Act are yet to be met by state and other non-state actors, so discrimination against persons with disabilities persists.

Through the above-mentioned FCDO-supported project, JONAPWD, by advocacy, called upon the House of Representatives to investigate all federal Ministries, Departments, and Agencies (MDAs) to ascertain their compliance with the Disabilities Act. Other critical actors—

donor agencies and policymakers—were engaged towards building synergies in disability mainstreaming and collaboration to push for effective implementation of the Act.

To ensure this is achieved, JONAPWD collaborated with the media—new and old—to increase public knowledge of the Discrimination Against Persons with Disabilities (Prohibition) Act, [2018], legal instruments, and disability-related matters in Nigeria. A technical representation of persons with disabilities at the legislative house was inaugurated to continue providing support to the National Assembly on legislative matters.

We can have the law; we know the root causes of inequality and why there is widespread discrimination against persons with disabilities. This can be on paper, but whatever it is that we are advocating, based on our experience, we know that if it is not in a gazette or in the budget of the government, advocacy would yield little or no results. We can only premise this advocacy on some sort of partnership from development partners as a stopgap measure. More importantly, the government, as the biggest enabler of rights, must take the lead. We must make the government understand that we want to partner with them on disability inclusion. JONAPWD is never confrontational in its approach. It is important for us, as persons with disabilities, to have the requisite skills to engage and make important recommendations on technical know-how so that we can propose modified buildings, modified policies, disability-inclusive budgets, and be able to measure from time to time whether our federating states or the country is on track in terms of disability inclusion.

In order to ensure that persons with disabilities were not left behind during the 2023 Nigeria general elections, JONAPWD engaged stakeholders, including the Independent National Electoral Commission (INEC), on the issue of continuous voter registration and education, checking on

INEC's level of preparedness to carry persons with disabilities along in its electoral preparatory activities. In the previous elections, there were complaints about the quality and quantity of the procured assistive devices, representation of eligible persons with disabilities, and accessibility to voting venues by persons with disabilities, especially in hard-to-reach communities. This action was carried out across zones in Nigeria.

It is important to mention that the heads of various clusters played crucial roles in mobilising, educating and representing various groups at state and national meetings. They are collectively an important connector within the movement. To ensure that no cluster of persons with disabilities was left behind, JONAPWD prepared voter education materials in braille, leaflets, and broadcast jingles on radio to educate persons with disabilities on electoral matters and the processes for their participation. Persons with disabilities were enlightened on the rule of priority voting for them during Continuous Voter Registration (CVR) and on election day.

Different clusters of persons with disabilities were also informed of the assistive devices to expect during the CVR and on election day—for example, braille ballot guides for the Blind to help them cast their votes independently; magnifying glasses during CVR and on election day to enhance the participation of the visually impaired and persons with albinism; use of written instruction posters for the Deaf and hard-of-hearing persons during CVR and on election day. JONAPWD mobilised persons with disabilities during CVR, ahead of the elections, including at the Internally Displaced Persons (IDPs) camps, where persons with disabilities also reside.

Under the MacArthur Foundation-funded partnership in Plateau and Oyo States, we are currently engaging the state ministries of local government to track the implementation of disability inclusion. In Oyo State, the Ministry of Local Government invited us and informed us of the activation of a line in their 2025 budget, ensuring there is a disability-related component for all local government councils in their budget. Persons with disabilities are included in the appointment of councillors in the state. Currently, the Oyo State Ministry of Works, in its city development programme, is involving the state chapter of JONAPWD in the programme design. The programme entails urban renewal through comprehensive road upgrading, water supply, public transportation, and climate adaptation measures on flood management, amongst other strategic activities. The involvement of JONAPWD at the early stage of this programme will ensure the use of universal designs and the provision of assistive devices as necessary to ensure full use of facilities by persons with disabilities.

JONAPWD is already established in the thirty-six states and the FCT. Now we are working to ensure that all the thirty-six state chapters also have local government chapters. In fact, many of the states already have local government chapters. In some of the states that already have local government chapters, JONAPWD is working with them to have ward leaders amongst persons with disabilities. Some states have leaders in the wards; that is the only way to effectively reach the grassroots level. There are many persons with disabilities in rural communities. They cannot come to the city where we have established our associations and offices because of financial and other forms of constraints.

Although we have JONAPWD officials across all thirty-six states in Nigeria, we are struggling to establish a functional secretariat in some of them. As at November 2025, twenty-eight states in Nigeria have now passed disability laws, the latest being Taraba and Sokoto states. These state offices and officials need quality resources to continue to perform effectively. If we have technical staff in our secretariats across the states, JONAPWD, at the state level, should be able to attract grants from international NGOs and governments to carry out their specific projects without depending on us at the national level. No matter the donor agency that gives us support, without structures, it would be difficult to function effectively and sustain the JONAPWD-enabled domestication of all these laws in the states. I say it everywhere, because we could not have progressed this far without the support of others. We appreciate their efforts; we appreciate their thoughts and actions. We also appreciate the partnerships that have been channelled into disability rights in Nigeria.

Presently, we have youth leaders in the thirty-six states of the country. We have a special group that provides guidance and ensures that young people are integrated into JONAPWD and that they participate fully in the movement.

Partnership for Progress

Partnerships have been the backbone of JONAPWD's evolution and strengthening. Being a joint association of persons with disabilities from across Nigeria, JONAPWD relies heavily on external funds. At a point in its early days, JONAPWD received annual grants of ₦1 million from the Federal Government through the Federal Ministry of Women Affairs and Social Development (FMWASD). Since I took over the leadership of JONAPWD as its current national president in 2023, JONAPWD has enjoyed the support of some international NGOs, amongst them the Disability Rights Fund (DRF). We have also enjoyed the support of Policy and Legal Advocacy Centre (PLAC), which sub-granted us from its MacArthur Foundation grant. There is indirect funding from MasterCard which came via Life for the World, who then sub-granted us.

Around the time the UNCRPD was signed, disability awareness was on the rise both in the country and globally. As far back as 2006, JONAPWD obtained technical assistance and funding support to implement an issue-based project (IBP) known as Affirmation of the Rights of Persons with Disabilities (ARPWD), which was an output under a DFID-funded project—Coalitions for Change. It was through this project that JONAPWD started learning the ropes, as Amina Salihu (PhD), her C4C team, and partners provided a number of leadership and project management training sessions for JONAPWD leaders especially, and the disability community as a whole. I remember between 2013 and 2015, when there was a crisis in JONAPWD, she worked tirelessly to resolve the issues.

JONAPWD is now over 33 years old, having taken on an associational posture in 1992, though informally then. The donor community was really eager to strengthen JONAPWD through various programmes. The association received technical support from organisations like PACT Nigeria, a capacity-building institution which really supported JONAPWD through USAID projects. Dr Ahmed Mohammed, the Deputy Country Representative for PACT Nigeria, was also quite helpful in the growth of JONAPWD. The International Republican Institute (IRI), under the leadership of Mourtada Deme, the then Country Director, was also quite supportive. The United Nations Development Programme (UNDP) through its Democratic Governance Development (DGD) in Nigeria, ActionAid Nigeria, and other national NGOs also played crucial roles in strengthening and helping JONAPWD to become what it is today.

These partners provided technical assistance to the leadership of JONAPWD and the disability community to hold sessions with the leadership of the National Assembly and other pro-disability inclusion legislators, which led to the passage of the disability bill by the parliament under previous administrations, including those of President Olusegun Obasanjo and President Goodluck Jonathan. Though none of the previous administrations assented to the bill, it was eventually signed by President Muhammadu Buhari in January, 2019.

CHAPTER THIRTEEN

Visions of Tomorrow: Hopes and Expectations for Disability Rights

Going back to the issues around the budget, we believe that any budget that doesn't have clear-cut disability-related costing should not be passed. No, it shouldn't. The law already exists; therefore, the budget should always take cognisance of that. Saying that certain ministries are responsible for this or that—that the Federal Ministry of Humanitarian Affairs and Poverty Reduction and the NCPWD are responsible for persons with disabilities – does not hold water. Every leader in Nigeria, starting from the Presidency to the Senate, the House of Representatives, the governors and the commissioners, must have a sense of responsibility towards our community. I think it should be like earning a certificate. Our political leaders should school themselves on Disability Awareness 101—that is, basic information on the disability inclusion process and its importance.

Image 09: JONAPWD hosting its first Conference of Stakeholders on Disability Inclusion in Nigeria at the prestigious Abuja Continental Hotel in Abuja, in 2024, under the leadership of Abdullahi Usman Aliyu

All leaders and decision-makers should be taught Disability Awareness 101, not just those in the mother ministry. Even though the disability inclusion issue is overseen by a particular ministry, it is important to note that everyone is a stakeholder in the disability discourse. Once you move away from being the everyday person and you get elected or appointed, you should be taught Disability Awareness 101. Maybe that's the next advocacy we should run. The same way you do security clearance and an educational qualification check, anyone who gets elected or appointed should be required to do a disability-related check because it is really important to us.

Secondly, we truly appreciate our development partners. They have done a lot to support us. However, we hope to have more support from them. Expectation is the starting point of action, so we have expectations that they will do more. As a civil society organisation or association, we can say that what we have achieved so far is because of our development partners, both nationally and internationally. The government has a big role to play; it is the pivot of sustainable development. They have to put the right policies in place and get the right people to implement them. Contributions from development partners—financial and technical—are add-ons. JONAPWD does not have the resources—human and material—and does not intend to usurp the duty of the government. Nevertheless, be assured that we will continue to nudge them in the right direction at all times. It is our right, as Nigerians, not only to have a say in the affairs of our country but to participate in designing those affairs.

JONAPWD is similar to disability groups across the globe: 'It is coalitions not on the basis of natural identification but on the basis of healthcare needs, information sharing, and support groups' (Siebers:72). Importantly too, the same way we are demanding from the government to be responsive and sensitive to disability-related costs is the same way we should be demanding from development partners. Every development partner-funded project in this country should have clear-cut disability-related costing. In fact, the National Planning Commission (NPC) should not sign or approve any development partner coming in without that.

For those that are already in, when they come to renew their licences, the Commission must demand that none of their projects should leave their coffers without disability-related costing. JONAPWD needs a lot of support from all partners, including the government. You wonder why we are asking for more like Oliver Twist? Well, the answer is straightforward. Let's open up the different layers of barriers; then, you will agree that the demand is a right also. More support is needed, not only for JONAPWD but for other OPDs as well, considering the barriers in place at the moment.

So, we appreciate how much the development partners have done, and we acknowledge that they have done a lot. They still need to be very strict about their borderline on disability-related costs. Don't do projects and then bring in disability issues like an afterthought. Yes, we have the thematic disability project. The commitment at this year's 2025 Global Disability Summit is 15 for 15. This means that for anything that has to do with budgets, participation and representation, 15% of every one of their frameworks must be for persons with disabilities, including the money. So, it is no longer a story. It is what they should be committed to. We know it is neither a political nor a legal commitment. But then, ethically, we expect that this should be followed through.

JONAPWD is making efforts towards ensuring a wider space for women through the office of the women leader. With a vibrant national and state women leader’s position, there is bound to be improved gender inclusion in JONAPWD's structure and system. Moreover, this would help our association to better engage state and non-state actors on the peculiar issues faced by women with disabilities. At the national level, advocacy has led to the setting up of disability desks in some government ministries in line with the existing laws concerning disability rights.

For the society, the support we need is for it not to be the barrier. Be the one who opens access for us. Because I'm in a wheelchair, don't say to me, ‘You can't do it.’ I don't expect the Blind to be driving a taxi for now because we don't have the technology to drive a car. We are not naïve. So, I will not demand what I can't do. But don't be the barrier by telling me, ‘You can't write an article,’ or ‘You can't work here,’ or ‘You can't do this or that.’ Don't reinforce the barrier against us. Let us use the right language at all times. It is both structural and psychological violence to use demeaning words and phrases to describe persons with disabilities.

Now, it is not about us and them. Persons with disabilities have a pivotal role to play. We also have expectations to improve ourselves. We should be very relevant in terms of quality representation. We also need to be accountable to others and to ourselves. We can't demand accountability from society when we are not also accountable. So we know, and we have this expectation from ourselves as well. By doing so, collectively as the ecosystem of Nigerian citizenry, we are moving forward and progressively towards the development goals of the country.

JONAPWD's reinvention is a priority. It is driven by the association's vision and mission and involves everyone—those elected to lead and all members. Our advocacy and development work are driven by creativity, adaptation and inputting practical lessons from within and outside the country to promote accessibility and the rights of persons with disabilities, irrespective of their location or position. Some of our members are active in party politics. This can be a doubleedged sword. It can drive and promote representation if they get elected. It can also lead to deep political divisions, weaken unity and shift attention from the goal of protection of the rights of persons with disabilities if they become partisan and discriminate based on party politics. JONAPWD already has conflict prevention, reduction, management and resolution mechanisms, which we will strengthen in the near future through programmes, including a broad constitutional review driven by our collective experiences over the decades.

We have come this far because people were so angry about stigmatisation, discrimination and everything that focused on our impairments and not our persons. Let's continue to demand our rights. Let's continue to advocate. Let's continue to reorganise. Are you a leader of persons with disabilities at national, state, local government or community level? Know the roles and responsibilities that have been bestowed on you. Let's continue to lead in every position we may occupy. Let's not fit into that role of the helpless ones that is created for us by the rest of society.

As Tobin Siebers argues in *Disability Theory* (ibid, p.109), we can't afford to fit into the attitudinal paradigm of society. We should challenge false expectations on disability. We should not struggle to prove to the rest of society that our impairments are not constantly confronted with societal created barriers. We should only ask for the removal of those barriers so we can also perform as the rest of the populace. It is a human rights issue.

SUPPLEMENT
Building Your Own Path: An Outline for Organisations of Person with Disabilities

Organising for Empowerment

The disability rights movement in Nigeria has achieved remarkable milestones—from the passage of the Discrimination Against Persons with Disabilities (Prohibition) Act 2018 to the establishment of state commissions and increased visibility in national discourse. These victories were won through organised collective action by persons with disabilities themselves. This supplement translates that movement's history, struggles and lessons into practical guidance for the next generation of leaders.

Strong, legitimate Organisations of Persons with Disabilities (OPDs) remain the backbone of sustained advocacy. They amplify individual voices into collective power, hold duty-bearers accountable and ensure 'Nothing About Us Without Us' becomes reality. This guideline provides emerging leaders with a roadmap to establish legally compliant, democratic and sustainable OPDs that can continue advancing rights and claiming space in Nigeria's development agenda.

Phase 1: Foundation and Vision (Defining Who You Are)

This phase establishes the identity, mandate and guiding principles of your organisation.

1. ***Establish Core Group and Constituency***
    a. *Action:* Select a group of committed founders; the majority of them should be persons with disabilities. This should be at least 60% of the members.
    b. Focus: Clearly define the specific group you represent (your constituency or cluster).

i. Cross-Disability: Representing all disability groups in a defined area (for instance, within the state of operation or geopolitical regions in Nigeria if it is a national OPD).
ii. Specific Disability: Focusing on one group. You may be addressing a specific disability cluster as your core and integrate other clusters (e.g., persons with albinism, persons with physical disabilities or the Deaf community).

Vision & Mission: Develop a Vision (your desired future) and a concise Mission (what you will do to achieve it, e.g., 'Advocate for the implementation of the Discrimination Against Persons with Disabilities (Prohibition) Act 2018).' Agree on Core Values (e.g., Transparency, Inclusion, Solidarity, Social Justice, Self-Determination, Disability-led Leadership) that will guide all your work.

2. Develop Governance Documents

a. Constitution: This document serves as the law of your OPD. Draft it to outline:

i. The formal name and address. Choose a name that promotes the interest of your organisation and will resonate with others, sending a clear message about the organisation's purpose.
ii. Objectives, membership criteria and democratic processes.
iii. The structure and roles of the Governing Board/Executive Council (Chairperson, Secretary, Treasurer, etc.). You can start small and expand as time progresses.
iv. Rules for elections, Annual General Meetings (AGMs) and financial accountability.

b. Tip: Ensure the constitution reflects principles of democracy, non-discrimination and gender equality across all aspects of the organisation.

Phase 2: Formalisation and Legal Status (Securing Recognition)

This phase ensures your OPD is legally recognised, which is essential for opening a bank account, entering contracts, applying for grants and having seamless operations.

3. *Register with the Corporate Affairs Commission (CAC)*

a. Action: To be a legal entity, the OPD must register with the CAC as an Incorporated Trustee (the typical legal structure for Nigerian NGOs/OPDs).

b. *Process:*

   i. Submit a unique name for availability check on the CAC portal.

   ii. Appoint at least three and up to seven Trustees (responsible for the organisation's property and legal compliance), who must be trustworthy Nigerian citizens, both male and female.

   iii. File the formal application, including the constitution/trust deed, minutes of the founding meeting and required fees.

c. Recommendation: Engage a legal professional or consultant experienced with CAC registration to ensure all statutory requirements are met correctly.

4. Establish Financial Systems

a. Bank Account: Open a corporate bank account in the OPD's registered name after receiving your CAC certificate.

b. Policy: Draft a simple Financial Management Policy detailing how funds (from dues, grants, donations) will be tracked, spent and accounted for. With time, also develop a communication strategy and other related documentation to strengthen your OPD.

c. Principle: Enforce Transparency and Accountability. Mandate that all withdrawals or payments require the signature of two authorised signatories (e.g., the Chairperson/Executive Director and the Treasurer/Account Officer).

Phase 3: Governance and Mobilisation (Building Power)

This final phase focuses on internal strength, community reach, and effective action.

5. Elect a Governing Council and Set Strategy

a. *Elections:* Hold a democratic election for your primary leaders (Executive Team) as stipulated in your constitution. This leadership is accountable to the general membership. Appoint staff members who are competent and believe in the organisational core goals.
b. *Strategy:* Develop an Initial Work Plan (1-year strategy) based on your Mission. Identify 1–3 urgent and achievable SMART goals (Specific, Measurable, Achievable, Relevant, Time-bound). Successfully achieving these initial goals builds credibility. Engage external experts to support your implementation, including volunteers

6. Mobilise and Engage Membership

a. *Recruitment:* Actively recruit members from your constituency through outreach and local networks. A large, diverse membership provides the necessary mandate for powerful advocacy
b. *Engagement:* Hold regular, accessible meetings – physical, virtual or hybrid, depending on resources and time (e.g., quarterly) – to gather input, ensure

accountability from the leadership and share information. Always incorporate members' lived experiences into your advocacy agenda.

7. Network and Capacity Building

a. *Affiliation:* Immediately seek affiliation with your state chapter of the Joint National Association of Persons with Disabilities (JONAPWD). This connects you to the broader national movement, providing support and collaboration opportunities.
b. *Growth:* Seek training for your leadership and members on core skills: advocacy techniques, proposal writing, resource mobilisation and detailed knowledge of the Discrimination Against Persons with Disabilities (Prohibition) Act 2018.
c. *Updates:* Constantly access information on trends in disability discourse, locally, nationally and internationally, to be conversant with changes that will strengthen the growth of your OPD.

8. *Conclusion:*

Following these steps will ensure your organisation is a solid, rights-based, and legally operating platform ready to champion the cause of persons with disabilities in Nigeria. Also, note that this is a guideline, you can make adaptation to it to ensure it works for you and your organisation.

REFERENCES

1. Affirmation of Rights of Persons with Disabilities/Coalition for Change (ARPWD/C4C) (2010). *Ability in disAbility*. Abuja, Nigeria: ARPWD/C4C.
2. Brown, S. E. (1995). 'Creating a Disability Mythology,' Disability Studies Quarterly, Kansas.
3. Charlton, J. I. (1998). *Nothing About Us Without Us: Disability Oppression and Empowerment*. Berkeley: University of California Press.
4. Federal Republic of Nigeria (2018). *Discrimination Against Persons with Disabilities (Prohibition) Act of 2018*. Abuja, Nigeria.
5. Federal Republic of Nigeria [FRN] (2024). NCPWD – *A Compendium of Operational Guidelines*. Abuja, Nigeria.
6. Federal Government of Nigeria [FRN] (2022). *NCPWD Strategic Plan (2022–2026)*. Abuja, Nigeria
7. Federal Republic of Nigeria (1999). *Constitution of the Federal Republic of Nigeria* [as amended]. Abuja, Nigeria.
8. NCPWD (2024). *Framework for the National Access to Work Scheme for Persons with Disabilities in Nigeria*. Abuja, Nigeria.
9. Obi, Florence Banku, PhD, & Avoke, Selete Kofi, Ed.D. (2007) 'Equalizing Educational Opportunities for the Nigerian-Ghanaian Blind Girl-Child', International Journal of Educational Research, March 2007; 3(1): Pp. 89-96, (Last accessed 09 November, 2025)
10. JONAPWD (2017). 'JONAPWD Annual Report 2016'. Abuja, Nigeria.
11. JONAPWD (2018). 'JONAPWD Annual Report 2017'. Abuja, Nigeria.
12. United Nations (2019). *Disability Inclusion Strategy*. New York: United Nations.

13. Secretary General Report (2020). *UN Disability Inclusion Strategy*. New York: United Nations.
14. United Nations (2006). *Convention on the Rights of Persons with Disabilities*. New York: United Nations.
15. United Nations (2019). *United Nations Disability Inclusion Strategy*. New York: United Nations. Available at: https://www.un.org/en/content/disabilitystrategy/
16. United Nations Department of Economic and Social Affairs (2019). *Disability and Development Report: Realising the Sustainable Development Goals by, for and with Persons with Disabilities*. New York: United Nations.
17. United Nations, Factsheet on Persons with Disabilities | United Nations Enable (Last accessed 09 November, 2025)
18. 16% of world population are persons with disabilities WHO – (Last accessed 09 November, 2025)

ABOUT THE AUTHORS

Abdullahi Usman Aliyu is a disability advocate with over 20 years of experience in the disability rights movement. He currently serves as the National President of the Joint National Association of Persons with Disabilities (JONAPWD) in Nigeria, having held this position since 2023. In this role, he promotes unity and a development agenda among diverse disability communities across Nigeria's 36 states and the Federal Capital Territory. He also holds the position of Public Relations Officer (PRO) for the West African Federation of Disabled (WAFOD) and is a Permanent Delegate of the Commonwealth Disabled People's Forum (CDPF). In March 2024, he was appointed the pioneer Executive Secretary of the Kebbi State Commission for Persons with Disabilities.

Prior to his election as National President, Abdullahi served as National Vice President and Acting National President of JONAPWD. He has been engaged in disability services and activities at both state and national levels, including as executive chairperson and member. His cross-sectoral experience includes strengthening grassroots organisations and movements led by organisations of persons with disabilities (OPDs), organisations for persons with disabilities (OfPDs), and other disability inclusion enablers advancing the rights of persons with disabilities in inclusive development agendas. He is skilled in providing strategic leadership on lobbying, policy design and implementation, and monitoring social interventions within private, public, and development sectors. Abdullahi holds a Bachelor's degree in Agriculture, specialising in

Agricultural Extension and Rural Sociology, from Ahmadu Bello University (ABU) Zaria, and a Master's degree in Development Studies and Policy Analysis from Kaduna State University. Previously, he worked with the Independent National Electoral Commission (INEC) in Nigeria and is a member of the Young African Leaders Initiative (YALI) network, as well as the Institute of Strategic Management of Nigeria (Chartered).

Ekaete Judith Umoh is a dedicated disability activist with over 25 years of experience specialising in disability justice and gender equity advocacy. She currently serves as the Convener of the Fight Inequality Alliance (FIA) Nigeria, a global social justice movement; as CEO of Inclusion Support Hub Africa; as Founder and Board Chairperson of FACICP Disability Plus, a non-governmental organisation promoting gender and disability inclusion in Nigeria; and as Vice Chairperson of the Resource Centre for Human Rights and Civic Education (CHRICED), Nigeria. Previously, Ms Umoh was the Inclusion Coordinator at the United Nations Resident Coordinator Office in Nigeria; the first female National President of JONAPWD; Country Director at CBM Global Disability Inclusion; Secretary of the African Disability Forum; Vice Chairperson of the West African Federation for Persons with Disabilities (WAFOD); Vice Chairperson of Rehabilitation International (RI) Africa Region; and a board member of global women's networks, including the Urgent Action Fund (UAF)-Africa and the Association for Women's Rights in Development (AWID). She played a key role in the passage of the Nigerian Disability Bill in 2019 and has consulted for several international NGOs in Nigeria on disability inclusion mechanisms. An alumna of the Ford Global Fellowship and the Women's Institute on Leadership and Disability (WILD) in the United States, Ms Umoh holds a Master's degree in Social Work and is currently pursuing a PhD programme.

Olumide Olaniyan is a creative writer, published in poetry and fiction, and an expert in governance, peacebuilding, and social inclusion with extensive experience in disability inclusion projects, civil society internal mechanism and institutional strengthening. Between 2009 and 2011, as the issue-based manager overseeing the Affirmation of the Rights of Persons with Disabilities (ARPWD) under the Coalitions for Change (C4C) project, he collaborated with the Joint National Association of Persons with Disabilities (JONAPWD) and other organisations of persons with disabilities. His technical support contributed to the publication of the book *Ability in disAbility*, produced by JONAPWD/ARPWD/C4C with support from the UK Department for International Development (DFID). More recently, Olumide Olaniyan led three research projects for the British Council's Rule of Law and Anti-Corruption (ROLAC 1) programme, which focused on access to justice for persons with disabilities, access to employment for persons with disabilities, and the development of toolkits and an action plan on disability inclusion for law enforcement agencies and Sexual and Gender-Based Violence (SGBV) responders in Lagos State. He consistently ensures the inclusion in all governance, peacebuilding, and institutional reform projects he undertakes.

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