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PERSPECTIVE

Down syndrome in Africa: Challenges, opportunities, and future directions

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Abstract

INTRODUCTION: As life expectancy improves for people with Down syndrome (DS) in Africa, the risk of developing DS-associated Alzheimer's disease (DSAD) will rise. There is a pressing need to plan for this emerging challenge, particularly in the context of existing health and social disparities.

METHODS: This work emerged from a pan-African collaboration, including discussions at the Brain Ageing and Dementia in Low- and Middle-Income Countries conference held in Nairobi in 2024, where stakeholders identified regional priorities for DS and dementia care.

RESULTS: Limited epidemiological, cognitive, biomarker data, delayed diagnoses, and gaps in specialized services may impact access to care. However, innovative solutions, such as mobile biomarker sampling and culturally adapted cognitive assessments, offer promising strategies.

DISCUSSION: Integrating global advances in DSAD research with Africa's strengths in community-based care offers opportunities. By prioritizing research, capacity building, and health system integration, this work advocates for the inclusion of DS in Africa's dementia strategies.

KEYWORDS
Africa, Alzheimer's disease, Down syndrome, equity, Global South

Highlights

- Projected increases in life expectancy for individuals with Down syndrome (DS) in Africa will lead to a substantial rise in DS-associated Alzheimer's disease (DSAD), necessitating urgent planning and response.

- There is a critical lack of epidemiological, cognitive, and biomarker data on adults with DS in Africa, hindering accurate diagnosis, care planning, and inclusion in global research.
- Innovative, scalable solutions—such as mobile biomarker sampling and culturally adapted cognitive assessments—offer an opportunity to integrate scientific advances with Africa's strengths in community-based care.
- Investment in research and capacity building is essential to address current gaps, reduce disparities, and ensure equitable access to emerging diagnostics and treatments for DSAD across the continent.

1 | BACKGROUND

Life expectancy and quality of life for people with Down syndrome (DS) show significant global disparities, with low- and middle-income countries (LMICs) experiencing significant unmet needs. While approximately 800,000 individuals with DS reside in high-income regions,[1,2] where advances in healthcare and societal inclusion have brought significant improvements in lifespan and quality of life, the majority—potentially over 5-million—live in LMICs, where access to care is limited and stigma persists.[3] This disparity underscores the importance of addressing the specific needs of people with DS in LMICs, including Africa, where unique challenges also present opportunities to inform global dementia research and care.

In adulthood, Alzheimer's disease (AD) is the primary life-limiting condition for individuals with DS,[4] with advanced AD pathology present universally by age 40 and lifetime dementia risk exceeding 95%.[5,6] While high-income countries (HICs) have made tremendous strides in understanding DS-associated AD (DSAD), its impact in Africa and other LMICs remains largely unexamined. This gap is concerning given projections that by 2050, 71% of all people with dementia will reside in LMICs.[7] People with DS, representing the largest population with a genetic predisposition to AD, must not be overlooked in these discussions.

Africa is experiencing a rising dementia burden, but with no country having yet established an integrated national dementia strategy.[8] Up to 75% of dementia cases in LMICs may go undiagnosed, reflecting significant underdiagnosis and inadequate healthcare infrastructure.[9] Between 1995 and 2015, dementia prevalence in Nigeria rose by 400%, signalling the growing impact of neurodegenerative diseases on the continent.[10] While similar data for individuals with DS are lacking, this likely reflects a lack of awareness, diagnostic infrastructure, and data collection rather than an absence of disease. Similarly, although life expectancy data for individuals with DS in Africa are scarce, gains in general population survival[11] and early improvements in healthcare access suggest that longevity in this population may also begin to increase. As more individuals with DS live into middle and older age, the near-universal predisposition to AD is likely to become increasingly evident, as seen in HICs. Preparing now for this emerging challenge is crucial to ensure equitable care and avoid exacerbating existing disparities.

The challenges of stigma, fragmented healthcare access, and inadequate data that hinder dementia care in the general population in Africa are strikingly similar to the systemic barriers faced by people with DS throughout their lives. Both groups encounter societal obstacles that delay diagnosis, fragmented health services that fail to meet their needs, and a lack of robust data to inform effective policies and interventions. Addressing these shared challenges offers an opportunity to develop integrated strategies that benefit both populations while improving healthcare systems more broadly.

HICs have pioneered research in biomarkers, clinical trials, and DSAD care models, yet these advances remain largely inaccessible to LMICs. Conversely, Africa's innovative approaches to community-based care and culturally sensitive diagnostic tools for dementia could inform global DSAD interventions. Bridging these approaches—adapting successful strategies from high-income settings and leveraging Africa's strengths—can yield transformative solutions.

This work emerged from a collaborative effort among the authors to advance a pan-African project in DS and brain health, in collaboration with the Global Brain Health Institute. It draws on discussions initiated during a pre-conference meeting held at the Brain Ageing and Dementia in Low- and Middle-Income Countries conference in Nairobi (December 3–6, 2024), which brought together project collaborators to identify challenges, regional priorities, and opportunities for collective action. It perspective takes a forward-looking approach to address and plan for DSAD in Africa. By examining epidemiological trends, exploring key aspects of DSAD detection, health and social care, identifying systemic challenges, and drawing on lessons from dementia research, it offers a foundation for developing strategies to address the shared and unique needs of these populations.

1.1 | DS research in Africa

Research on DS in Africa has predominantly centered on health-related issues in children, with a strong focus on comorbidities such as congenital heart disease, leukemia, thyroid dysfunction, and other medical conditions such as oral health, nutrition, and broader aspects

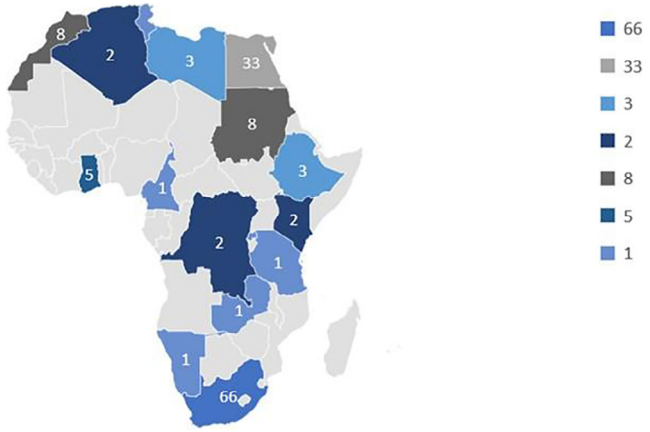

FIGURE 1 Geographic distribution of identified Down syndrome (DS) studies across Africa. This figure illustrates the geographic distribution of identified published studies on DS across the African continent.

of general health (see Tables S1 and S2 for a breakdown by topic area and articles on DS across Africa, and Appendix 1 for details on the search strategy). In contrast, research involving adults with DS appears limited, and focused largely on functional fitness and exercise programs. Others included case studies on comorbidities (e.g., obesity, cancer) and one study examined stigma and social inclusion. No studies addressed ageing or dementia, leaving a significant gap in understanding the lifelong needs of adults with DS. As life expectancy improves, bridging this research gap will be essential for providing comprehensive care across the lifespan.

Geographically, most DS research in Africa originates from South Africa and Egypt, with some contributions from countries such as Nigeria, Morocco, and Sudan, (See Figure 1) however, vast regions remain underrepresented. Expanding research efforts in DS across all regions, is critical to ensure equitable representation and address disparities in DS care. Collaborations between existing DS research groups, underrepresented regions, and established research institutions across Africa, particularly those with expertise in AD, could enhance capacity building and promote integrated, regionally relevant solutions. This approach would help to embed DS research within broader scientific frameworks, leveraging the strengths of established institutions to advance inclusive and impactful outcomes.

2 | EPIDEMIOLOGY

Epidemiologic data on DS in Africa remain limited.[12] The true prevalence of DS in Africa remains unclear, with historical data highlighting wide variability in incidence rates. Similarly, early studies on incidence revealed wide variability across African countries, from 1 in 555 in Egypt[13] to 1 in 18,000 in Sudan,[14] with an intermediate figure of 1 in 865 live births in Nigeria,[15] likely reflecting differences in prenatal and postnatal diagnostic practices, cultural factors, whether births are reported due to stigma, and availability of medical resources.

To better understand life expectancy and the potential future burden of DSAD in Africa, we examined mortality data from the Global Burden of Disease dataset. The global burden of disease (GBD) dataset is a comprehensive epidemiological resource developed by the Institute for Health Metrics and Evaluation (IHME), combining data from diverse sources like censuses, disease registries, and databases around the world to quantify health loss globally. It provides global population estimates on prevalence, incidence, mortality, and disability-adjusted life-years (DALYs) among various diseases, injuries, and risk factors across age groups, sexes, countries, regions, and time.[16] While death records as a source of cause-of-death data have significant limitations,[17] especially in DS populations, they provide valuable regional and age-specific trends.

In Northern, Eastern, Central, and Southern Africa, infant mortality attributed to DS has decreased between 2000 and 2021 by 42%, 19%, 26%, and 16%, respectively (Tables 1 and 2) (see Table S3 for change in death rate for DS from 2000 to 2021). However, even in 2021, mortality rates in African regions were at least seven times higher than in the United States (approximately 17.8 per 100,000 vs. 2.42 per 100,000), a disparity that mirrors that observed in the general infant population, where mortality is approximately eight times higher in Africa than in the United States (42 per 1000 vs. 5 per 1000).[18] The elevated risk in infancy accounts for most of the difference, with mortality rates for people with DS in Africa becoming more comparable to the US in later childhood and adolescence. By mid-adulthood (35 years and older), these differences largely disappear, aligning with trends observed in other continents.[2] While this lack of differences in mortality could reflect underreporting or limitations in death records, it cautiously suggests that some individuals with DS in Africa may be living to ages associated with DSAD.

Dementia prevalence in the general population in Africa is reported to range from 2.3% to 20%. These figures vary widely, perhaps due to differences in the age composition of study cohorts and differences in how dementia is assessed and reported.[19] For DS populations, these limitations are even more pronounced, as there are no data on AD incidence or prevalence in DS in Africa, underscoring the need for direct studies in African cohorts. Data from the United States provide important context.

Current projections of dementia prevalence in Africa must rely on parallels drawn from studies in the Global North, where recent studies have shown that AD might now cause up to 70-80% of deaths in individuals with DS.[4,20] This is due to the fact that more than 90% of individuals with DS will develop AD dementia by the seventh decade of life[6] and with more individuals with DS living into old age. As infant mortality improves, survival gains will result in an increase in the prevalence and incidence of AD within DS populations in the continent. Using current DS death rates and population data, we projected DS dementia cases in Africa for 2080, assuming infant mortality matches US levels and 23% of the DS population is over 40-years and at risk for AD. If DS infant mortality were reduced to US rates, the proportion of DS-related AD cases would increase regionally by 12%–23% (Table 2). These projections emphasize how reducing infant mortality will lead to a transition in the epidemiological burden from

TABLE 1 Rate of death reported to be caused by DS per 100,000 people (with and without DS).

	2000							2021						
Age	Northern Africa	Eastern Africa	Central Africa	Southern Africa	Western Africa	Africa	United States	Northern Africa	Eastern Africa	Central Africa	Southern Africa	Western Africa	Africa	United States
<1 year	25.86	21.46	21.73	22.45	16.23	20.48	3.05	14.96	17.34	16.01	18.93	19.29	17.80	2.42
2–4 years	0.72	1.29	1.30	1.10	1.56	1.27	0.05	0.45	0.99	0.98	0.91	1.64	1.14	0.05
5–9 years	0.28	0.22	0.23	0.21	0.24	0.23	0.03	0.21	0.21	0.22	0.21	0.31	0.25	0.04
10–14 years	0.24	0.17	0.16	0.14	0.18	0.18	0.04	0.21	0.16	0.18	0.17	0.22	0.19	0.04
15–19 years	0.16	0.16	0.16	0.10	0.15	0.15	0.07	0.17	0.16	0.18	0.15	0.18	0.17	0.07
20–24 years	0.15	0.15	0.13	0.10	0.15	0.14	0.09	0.17	0.15	0.17	0.13	0.19	0.17	0.11
30–34 years	0.09	0.12	0.13	0.09	0.17	0.12	0.12	0.11	0.11	0.16	0.1	0.2	0.14	0.14
35–39 years	0.10	0.13	0.17	0.09	0.23	0.15	0.14	0.12	0.12	0.19	0.12	0.27	0.17	0.15
40–44 years	0.09	0.15	0.16	0.10	0.20	0.14	0.19	0.12	0.13	0.18	0.13	0.23	0.16	0.21
45–49 years	0.11	0.20	0.24	0.15	0.26	0.19	0.33	0.13	0.17	0.26	0.20	0.27	0.21	0.47
50–54 years	0.12	0.32	0.54	0.29	0.81	0.43	0.52	0.14	0.26	0.54	0.34	0.83	0.44	0.94
55–59 years	0.13	0.33	0.74	0.36	1.51	0.66	0.74	0.15	0.28	0.75	0.40	1.52	0.66	1.56
60–64 years	0.11	0.24	0.59	0.26	1.42	0.57	0.73	0.13	0.21	0.64	0.30	1.54	0.60	1.46
65–69 years	0.08	0.20	0.44	0.18	0.99	0.41	0.49	0.1	0.19	0.51	0.22	1.2	0.46	0.86

Abbreviation: DS, Down syndrome.

childhood-related conditions to AD in later life, highlighting the need for tools to refine our understanding and early detection of DSAD in Africa.

3 | COGNITIVE ASSESSMENT AND BIOMARKERS

3.1 | Cognitive assessment

Cognitive assessment is critical for detecting early signs of DSAD, guiding interventions, and understanding disease progression. The cognitive profile of DSAD is defined by early declines in episodic memory, attention, and executive function, which precede dementia onset.[21,22] Cognitive assessment in this population is challenging due to pre-existing intellectual disability (ID), variability in cognitive baselines, and floor effects in standardized tools.[21,23,24] Notably there are no published studies in Africa on the cognitive profile of adults with DS, leaving regional and cultural considerations unexplored.

In HICs, tools such as the Cambridge Cognitive Examination for Older Adults with Down Syndrome (CAMCOG-DS) and the modified Cued Recall Test (mCRT) have shown high diagnostic accuracy for detecting AD dementia in DS populations,[25] particularly when stratified by ID levels.[24] These offer critical insights into disease progression but remain unexplored in Africa where their direct applicability in African contexts raises important questions about adaptation to cultural, linguistic, and logistical realities.

Lessons from broader dementia research emphasize the importance of culturally sensitive tools. For instance, the Community Screening Instrument for Dementia (CSI-D) and the Kiswahili version of the Montreal Cognitive Assessment (MoCA) have shown validity and reliability in diverse African contexts by addressing linguistic and educational biases.[19,26] These successes highlight the potential for adapting DS-specific tools like the CAMCOG-DS and mCRT to the linguistic and cultural nuances of African populations, involving partnerships with local communities to ensure relevance and accuracy.[27,28] These partnerships not only ensure cultural relevance but also foster local capacity building and long-term sustainability in cognitive assessment practices.

Beyond cultural and linguistic considerations, infrastructure and service access present additional challenges. Tools such as CAMCOG-DS and mCRT require in-clinic administration, significant infrastructure, and neuropsychological expertise—resources that are often unavailable across much of the continent, with few neuropsychologists in Botswana (population: 2.4 million) and in the Democratic Republic of Congo (population: 102 million), for example. Neuropsychology has been slow to develop in parts of Africa due to limited accredited training, influence of traditional healing practices, and economic constraints.[29] Services are typically concentrated in urban centers, leaving rural populations underserved.[30] An example of non-clinician implemented assessment has been used in Malawi with the Mature Adults Cohort of the Malawi Longitudinal Study of Families and Health (MLSFH-MAC), which could have potential for adaptation for a DS population.[31] Alternative models, such as mobile cognitive assessments, also offer promising solutions. Brief assessments conducted in home environments using mobile technology can mitigate logistical and financial burdens while capturing daily fluctuations in cognition.[32] These approaches reduce logistical and financial barriers while capturing daily fluctuations in cognition and minimizing stress caused

TABLE 2 DSAD projections rates in 2080.

Scenario	DS infant mortality rate 2000	No. estimated to survive past infancy with DS 2000–2080	Estimated population with DS and AD in 2080	Projected 2080 total AD cases in Africa (from PDF)[a]	Proportion of total AD cases from DS
Africa current DS infant mortality rate 2000	0.16	20,019,596	4,604,507	32,860,000	14.01%
Improved DS infant mortality rate (US rate 2000)	0.02	23,358,814	5,372,527	32,860,000	16.35%
% change	**−85%**	**17%**	**17%**	**0%**	**17%**
North Africa current DS infant mortality rate 2000	0.21	529,339	121,748	19,260,000	0.63%
Improved DS infant mortality rate (US rate 2000)	0.02	651,130	149,760	19,260,000	0.78%
% change	**−88%**	**23%**	**23%**	**0%**	**23%**
East Africa current DS infant mortality rate 2000	0.17	1,940,844	446,394	6,600,000	6.76%
Improved DS infant mortality rate (US rate 2000)	0.02	2,285,942	525,767	6,600,000	7.97%
% change	**−86%**	**18%**	**18%**	**0%**	**18%**
Central Africa current DS infant mortality rate 2000	0.17	41,758	9,604	1,490,000	0.64%
Improved DS infant mortality rate (US rate 2000)	0.02	49,311	11,342	1,490,000	0.76%
% change	**−86%**	**18%**	**18%**	**0%**	**18%**
Southern Africa current DS infant mortality rate 2000	0.18	264,987	60,947	1,200,000	5.08%
Improved DS infant mortality rate (US rate 2000)	0.02	315,117	72,477	1,200,000	6.04%
% change	**−86%**	**19%**	**19%**	**0%**	**19%**
Western Africa current DS infant mortality rate 2000	0.13	2,708,339	622,918	4,260,000	14.62%
Improved DS infant mortality rate (US rate 2000)	0.02	3,036,522	698,400	4,260,000	16.39%
% change	**−81%**	**12%**	**12%**	**0%**	**12%**

Abbreviations: AD, Alzheimer's disease; DS, Down syndrome; DSAD, Down syndrome-associated Alzheimer's disease; US, United States.
[a]Used 2050 projections and multiplied by projected AD rates for each region.

by artificial testing environments, particularly for individuals with emerging AD pathology.[32–34]

By working collaboratively and building on Africa's existing strengths, such as its traditions of community-based care, approaches can be developed that are not imposed but co-created, ensuring sustainable and contextually relevant solutions for DSAD cognitive assessment.

3.2 | Biomarkers

Fluid biomarkers, in particular the rapid development of blood-based biomarkers for AD pathophysiology, offer a critical opportunity to advance understanding and diagnosis of DSAD globally, but no studies to date have examined these biomarkers in individuals with DS in Africa. This is a significant gap as studying DSAD biomarkers in African populations provides an unparalleled opportunity to explore the interplay between genetic, environmental, and sociocultural factors in AD pathology. Africa's exceptional genetic diversity combined with the biological clarity of DSAD as a model of AD creates a perfect intersection for understanding how these factors influence disease progression.

Much of what we have learned from cerebrospinal fluid (CSF) can be translated to blood, a more easily accessible and tolerated sample collection procedure. The amyloid-β (Aβ)42/Aβ40 ratio, well established disease defining metric in CSF, reflect amyloid changes decades before clinical symptoms emerge,[35] but has less effect in blood due to peripheral interference.[36] Tau pathophysiology biomarkers, including phosphorylated tau (p-tau181 and p-tau217), track Aβ-mediated tau phosphorylation and downstream neurofibrillary tau tangle changes. The p-tau217 is considered by many to have desired predictive value and for clinical use in AD.[37] Markers like neurofilament light chain (NfL) provide insights into neurodegeneration,[38] while others, such glial fibrillary acidic protein (GFAP), highlight synaptic and astrocytic changes.[39] These biomarkers have proven useful in research studies in DSAD.[40]

The absence of fluid biomarker data for individuals with DS in Africa is paralleled by minimal research in the general population, with only two published studies on fluid biomarkers of neurodegeneration—one in Tunisia and one in Congo.[26] This underrepresentation limits the global applicability of biomarker findings and overlooks potential variations in biomarker trajectories influenced by Africa's genetic and environmental diversity. For example, while the apolipoprotein

E (APOE) ε4 allele is a well-established risk factor for AD in White populations, its role in sub-Saharan Africa remains inconclusive.[19] Given the continent's extensive genetic diversity, unique variants at known loci or novel loci associated with AD risk or protection likely remain undiscovered.[41,42] Leveraging this diversity requires appropriate methods, such as large population-specific reference panels, since standard imputation panels (mostly European-derived) often fail to capture African genetic variation.[43]

As with neuropsychological assessment, infrastructure challenges present opportunities for innovation. Technologies like dried blood spot (DBS) sampling can circumvent logistical challenges, providing a minimally invasive, scalable method for biomarker collection and facilitate widespread participation, especially in rural or resource-limited settings.[44] This could be transformative in rural settings, where access to phlebotomy, laboratory infrastructure, and cold chain logistics is often limited. Feasibility of DBS sampling has already been demonstrated in African contexts,[45] and recent work has shown that a range of AD biomarkers, including p-tau181, p-tau217, GFAP, and NfL, can be reliably measured in DBSs, even when samples are collected and stored in remote areas with limited temperature control.[44] For these innovations to reach their potential, they must be supported by healthcare systems capable of managing the broader needs of individuals with DS.

4 | HEALTH CHALLENGES

Non-communicable diseases (NCDs) are emerging as a significant health concern in Africa, particularly in sub-Saharan regions. Historically dominated by communicable diseases like malaria, tuberculosis, and human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome(AIDS), these regions are now experiencing a rapid epidemiological transition due to demographic changes such as population growth and aging.[46] This shift presents new challenges for health systems that have traditionally focused on infectious diseases and maternal and child health, and is an important shift for people with DS who experience higher levels of chronic conditions compared to the general population.[47]

Early diagnosis of DS is crucial for managing associated health conditions and improving life expectancy, but in South Africa, for example, delays are common, with just over half of clinical cases confirmed by cytogenetic testing and at an average age of over 1 year.[48] These delays in diagnosis hinder the prompt management of common treatable conditions in DS such as cardiac, hearing, and hematological disorders, where screenings were often delayed or inconsistently performed,[49] with consequent impact on life expectancy.

Up to 50% of children with DS are born with congenital heart disease (CHD), requiring surgery early in life.[50] In HICs, timely surgical intervention results in survival rates exceeding 90%,[51] but in contrast, only an estimated 3% of all children in sub-Saharan Africa who require cardiac surgery receive it.[52] Studies on DS-specific access to cardiac surgery in the region are limited but data from a specialist cardiac center in Sudan reported that just 15% of children with DS and CHD underwent surgery,[53] which, while higher than the regional average is alarmingly low compared to HICs. In an Ethiopian study, 19% of DS children with CHD died, with two-thirds of these deaths occurring during infancy.[54] This disparity has far-reaching implications for severe complications, such as pulmonary hypertension, heart failure, and early mortality. Access to cardiac surgery has been a defining factor in the increase in life expectancy for individuals with DS in HICs. This could similarly be the single biggest factor impacting prognosis in life expectancy for people with DS across Africa and is dependent on improving access to cardiac surgery and strengthening health systems.

While healthcare infrastructure forms the foundation of improved outcomes, the broader social and educational environments also play a critical role in shaping the lifelong trajectories of individuals with DS. Education, in particular, has implications that extend far beyond early childhood, influencing cognitive reserve, social integration, and potentially, even long-term dementia risk.[55] These interconnections highlight the need to consider how access to education and inclusive social structures can complement medical advances in improving outcomes for individuals with DS.

5 | SOCIAL AND EDUCATIONAL FACTORS

Education has been identified as an important early-life modifiable factor related to dementia, with at least 7-years of formal education estimated to prevent approximately 5% of dementia cases at a population level.[55] In the general population across Africa, the association between educational attainment and dementia risk has been extensively explored, with studies often demonstrating a link between low levels of education and increased dementia risk.[19,56,57] However, this relationship is complex. Many older Africans included in these studies had little or no formal education, and this may not accurately reflect their cognitive reserve. Traditional systems of learning and lifelong communal responsibilities, which are culturally ingrained, likely play a significant role in maintaining cognitive abilities, even among those with minimal formal education.[19]

This dynamic differs significantly for individuals with DS. Education levels are typically lower and are not supplemented by these traditional forms of cognitive engagement, with fewer educational opportunities constrained by resource limitations, insufficient specialized programs, and the broader challenges of inclusive education systems. Mainstream educational challenges persist. Opoku et al.[58] found that Ghanaian secondary school teachers often felt unprepared to meet the unique needs of students with DS, a finding echoed in South Africa, where teachers struggled with the developmental pace and learning requirements of students with DS.[59] Addressing these educational disparities is essential for enhancing cognitive reserve and improving life outcomes for individuals with DS in Africa. By integrating culturally relevant cognitive activities and leveraging innovative assessment tools, we can create inclusive educational environments that foster skill development and cognitive resilience.

However, the effectiveness of such interventions often hinges on broader systemic factors that influence access to services and support. A growing body of evidence highlights other early-life exposures, such as socioeconomic disadvantage, household crowding, family instability, and limited parental education, also linked to increased dementia risk.[60–62] These effects are thought to operate through cumulative impacts on adult socioeconomic status, cardiovascular health, and psychological factors such as personality traits known to influence cognitive ageing. While these pathways are well described in the general population, their relevance to individuals with DS, and particularly within the African context, remains largely unknown.

These structural challenges may have additive impact on dementia risk, highlighting the importance of addressing entrenched barriers within families, communities, and healthcare systems.

6 | SYSTEMIC BARRIERS AND SOLUTIONS

6.1 | Stigma and cultural perceptions

Stigma surrounding DS and ID significantly affects care and quality of life across Africa. This stigma manifests across families, communities, and healthcare systems, limiting service access and creating social isolation for individuals with DS and their families. Historically, people with DS in many African communities have faced significant exclusion, with families often concealing a diagnosis due to societal shame or fear of ostracization. Studies from South Africa, Kenya, and Namibia reveal ongoing challenges, including societal rejection, financial strain, and the isolation of caregivers who lack both community and systemic support.[63–65] In rural areas, ID can sometimes be perceived as misfortune or divine punishment, further entrenching barriers to education and employment.[66] Such stigma contributes to widespread misunderstanding and a lack of empathy toward those affected, creating significant barriers to effective care and support[8] and perpetuate a cycle of exclusion, limiting opportunities for individuals with DS to participate in society and access adequate care. This marginalization may also increase vulnerability to dementia, as social isolation and limited social engagement have been identified as risk factors.[55] Stigma surrounding dementia in Africa parallels these experiences. Cultural beliefs attributing symptoms to supernatural causes occur and may exacerbate care-seeking behavior. In Kenya, a lack of evidence on dementia care pathways, coupled with minimal presentation of dementia-related symptoms in healthcare facilities, reflects stigma compounded by limited knowledge and inadequate infrastructure.[67] These beliefs create obstacles to care and emphasize the need for public education initiatives targeting both the general population and healthcare providers to improve understanding and encourage care-seeking.[19]

The role of indigenous knowledge systems in conceptualizing dementia and DS, however, is complex and multifaceted. With over 200,000 traditional healing practitioners (THPs) in South Africa alone versus approximately 40,000 registered medical doctors (MDs), they play a central role in healthcare delivery, particularly in rural and underserved areas where access to medical doctors is limited.[68] THPs provide culturally congruent care, often reflecting community norms and beliefs. Improved communication and collaboration between THPs and medical professionals could bridge knowledge gaps, fostering trust and ensuring culturally relevant care for individuals with DS and dementia. Efforts to bridge both knowledge systems in dementia research should be grounded in ethical, reciprocal partnerships. Community-Based Participatory Research provides a useful model for engaging THPs and MDs in a way that centers local knowledge and promotes shared ownership of the research process.[69,70] Research that challenges reductive views of THPs and examines how dementia is understood within both systems could support the co-development of shared, non-stigmatizing language and reduce miscommunication between THPs and MDs.

Community engaged research approaches, like community based participatory research and patient centered outcomes research are pivotal for addressing stigma, improving service access and increasing health equity. Projects like Africa-FINGERS show the importance of involving local stakeholders in designing health interventions, fostering community ownership, and promoting culturally appropriate solutions.[71] Applying similar methodologies to DS and particularly in broaching DSAD could reduce stigma, enhance service access, and ensure that care strategies align with the lived realities of affected individuals and their families. Tackling the dual stigma of DS and AD will necessitate the integration of community-based initiatives with broader healthcare strategies, using the shared learning from the ID and the AD landscape in Africa.

6.2 | Family and caregiving

Caregiving for individuals with DSAD in Africa presents unique challenges, yet little is known about the specific needs of this population. Insights must be drawn from broader caregiving experiences for DS and AD which can both place significant emotional, social, and financial burdens on families, and an overreliance on informal care.[19] For families caring for individuals with DS in Africa, the caregiving role often intersects with deeply ingrained societal stigmas and structural inequities. Mothers, who typically bear the primary caregiving responsibilities, report compounded burdens of caregiving, isolation, and economic hardship, while fathers report emotional distress and alienation due to societal pressures.[63,65]

For DSAD, caregivers face the dual challenges of managing progressive cognitive decline alongside the lifelong care associated with ID. Cognitive decline in DS typically has onset at an earlier age than in sporadic AD.[35] These intersecting demands highlight the need for caregiver training and support programs that address both conditions simultaneously. Community engaged approaches provide a model for integrating culturally appropriate interventions and leveraging local networks to support caregivers effectively.[71] Addressing the needs of caregivers for individuals with DSAD requires a multifaceted strategy that incorporates insights from both DS and AD caregiving in Africa.

TABLE 3 Service type available across Africa.

Service type	Countries	No. of organizations	Notable services provided
Advocacy	Algeria, Benin Republic, Botswana, Cameroon, Egypt, Eritrea, Eswatini, Ethiopia, Ghana, Kenya, Libya, Mauritania, Mauritius, Morocco, Nigeria, Rwanda, Seychelles, South Africa, Tanzania, Togo, Tunisia, Uganda, Western Sahara, Zambia, Zimbabwe	42	Policy advocacy, awareness campaigns, rights promotion
Education	Cameroon, Democratic Republic of Congo, Egypt, Ethiopia, Gambia, Ghana, Mauritania, Morocco, Nigeria, Rwanda, South Africa, Sudan, Tunisia, Uganda	21	Inclusive education programs, vocational training, specialized schools
Healthcare	Algeria, Egypt, Ethiopia, Mauritius, Morocco, South Africa, Sudan, Tanzania, Uganda & Rwanda	10	Specialized clinics, medical care, rehabilitation services
Employment support	Algeria, Democratic Republic of Congo, Egypt, Eswatini, Gambia, Morocco, Sudan, Tunisia, Uganda, Western Sahara	14	Job training, employment placement, vocational skills development
Community outreach	Cameroon, Egypt, Ethiopia, Ghana, Kenya, Mauritania, Mauritius, Rwanda, Seychelles, Uganda	13	Family support services, community education, outreach programs

Policies should focus on strengthening informal caregiving networks while expanding access to formal healthcare and support services.

6.3 | Access to services

The availability of services for people with DS across Africa reveals significant regional disparities and gaps that must be addressed to plan effectively for DSAD (See Table 3). Advocacy and awareness dominate the service landscape, with organizations in countries such as Ethiopia, Kenya, Uganda, Nigeria, Ghana, and South Africa leading efforts to promote rights and societal inclusion. While these services provide important groundwork, specialized services such as healthcare, education, and employment remain insufficient and unevenly distributed, often limited to countries like Morocco, Egypt, and South Africa, which provide isolated examples of integrated care (See Table S4 and S5 for services by type and country). In many Central and West African nations, services are virtually non-existent, reflecting systemic challenges that extend beyond awareness to include the absence of essential lifelong supports like health monitoring and social integration.

Planning for DSAD requires embedding care into primary healthcare systems to ensure services are accessible across all regions. People with DS require health monitoring throughout life due to their unique age-specific health trajectories, which differ significantly from the general population.[50] Early intervention, ongoing health surveillance, and support tailored to their elevated risk of AD are critical components of care. Regional networks can further enable collaboration among countries, allowing for resource sharing and the replication of effective models while fostering standardized approaches to DSAD that can be adapted to local contexts.

Lessons from HIV/AIDS care in Africa demonstrate the power of decentralized, integrated healthcare. Investments in training, diagnostics, and community-based outreach ensured scalability and accessibility of care, even in underserved regions. Similarly, DSAD-related care should be integrated into existing primary healthcare systems and linked to maternal and child health programs and disability frameworks. Community-based approaches, which were highly effective in HIV/AIDS care, could be employed to extend services to individuals with DS, leveraging local networks for outreach and education.

While advocacy has laid a strong foundation, the uneven availability of services across African regions highlights the need for targeted investment and strategic planning. The multi-sectoral strategies that transformed HIV/AIDS care—regional and international collaboration, integration into existing systems, and community outreach—provide a clear roadmap for strengthening DS services. Applying these lessons will be essential to address disparities, ensure lifelong health monitoring, and prepare for the evolving needs of individuals with DS as they face age-related challenges like DSAD.

7 | FUTURE PLANNING AND RECOMMENDATIONS

To advance care and research for DS and DSAD in Africa, it is imperative to adopt a forward-looking approach that anticipates the growing significance of DSAD as life expectancy improves for people with DS. People with DS in Africa, like their counterparts in HICs, are living longer due to gradual improvements in healthcare, and as this trend continues, the near-universal predisposition of DS to develop AD pathology will inevitably emerge as a pressing issue. Proactive planning

is essential to ensure that Africa is prepared to address the needs of this overlooked and vulnerable population.

The study of DSAD in Africa presents a remarkable scientific opportunity. DSAD provides a clear biological model for studying AD, while Africa's genetic diversity offers a setting to investigate the interplay between genetic and environmental factors in AD progression. Integrating African DS populations into biomarker research and therapeutic trials will not only bridge gaps in global health equity but also uncover novel insights with implications for AD research worldwide.

To prepare for the increasing prevalence of DSAD, increased training and awareness is needed for healthcare providers to recognize the dual challenges of ID and dementia. In regions with limited healthcare infrastructure, scalable innovations such as mobile technologies and DBS biomarker sampling can facilitate early diagnosis and research participation without the need for specialized centers. The advent of disease-modifying therapies for AD underscores the urgency of these efforts. Ensuring equitable access to these treatments for people with DS in Africa requires the establishment of longitudinal cohorts, biomarker studies, and the integration of DS populations into clinical trials. Without these foundational steps, African populations with DS are at risk of being excluded from advances in dementia care, perpetuating global health inequities.

Most sub-Saharan African countries are still in the early stages of developing or operationalizing national dementia strategies.[72] This presents an opportunity to ensure that DS is explicitly included in these plans from the outset. Doing so will not only prepare for the anticipated rise in DSAD prevalence but also foster an integrated approach that addresses the broader challenges faced by individuals with DS—challenges that often mirror those experienced by the general population living with dementia in Africa. The time to act is now—addressing DSAD in Africa is not just an ethical imperative but a necessary step in preparing for an aging population that will increasingly confront the challenges of AD.

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CONFLICT OF INTEREST STATEMENT

J. F. reported receiving personal fees for service on the advisory boards, adjudication committees or speaker honoraria from AC Immune, Adamed, Alzheon, Biogen, Eisai, Esteve, Fujirebio, Ionis, Laboratorios Carnot, Lilly, Life Molecular Imaging, Lundbeck, Perha, Roche,

and, outside the submitted work. J. F. reports holding a patent for markers of synaptopathy in neurodegenerative disease (licensed to Adx, EPI8382175.0). No other conflicts of interest to report. Author disclosures are available in the Supporting Information.

CONSENT STATEMENT

Consent was not necessary.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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