

Exploring the Potential of a Rights-Based Approach to Work and Social Inclusion for People with Lived Experience of Mental Illness in Ghana

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Abstract

Much of the focus on human rights and mental health in low- and middle-income countries (LMICs) has been on protection from coercion and abuse and on expanding access to mental health services, rather than on promoting and protecting social and economic rights. Despite the importance of work for mental health, there has been very limited consideration of the relationship between work and mental health in LMICs. This paper draws on ethnographic and participatory research in urban and rural sites in Ghana to illustrate the meanings and value of work, as well as experiences of support, exclusion, and discrimination, among people with lived experience of mental illness in Ghana. The paper outlines the policy context of mental health and human rights in Ghana and evaluates the challenges of implementing mental health, disability, and labor legislation to protect the rights of persons with mental illness—particularly the poorest and most vulnerable—in both formal and informal employment. The paper closes by discussing the potential of practices of solidarity and social activism to promote the rights of people with mental illness and push for change.

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Introduction

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) asserts that persons with disabilities, including psychosocial disabilities and mental health problems, have the right to "full inclusion and participation in all aspects of life" (article 26) and to inclusive, accessible employment.1 Article 27 commits state parties to "safeguard and promote the realization of the right to work, including for those who acquire a disability during the course of employment." This involves taking appropriate steps to prohibit discrimination on the basis of disability.2 Although the CRPD has been ratified by 181 countries, including 46 of 54 states in Africa, there has been a paucity of research on the work experiences of people living with mental illness in low- and middle-income countries (LMICs). In many LMICs, particularly in Africa, rights-based initiatives have tended to focus on civil rights and freedom from coercion and restraint rather than on social and economic rights, such as the right to work.3

The economic rationale for scaling up mental health treatment has emphasized the lost productivity of people with mental health problems and implications for growth and development.4 Efforts to improve access to work thus risk being reduced to arguments for a "return on investment." Furthermore, this approach may leave behind those most affected by severe mental illness (such as psychosis) and overlook the potential harms of poor working conditions on mental health.5 This includes precarious employment, overwork, and unsafe working environments. Nonetheless, for many people, meaningful work and being able to provide for oneself and one's family is inherent to a sense of well-being and identity. In many societies, working and contributing to household income and the wider community is an important milestone in gaining social status and respect. From a rights-based perspective, the argument is not to simply increase the productivity (and by correlation reduce the welfare dependency) of people with mental illness but to ensure fair pay, safe and flexible working conditions, and equal opportunities as beneficial for all.6 As articulated by the United

Nations Special Rapporteur on the right to health, "the right to health is not the right to be healthy, but a right to both conditions and services that are conducive to a life of dignity and equality, and non-discrimination." Rights are thus interdependent, with labor rights to health and safety at work and fair remuneration, for example, as crucial to mental health as specific disability or mental health rights, such as the rights to inclusive workplaces and suitable accommodations.

Much of the research in this field has been conducted in high-income countries, with very little known about the relationship between work and mental health in LMICs. A recent review found only eight studies on mental health and employment from Africa.8 A study of experiences of persons with a diagnosis of mental illness in Kenya found that barriers to employment included mental illness factors, social exclusion and stigma, a non-accommodative environment, and socioeconomic status. Factors that facilitated employment included self-awareness and acceptance, self-employment, provision of reasonable accommodation, improved health services, removal of discriminatory laws and practices, and social development programs.9 Scaling up mental health care in LMICs has focused largely on improving access to psychiatric treatment, with few services that support reintegration into work and other opportunities for social inclusion.10 Psychosocial interventions in LMICs are predominantly concerned with psychoeducation and therapy, rather than vocational support.11 A few nongovernmental organization (NGO) projects support sustainable livelihoods for people with mental illness by providing capital, loans, and training.12 However, these tend to be small scale, unevenly distributed, and short lived. While legislation is advocated to protect the rights of people with mental illness, including access to work and protection from discrimination, there are challenges to implementation. Legal protections may be least accessible to the most disadvantaged, such as those without formal education, who may be unaware of avenues for redress and struggle to access legal representation.13 This reinforces gender inequities, as women generally receive less education. A further concern is how such protections can be enforced in informal employment and across both private and public sectors.

Questions also remain as to the social and cultural meaning of work in LMICs and the impact of changing economies. With the global transition to neoliberal economies, the labor market is changing in low- and high-income contexts alike, with increased precarity, public sector retrenchment, and reduced worker protections. Following the international epidemiological studies on schizophrenia by the World Health Organization (WHO) in the 1960s, researchers speculated that better outcomes in "developing" countries might be a consequence of greater opportunities for integration into informal work.14 This was hypothesized to be due to greater flexibility, with less rigid workplace demands than in industrialized economies.¹⁵ This argument overlooks precarity within the informal economy and changing aspirations for young educated Africans.¹⁶ Over 85% of Africans are estimated to work in informal employment, with few social protections in the event of sickness, disability, or pregnancy.¹⁷ Women perform the majority of unpaid labor, such as child care and household chores, which are often labor intensive, reducing their potential to generate income outside the home. As more people complete secondary education, many aspire to professional, service, and sales jobs, rather than farming and manual labor. Public sector positions that offer greater workplace protections, such as nursing and teaching, can be increasingly attractive compared to precarious lower-level private sector employment. In sub-Saharan Africa, economic growth has not been accompanied by a rise in jobs, and youth unemployment and underemployment remain high.¹⁸ Access to "decent work for all," as articulated in the Sustainable Development Goals, is a struggle for many Africans, not only those with mental illness.19

In this paper, we explore the aspirations and work experiences of people with diagnoses of mental illness in Ghana, including their experiences of support, discrimination, and exclusion. We consider the potential of legislation, social protection programs, civil society, and community support to promote the right to work as an important com-

ponent of mental health and social inclusion. This focus arose out of ethnographic and participatory research on the meaning of article 19 of the CRPD (the right to live independently in the community) in rural and urban settings in Ghana. Ghana has been the focus of considerable concern regarding the human rights of persons with mental illness following the exposure of abuses in prayer camps, shrines, and psychiatric services.20 There have been substantial efforts to improve mental health care, with support from international agencies such as WHO and the UK Department for International Development. In 2012, Ghana ratified the CRPD and passed a new Mental Health Act that draws on many of the principles of the convention, including the right to equal participation in employment. However, with international attention on human rights violations by traditional and faith healers and on scaling up treatment, there has been a policy focus on expanding community mental health care and collaboration with healers.21 Less attention has been paid to social and economic rights, including the right to work and participate in society in meaningful ways. Although the mental health workforce has expanded, it is made up primarily of mental health nurses, with very few social workers, psychologists, and occupational therapists. As in other low-resource settings, treatment is generally restricted to the provision of psychotropic medication and crisis management, with very limited psychosocial interventions. Sustainable livelihood initiatives are provided through NGOs as short-term projects that are unevenly distributed throughout the country.

Our research in Ghana included observation, conversations, and interviews with people with lived experience of mental illness and their family members, as well as with stakeholders such as mental health workers, human rights organizations, and other NGOs. We considered the following questions: What is the meaning of work for people living with mental illness in Ghana? What role does it play in perceptions of recovery and social inclusion? What is the experience of accessing and remaining in work? What is the potential of legislation, social protection programs, civil society, and

peer support to promote the rights of people with lived experience of mental illness in this context, and how can they be made accessible to the least advantaged? What could be the role of communities in supporting the right to social inclusion for people living with mental illness?

Methods

This research forms part of a larger collaborative research project on mental health and justice. Ethnographic research was conducted in the capital, Accra, and in Kintampo South in the Bono East region. Research questions focused on the meanings of article 19 of the CRPD and barriers and resources that affect the social inclusion of people with lived experience of mental illness. The study employed various methods, including participatory research, naturalistic observations, and in-depth interviews with people with lived experience of mental illness, family caregivers, mental health workers, healers, social workers, civil society organizations, and policy makers.

Fieldwork took place over 22 weeks spread over five field visits between 2018 and 2020. We visited participants at their homes and in community spaces, such as churches, social venues, and workplaces, where we engaged in observation and informal conversation. We recorded our observations in fieldnotes and photographs. Interview participants were purposively sampled. Participants with lived experience of mental illness had been diagnosed with schizophrenia, schizoaffective disorder, and bipolar affective disorder (BPAD).

Interviews were conducted in English or Twi and audio recorded with participants' consent. One participant chose not to be recorded. Recordings were transcribed verbatim and translated into English.

Two participatory groups of people with lived experience of mental illness were formed in Accra and Kintampo in 2018. To date, six meetings have been held in Accra and four in Kintampo, with a total of 27 participants (13 men and 14 women), 15 of whom participated in the interviews. Participants

were recruited through NGOs, people receiving treatment from mental health services, and participants from previous research.²² Participants ranged from university graduates to those with no formal education. Through activities such as the Tree of Life narrative approach, our meetings involved discussions on the meanings of, opportunities for, and barriers to social inclusion.²³ The participatory groups were facilitated by the researchers alongside two occupational therapists in Accra and a community mental health worker in Kintampo.

Initial analysis was conducted manually through listening to interview recordings and by close reading of fieldnotes and interview transcripts. Conceptual and theoretical development was developed through triangulation of audio, visual, and written data. Themes were developed inductively through an iterative process and summarized as codes. Fieldnotes and transcripts were then coded using NVivo, and codes were further refined. Three members of the Accra participatory group also read a draft of our paper and provided feedback. Our analysis took an interpretive case study approach, drawn from anthropological theories of illness narratives and situation analysis.24 This explores how lived experience of crisis or social change is situated within the historical, political, social, and cultural context. It includes a consideration of how socioeconomic status, education level, rural/urban location, age, and gender intersect to affect lived experience.

Ethics

Ethical approval for the study was granted by King's College London (approval no. HR-17/18-5393) and Ghana Health Service (approval no. GHSERCoo8/11/17). Participants were provided with information on the study in English or Twi and were asked to sign a consent form. If the person was unable to read or write, they were asked to provide a thumbprint in the presence of a witness. Several participants with lived experience of mental illness have become public advocates for mental health and spoken openly about their experiences. Participants were therefore asked to choose whether they wished to disclose their identity in research out-

puts. Pseudonyms are used for those participants who chose to remain anonymous. All participants whose first names are used have read the paper and given consent for their real names to be used.

Findings

The meaning of work for social inclusion

The desire to work and earn sufficient money to support oneself featured prominently in concepts of recovery and social inclusion articulated by people with lived experience of mental illness and family caregivers across urban and rural settings. During group meetings, participants spoke about aspirations to work as central to "living independently and being included in the community." For example, during discussions on "What does being independent mean to you?," participants generated statements such as "having the strength to work and take care of myself," "support in all areas, especially with work for example, support to begin a business," and "being able to go back to work." Participants also engaged in spontaneous discussions regarding experiences of discrimination in the workplace, pressures from family and peers, and the challenges of finding employment. These themes recurred in interviews and informal conversations. Alex, a 31-year-old graduate from Accra, explained how he wanted to achieve financial independence and no longer rely on family support: "I just trust God that what happens the sickness will not come back any more, so I'm just looking forward to get a job now." Work would enable him to get together enough money to rent his own place and meet social expectations of independence and maturity: "as a man growing up, you need to stay on your own."

For young men, being able to work is also important to attract a marriage partner. Henry, who lives in Kintampo and has a diagnosis of BPAD, complained that his relationship with a nurse had ended because of his difficulty holding down a job:

She planned to marry me, but she saw that I'm not working ... She told me if I had worked, I'd had a work, a menial job. She understands my problem and everything. She said if I have had a menial

work to do, for her to respect me as a husband, she would marry me.

Earning a livelihood and being able to provide for others (importantly, a spouse, children, siblings, and older parents) is central to achieving adulthood and respectable social status in Ghana, particularly for young men, and thus crucial to individuals' sense of identity and self-worth. Persons who are unable to work may be perceived as lacking moral and social value. Indeed, it is common to hear people with mental illness fear being labeled "useless" because they are seen as not contributing to society or to the household. The impact of mental illness on work status can lead to prolonged dependence on a parent, spouse, or sibling to meet everyday needs. Kwame developed mental health problems when he was at university and had to return to live with his mother in Kintampo. Despite several attempts to resume his education, he continued to experience poor mental health, which prevented him from getting his degree and moving on to the professional employment he hoped for. Whereas normative expectations are that a son should support his mother as he moves into adulthood, in this case the mother continued to support her adult son even though she was in her seventies. She explained:

You know as a young man in his thirties he should be doing his own work. When he wakes up in the morning I have to give him money, if he's going to barber his hair I have to give him money, if he wants to wash his clothes, I have to buy soap. The phone that he's using I had to buy it for him. I am not supposed to be the one to provide for him at this moment but I'm the one doing everything.

Like Alex, Kwame was acutely aware of the stigma attached to his status as a person with a diagnosis of mental illness and no independent income. He explained that socially he's "considered as a kid" because he isn't earning any money and remains dependent on his mother's support: "I'm under her care and I don't have any business, I don't have any employment, and, I'm also considered as a patient at the psychiatry." He continued, "I'm not a fully equipped adult because I lack a lot of things that make up an adult."

Experiences of work and mental illness

Nearly all participants reported challenges in both finding and remaining in employment. At one level, the illness itself created difficulties in the workplace. Several participants described how they had argued with members of the public or work colleagues when unwell. Some had caused concern by expressing unusual beliefs or engaging in behavior that transgressed social norms. John grew up in Accra and has a diagnosis of BPAD. His symptoms began just as he started his career after graduating from university. He had accepted a prestigious position working for a large pension company. Shortly after commencing, he experienced a serious manic episode and was hospitalized. He described how he had gone from being "really, really depressed" and not talking to anyone to being "all over the place" and confronting his colleagues:

So one time I barged into work, running and started shouting and started talking: "The boss is sleeping with this girl" and they are thieves. So they realized something was wrong and they called my dad ... and I had a big notebook of all ... a lot of ambitions, I wanted to be president and I was writing my manifesto, crazy stuff man!

For John, this led him to worry about the impact on his long-term work prospects: "I don't think I would be able to hold onto a job for a long time ... when my mood disorder comes, I mean, no one wants someone like that."

The majority of Ghanaians, even those living in urban settings, work in the informal sector. This includes running small shops, street trading, and food preparation, and trades such as tailoring, hairdressing, and soap making. In Kintampo, farming is the most common occupation for men. Informal enterprises offer a degree of flexibility and independence, which can make them attractive to people who experience fluctuations in their mental health. Like Kwame, Henry had been unable to complete his studies and establish a professional career. He had been fired from his first job in a bank following a "misunderstanding": "They were potential customers, they were students. I had an exchange of words and they reported it to the manager.

2016 January, the manager fired me. He won't let me work with the bank again." Later, he got into an altercation at the college where he worked as a security guard: "Because of my problem, I had a loggerhead. I had an exchange of words with the students and some of the lecturers." Again, he was fired. Henry was also trained as a tailor and said that he preferred such work because it allowed him to be his "own master": "If I work, they would fire me because they don't understand me. They don't know my condition. But for the tailoring work I'm a master of my own." Similarly, Alex stated his preference to set up his own business to avoid the stress of formal employment and commuting, a major concern in Accra, where rush-hour commutes typically last well over an hour:

The kind of work or job I need now is something that I should be controlling, go and visit it at my own time, you get it? Not something I have to go to maybe like a bank job, do from morning to evening and close. By the time you get home, traffic, you can be stressed and all that ... the body may break down at a time because you need rest.

However, many individuals, particularly those from poor families, found it difficult to obtain capital to establish a business. Henry described the struggle he faced obtaining the resources to set up a business as a tailor: "You need money. Maybe you want to open a shop like this my work, I have to get a container, get my set of machines ... buying my own threads." As Alex complained, bank loans require collateral and are thus unavailable to many. A few received gifts or loans from relatives, friends, or church members, as described below. Success in business also lies in establishing a customer base, which is not easy when fluctuations in mental health could result in prolonged absence from a competitive market. Such enterprises offer few protections (such as paid sick leave), and a small business can easily fold if the person becomes unwell. This was the case with Justice, whom we met in a healing shrine near Kintampo. Justice had set up a successful barbering shop in town and had invested significant capital in the tools of his trade, such as sterilizing equipment and a barbering chair.

However, during the months he spent at the shrine, his customers "scattered." On his return, he was faced with the challenge of rebuilding his customer base from scratch.

Experiences of discrimination in the workplace

Aside from Henry, other participants described being dismissed from work after experiencing a deterioration in their mental health. Cecilia was a teacher in a private school in Accra and has a diagnosis of BPAD. Although she had been receiving treatment for her condition, she had been unable to afford the costs of medication and experienced a relapse. She described what happened:

Things were getting very difficult for us. Even what to eat was difficult, so we couldn't buy the medication. So one time I was going to work without taking the medication for some time. And then I had a crisis there. I don't really remember everything. They said I broke the glass, the louvre pane. So when like I came to normal the school governors were like if it should happen again they would sack me. So it didn't happen again, I was working alright. But sometime then I felt a sharp pain in my head, a very sharp pain. So they took me to the hospital. So when we came back then they told my husband that I should stay home and take care of myself. But I didn't know they've sacked me. So when I became ok after about two weeks I was at home, then the following, the third week I went back to work. And that very day they told me that they have taken someone else, and that they have told my husband I should stay home and take care of myself, they have taken someone in place of me.

Cecilia's story illustrates the intersection of structural factors affecting mental health and social inclusion. Due to shortages of psychotropic medication in public hospitals, Cecilia and her husband were forced to purchase them out of pocket. But since they worked in low-wage jobs, they were unable to afford such treatment in the long term, and the precarity and struggle to survive negatively affected Cecilia's mental health. After not taking her medication for some time, Cecilia relapsed, setting in motion events that led to her dismissal.

Cecilia's experience also highlights the weak employee protections within the private sector and the potential consequences of disclosing a diagnosis of mental illness to employers. Yaa, a young graduate, also has a diagnosis of BPAD and was dismissed from her job as a teacher in a private school in the capital. She had confided her condition to a colleague, who then told her employers. To her distress, her employers told her she was unfit to work with children and that she should have disclosed her condition upon being hired. However, Esenam knew that had she done so she would not have been offered the job in the first place. Esenam also described difficult working conditions that she feared would affect her mental health—she was expected to work long hours from early in the morning until late in the evening. Her long commute home in heavy traffic was exhausting. She would then become sleepy during the working day, worsened by the effects of her medication. Like many other employees in the private sector in Ghana, Esenam's ability to seek justice was further compromised by the fact that she did not have an official contract setting out the terms and conditions of her employment.

Alex's story reveals the ways in which negative stereotypes about mental illness, such as a popular association with drug use, could exclude people from the workplace and in turn exacerbate mental distress. After passing a rigorous recruitment process, Alex had been offered a job in a bank. However, just before starting, he was asked to meet with the managing director (MD). His sister explained what happened:

We heard that the MD just wanted to meet him one on one, even though he's gone through all the interviews, just to have an interaction with him. In the course of the interaction the MD needed to know the reason for the gap in his schooling, like why he deferred his course and all that. So that was where the issue was ... Alex is someone who likes honesty, he doesn't believe in lying, just like me, he wants to be plain, because he doesn't believe in twisting things, he wants to say things the way they are, so in trying to be honest about it he told the MD he took ill, he needed to seek some medical help. Then the MD was curious to know what sickness could

take you out of school for a whole year so he probed further and he explained that it was more like a mental-related thing and of course no MD would want to ... he would not want to probe to know what resulted to that, were you were doing drugs? But the general overview would be that, mental issue, ok, that means maybe you were smoking weed or you were in a bad peer group or something ... you were a bad boy or coming from a bad home, it could be any of those ... So that was the blast for him, he lost that job and he went right down into serious depression.

For those who were self-employed and in informal work, stigma and discrimination in the community could also affect social inclusion and opportunities to earn a livelihood. This was particularly evident in Kintampo, where people were more likely to be engaged in informal work and known to people in their neighborhood. When Justice returned from the shrine and reopened his barbering salon, he was careful not to disclose where he had been to people in his community, telling them only that he had "traveled." Akua, a middle-aged woman from a poor background in Kintampo, has a longstanding mental illness and has experienced several serious breakdowns. Akua was desperate to work to support herself, given that she is unmarried and does not have the financial support of a husband. Over the years, she has engaged in various kinds of smallscale trading, disrupted by periods when she is unwell and unable to work. Most recently, a church friend offered her work helping sell fish. However, people avoided buying from her—she suspects due to her "madness" and the belief that she is being followed by mmotia, forest-dwelling spirits-and she had to stop. Mental illness is perceived by many to be transmissible via such malign spiritual forces, and people may fear that eating her fish might in turn infect them with madness.

Experiences of workplace protection

Those working in the public sector as part of a unionized workforce generally have access to greater legal protection in the event of illness. Upon hearing Esenam's story during a meeting of the Accra participatory group, Ruth, a former teacher with the government-run Ghana Education

Service, expressed her outrage. Her own experience had been very different, even though she suffers from a longstanding psychotic illness, with disturbing visual and auditory hallucinations. Ruth's employers had given her regular paid leave from work when she experienced a crisis, and when she was unable to work in the classroom, she was placed on "light duties," working in office administration. As she explained, at the Education Service she was protected from dismissal:

They have a law ... that if a person is sick, or something has happened to that person, you don't terminate his or her appointment, unless it is a grievous offence, the person has committed a grievous offence ... they will transfer you and give you a light duty.

Ruth remained in full-time employment until her retirement and now lives on her teacher's pension.

In contrast to small businesses, larger private companies may also offer a higher level of worker protection, although it is unclear how widely this is the case. Although John was unable to return to work following his breakdown, his employer continued to pay his salary for well over a year. Janet, another participant in the group, works at a professional level for a large international company. She told the group that she had informed her employer of her condition and was able to negotiate time off when she was unwell.

The potential of human rights legislation

These examples illustrate inequities in workplace protection and how those with the lowest socioeconomic status are most likely to suffer the consequences of discrimination and exclusion. How, then, might human rights legislation work to protect the most disadvantaged? Could it protect people such as Akua from the stigma and fears surrounding mental illness, as well as enable people such as Cecilia to seek redress? Ghana's Disability Rights Act and the CRPD set out a state duty to prohibit discrimination and ensure "reasonable accommodation" in the workplace. Ghana's Labour Law also provides safeguards against employment-related discrimination under broader

provisions for persons with disabilities. According to these provisions, mental illness cannot be used as the sole basis for denial or termination of employment. In addition, Ghana's Mental Health Act, which was praised by WHO and researchers in global mental health for its rights-based credentials, reiterates the illegality of terminating employment due to mental illness.25 Consistent with Ruth's experience (which predated the Mental Health Act), if a person's mental health condition occasions "dysfunctions in performance of duties," the law directs employers to assess whether the person's residual capacity would allow for a reassignment of duties in the same employment or a corresponding position. Where necessary, adjustments may include training at the employer's expense or assistance in receiving medical attention. Should it become necessary to terminate employment, the employer should provide appropriate remuneration.

Most of this legislation, including the CRPD and the Mental Health Act, has been only partially implemented. Ghana's first report to the Committee on the Rights of Persons with Disabilities, submitted four years behind schedule, notes that discrimination in access to employment for persons with disabilities is "very high" and that people are denied "facilities and conditions that would enable them to work effectively," but it does not identify concrete steps to address this.26 The Mental Health Review Tribunal mandated to provide redress specifically for contraventions of the Mental Health Act, including employment-related cases, has yet to be established, apparently due to insufficient funds. The Commission on Human Rights and Administrative Justice (CHRAJ) and the Legal Aid Commission, which were set up under the Ghanaian Constitution, provide legal support and representation, ostensibly free of charge. However, as with many government services, both entities face significant financial and human resource constraints. As a CHRAJ director complained, "We have as one of our mandates, CHRAJ, to conduct public education, you know, either through the media, or visits to communities, organize people, talk to them and then ... but again the resource constraints, resources are not provided."

An NGO worker further noted that people with mental illness are often unaware of their rights, which prevents them seeking legal redress:

People with mental disorders themselves do not know that they have a certain right. So once they don't know, or even if it's trampled upon it, they don't even know that such a thing has happened, because they don't know what it means, or they don't know what constitutes it. So if there's a violation and a breach, he doesn't have an idea! It is somebody who can draw his attention or your attention, that look this thing that was done to you, you could go to the court and get judgement or something.

Access to social protection programs

Aside from legislation, Ghana has two social protection programs that should in principle be available to people with mental illness who are unable to work. The Livelihood Empowerment Against Poverty (LEAP), a cash transfer program adopted in 2008, provides small monthly payments to people with "severe" disabilities. Secondly, a proportion of the "Common Fund" is allocated to local government to be made available to those with disabilities. In practice, these funds are difficult to access and inconsistently distributed.²⁷ Some mental health workers and NGOs work with Social Welfare officers to help people with mental health problems apply to their local district assembly for these funds, but most of those we interviewed had not received them. Mental health and social workers complained of long delays in accessing the funds: "The [district] assembly too is not fast enough. Sometimes we go and they say they don't have funds. All the funds are finished." This was corroborated by an NGO worker who claimed that some district assemblies might deliberately withhold the money to use for other activities:

Unfortunately some of the district assemblies don't disperse the money to persons with disabilities. They wait, when their budgetary allocation for them is almost exhausted then they fall on the Common Fund for persons with disabilities and use for their activities in the district, do you understand? So sometimes it's deliberate.

A further problem was the lack of recognition of people with mental illness under the category of "persons with disabilities," as described by this human rights worker:

Most of the district assemblies they don't consider people living with mental diseases as beneficiaries of the District Assembly Common Fund, because when they talk about disabilities, they end up having separate sides of disabilities. But they end up talking about physical disabilities without specifically talking about mental health.

The Mental Health Authority, the government body overseeing mental health in Ghana, has brought much-needed attention to mental health, pushing for implementation of the Mental Health Act and leading the reform of services. However, the establishment of a separate body for mental health has arguably created silos, which may hinder the shared policy action needed to address the social and economic rights of persons with mental illness.28 There are concerns that people with mental illness are not considered by agencies such as the National Council on Persons with Disability (NCPD) under the category of "disability," partly as a consequence of this organizational distinction. As argued by a human rights worker, the creation of the Mental Health Authority and the NCPD under the Mental Health and Disability Acts, respectively, as "two completely different agencies" presents a "divided front" in the struggle for social and economic rights:

NCPD can push for benefits for persons with disabilities but the category of disabilities they are concerned with looking at does not include persons with mental illnesses. So NCPD talks a lot about, for example, the disability Common Fund, social and economic opportunities for persons with disability and they can push through the government to get things if they want them but then their categories of disabilities ... They said, "Yeah we know what mental illness is," but in terms of policy and receiving budget allocation or specific interventions, they don't consider mental illnesses because the Mental Health Authority has been set up. I see it as more of a divided front which is not helping particularly when it comes to social and economic opportunities.

Civil society and advocacy

NGOs and civil society organizations in Ghana are increasingly active in campaigns to improve public awareness of the rights of persons with mental illness, counter stigma and social exclusion, and implement the Mental Health Act and the CRPD. Some receive training and funding from international groups such as the WHO Quality Rights initiative and the "Time to Change" global anti-stigma campaign.29 NGOs have established peer support groups and provided capacity building on skills such as public speaking and assertiveness. These efforts aim to empower people with mental illness "to do their own advocacy, as rights holders demand their rights from duty bearers directly," as an NGO worker put it. Several people with lived experience of mental illness, such as Cecilia, have become active mental health advocates and shared their stories on social media, TV, and radio. They have also engaged in "awareness raising" in markets and shopping malls. WhatsApp groups and meet-ups provide fora in which people with lived experience of mental illness are beginning to offer mutual support, as emerged in the participatory group meetings.

However, the recovery narratives produced through international campaigns are often depoliticized, focusing on individual behaviors to challenge stereotypes and emphasizing the productive contributions of people with lived experience of mental illness.30 Wider structural issues and political and judicial pathways to justice are seldom discussed. The NGO worker also expressed disappointment that in his experience, despite training, the poorest and those with the least education often lack the confidence to advocate for themselves, for example in petitioning their district assembly for funds. This suggests that training in empowerment may have the unintended effect of reinforcing inequalities, particularly in a context of entrenched hierarchies. It is notable that, as in a recent article highlighting the emergence of "middle-class, young and educated" Ghanaian men discussing their mental health, such advocacy is concentrated in the capital and reaches primarily younger, educated groups.31

Social media is accessible to only a small section of society, and the poorest, who do not speak English or have reliable access to the internet, are most likely to be excluded from such conversations. No participants in Kintampo were regularly engaged on social media, even those who spoke English. In addition, despite substantial provisions for work-place protections for people with mental illness in the Mental Health Act and the CRPD, these have received less attention than education on mental illness as a medical condition, improving access to psychiatric treatment, and regulating traditional and faith healers.

A few NGOs are involved in livelihood support for people with mental illness and their families in rural areas, providing capital and training to set up small businesses such as mushroom farming and goat rearing. However, these initiatives are often driven by external priorities and unevenly distributed. The only mental health-focused NGO in Bono East is now targeting maternal mental health and is not operating in Kintampo North. In Accra and Kintampo, informal networks made up of family, friends, work colleagues, and church members rather than formalized social or legal interventions were the most common resource for those seeking to reintegrate into work. Frank, for example, after recovering from addiction and psychosis, had been given funds by his sister to set up a chicken farm on the outskirts of Accra. This provided him with a livelihood selling eggs to local storekeepers. Henry was supported by his sister and mother, who bought him an overlocking machine that he operates in his sister's tailoring shop.

Such small-scale enterprises could offer informal workplace accommodations grounded in familiarity with the day-to-day needs and preferences of the person. Kwame has continued working in a modified role at his mother's wholesale food business. Although his mother had to contract her business due to the failure of creditors to pay their debts, Kwame attends the store every weekday, awaiting those who come to pay and recording their accounts. He is not paid by his mother for the work, but, as she describes above, she supports all his daily needs. Aside from the family, there are

other community-based networks that can provide access to employment opportunities, such as religious groups and local businesspeople who engage in philanthropic activities. After Akua lost her job selling fish, another member of her church engaged her to help bake bread. Such forms of mutual aid and support are an essential aspect of getting by or "managing" everyday life in Ghana, making things possible in the context of under-resourced state infrastructure and scant welfare systems.32 From paying a sibling's school fees, to contributing to health care costs, to supporting elderly relatives, to give but three examples, these practices are embedded in everyday social relations and moral economies. Despite the danger of entrenching patronage and hierarchies, their social embeddedness gives them a pragmatic scope and local accountability seldom matched by NGO projects, government programs, and state legislation.33

Discussion

As we have shown, social inclusion through work is a common aspiration for people with lived experience of mental illness in Ghana as elsewhere. Having the means to support oneself is valued not only for its economic but also for its social value and is thus central to a rights-based approach to social inclusion. Nonetheless, work itself can produce stress, and social expectations can present challenges for those who experience ongoing struggles with their mental health and face enduring discrimination. The fluctuations in mental health experienced by participants in this research show the importance of workplace accommodations, such as paid sick leave and flexible working hours, to enable those with serious and enduring mental health difficulties to exercise their right to work. However, experiences of exclusion and discrimination, particularly in the private sector, reveal the extent to which the right to work and to workplace accommodations as described in the CRPD and Ghana's mental health, disability, and labor laws are routinely flouted. In addition, these protections might be least available to the most disadvantaged. Aside from the challenges and costs in accessing legal representation, legislation is more difficult to implement within the informal sector, where most Ghanaians work, particularly women and those with little education. Legislation may also be less efficacious in addressing the kind of community stigma that Akua and others experienced. An adversarial approach may conflict with the ethics of civility within Ghanaian society and disrupt the vital social networks on which people depend.³⁴ As we found in this research, such networks are often the most important facilitators of employment.³⁵

Analyses of social protection programs such as LEAP have shown that even small cash transfers may not only reduce absolute poverty but enhance social inclusion by providing some measure of financial independence and funds to engage in social networks.³⁶ However, they have been criticized from a social justice perspective as failing to empower recipients and address the root causes of poverty and inequality.³⁷ There are justifiable critiques of the charity model, which can increase dependence and reinforce hierarchies. Indeed, the CRPD explicitly states that support services must be considered a right rather than a form of charity. In the case of persons living with mental illness in Ghana, confusion over the definition of mental illness as a "disability" and inefficiencies in administration have reinforced dependence on intermediaries to access such benefits and deprived many of entitlement to basic social protection.

The emergence of peer support and advocacy in LMICs suggests the potential for building solidarity through which to build collective action to claim rights.38 However, to date, these have had a limited influence on mental health policy, and activities are hampered by lack of resources.39 There might also be potential to nurture solidarity within communities, building on the social commitments evidenced by those who provided support for people living with mental illness to establish a livelihood. While NGO projects tend to be shortlived, unevenly distributed, and driven by external funding and agendas, community networks and resources such as church groups, youth clubs, trade unions, and professional societies are rooted in organic social values and relationships.40 These

might be mobilized to support social inclusion through enabling opportunities for participation in work and other socially valued activities, as well as organizing to address injustice and claim rights.⁴¹ Building these forms of practice-based solidarity could contribute to overcoming discrimination at the community level, such as by encouraging owners of small businesses to employ people with lived experience of mental illness. However, community participation should not be confined to the "lowest rung" but reach upstream to challenge those in power and hold them to account.⁴²

Conclusion: Community mental health as social activism

In a recent editorial to mark the anniversary of the Centre for Global Mental Health, Richard Horton argued that "mental health professionals and civil society need not only to rediscover their solidarity but also their raging soul." The "mental health community," he claimed, "has failed to devise any credible means to hold political leaders accountable for their promises and commitments."43 Since publication of the Lancet's seminal series on global mental health, Ghana has become a significant focus of activities that aim to promote the rights of people with mental illness, including ratification of the CRPD.44 However, while the human rights community has focused on abuses by traditional and faith healers, as we have shown, rights to social inclusion and participation in the workplace are routinely contravened. Political leaders in Ghana have not been held to account for their failure to implement the CRPD and protect the rights of some of their most vulnerable citizens. The emphasis is often on individual stigmatizing behavior and "harmful cultural practices" rather than on challenging the ways in which discrimination is embedded into social and political structures.⁴⁵

In the face of such injustice, we would argue that national and global efforts should move from a narrow focus on service development and individualized interventions to considering how best to work across different sectors to challenge social, structural, and political barriers to social

inclusion.⁴⁶ Building on recent work on "community competencies" and social activism for mental health, we suggest that bringing together people with lived experience of mental illness alongside allies within families, communities, and civil society could hold local and national government and employers in the private and public sectors to account and ensure full and equitable participation in all aspects of life, including work.⁴⁷ In this way, it may not be the Mental Health Act that becomes Ghana's pioneering legacy for mental health and human rights, but the ways in which Ghanaian citizens and their allies built a social movement to fight for social justice and inclusion.

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References

- 1. Convention on the Rights of Persons with Disabilities, G.A. Res. 61/106 (2006).
 - 2. Ibid.
- 3. N. Drew, M. Funk, S. Tang, et al., "Human rights violations of people with mental and psychosocial disabilities: An unresolved global crisis," *Lancet* 378/9803 (2011), pp. 1664–1675.
- 4. J. Campion and M. Knapp, "The economic case for improved coverage of public mental health interventions," *Lancet Psychiatry* 5/2 (2018), pp. 103–105.
- 5. V. Patel and P. E. Farmer, "The moral case for global mental health delivery," *Lancet* 395/10218 (2020), pp. 108–109.
- 6. D. Pūras, Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attain-

- able Standard of Physical and Mental Health, UN Doc. A/HRC/41/34 (2019).
- 7. Ibid.; G. Macnaughton and D. Frey, "Challenging neoliberalism: ILO, human rights, and public health frameworks on decent work," *Health and Human Rights Journal* 20/2 (2018) pp. 43–55.
- 8. I. D. Ebuenyi, E. V. Syurina, J. F. G. Bunders, and B. J. Regeer, "Barriers to and facilitators of employment for people with psychiatric disabilities in Africa: A scoping review," *Global Health Action* 11/1 (2018).
- 9. I. D. Ebuenyi, M. Guxens, E. Ombati, et al., "Employability of persons with mental disability: Understanding lived experiences in Kenya," *Frontiers in Psychiatry* 10/539 (2019).
- 10. Patel and Farmer (see note 5); V. Iemmi, K. Blanchet, L. J. Gibson, et al., "Community-based rehabilitation for people with physical and mental disabilities in low- and middle-income countries: A systematic review and meta-analysis," *Journal of Development Effectiveness* 8/3 (2016), pp. 368–387.
- 11. C. Brooke-Sumner, I. Petersen, L. Asher, et al., "Systematic review of feasibility and acceptability of psychosocial interventions for schizophrenia in low- and middle-income countries," *BMC Psychiatry* 15/19 (2015).
- 12. C. Raja, C. Underhill, P. Shrestha, et al., "Integrating mental health and development: A case study of the Basic-Needs model in Nepal," *PLOS Medicine* 9/7 (2012).
- 13. D. Reubi, "The promise of human rights for global health: A programmed deception?," *Social Science and Medicine* 73/5 (2011), pp. 625–628.
- 14. R. Warner, Recovery from schizophrenia: Psychiatry and political economy, 2nd edition (London: Routledge, 1994).
- 15. J. Cooper and N. Sartorius, "Cultural and temporal variations in schizophrenia: A speculation on the importance of industrialisation," *British Journal of Psychiatry* 130 (1977), pp. 50–55.
- 16. J. K. Burns, "Social integration and human rights: A view from a low- and middle-income context," *Epidemiology and Psychiatric Sciences* 22/1 (2013), pp. 43–45.
- 17. International Labour Organization, *Women and men in the informal economy: A statistical picture* (Geneva: International Labour Organization, 2018).
- 18. ILO, World employment social outlook: Trends 2019 (Geneva: International Labour Organization, 2019).
 - 19. Burns (see note 16).
- 20. Human Rights Watch, "Like a death sentence": Abuses against persons with mental disabilities in Ghana (Washington, DC: Human Rights Watch, 2012); Commwealth Human Rights Initiative, Human rights violations in prayer camps and access to mental health care in Ghana (Accra: Commwealth Human Rights Initiative Africa, 2008); J. E. Mendez, Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment: Addendum; Mission to Ghana, UN Doc. A/

HRC/25/60/Add.1 (2014).

- 21. B. Akpalu, C. Lund, V. Doku, et al., "Scaling up community-based services and improving quality of care in the state psychiatric hospitals: The way forward for Ghana," *African Journal of Psychiatry* 13/2 (2010), pp. 109–115; L. Kpobi and L. Swartz, "Indigenous and faith healing in Ghana: A brief examination of the formalising process and collaborative efforts with the biomedical health system," *African Journal of Primary Health Care and Family Medicine* 11/1 (2019), pp. e1–e5.
- 22. U. M. Read, E. Adiibokah, and S. Nyame, "Local suffering and the global discourse of mental health and human rights: An ethnographic study of responses to mental illness in rural Ghana," *Globalization and Health* 5/1 (2009), p. 13; U. M. Read, "Rights as relationships: Collaborating with faith healers in community mental health in Ghana," *Culture, Medicine and Psychiatry* 43/4 (2019), pp. 613–635.
- 23. N. Ncube, "The tree of life project," *International Journal of Narrative Therapy and Community Work* 1/3 (2006).
- 24. B. Kapferer, "Situations, crisis, and the anthropology of the concrete: The contribution of Max Gluckman," *Social Analysis: The International Journal of Social and Cultural Practice* 49/3 (2005), pp. 85–122; A. Kleinman, *The illness narratives: Suffering, healing and the human condition* (New York: Basic Books, 1988).
- 25. A. Alem and C. Manning, "Coercion in community mental health care: African perspectives," in A. Molodynski, J. Rugkasa, and T. Burns (eds), *Coercion in community mental health care: International perspectives* (Oxford: Oxford University Press, 2016), pp. 301–314.
- 26. Committee on the Rights of Persons with Disabilities, Initial Report Submitted by Ghana under Article 35 of the Convention, Due in 2014, UN Doc. CRPD/C/GHA/1 (2019).
- 27. M. P. Opoku, W. Nketsia, E. Agyei-Okyere, and W. K. Mprah, "Extending social protection to persons with disabilities: Exploring the accessibility and the impact of the disability fund on the lives of persons with disabilities in Ghana," *Global Social Policy* 19/3 (2019), pp. 225–245; S. Handa, M. Park, R. O. Darko, et al., *Livelihood empowerment against poverty program impact evaluation* (Carolina Population Center, University of North Carolina at Chapel Hill, 2014).
 - 28. Pūras (see note 6).
- 29. E. M. Appiah, "Quality rights and mental health in Ghana," *Journal of Public Mental Health* 12/4 (2013), pp. 224–229.
- 30. A. Woods, A. Hart, and H. Spandler, "The recovery narrative: Politics and possibilities of a genre," *Culture, Medicine and Psychiatry* (2019).
- 31. K. G. Asiedu, "Beyond the language of denial: Men talk mental health in Ghana," *Al Jazeera* (April 16, 2020) https://www.aljazeera.com/indepth/features/language-denial-men-talk-mental-health-ghana-200414064651481.html.
 - 32. T. Langevang, "We are managing!' Uncertain paths

- to respectable adulthoods in Accra, Ghana," *Geoforum* 39/6 (2008), pp. 2039–2047.
- 33. H. Englund, *Human rights and African airwaves: Mediating equality on the Chichewa radio* (Bloomington: Indiana University Press, 2011).
 - 34. Read (2019, see note 22).
 - 35. Ebuenyi et al. (2019, see note 9).
- 36. S. Pavanello, C. Watson, W. Onyango-Ouma, and P. Bukuluki, "Effects of cash transfers on community interactions: Emerging evidence," *Journal of Development Studies* 52/8 (2016), pp. 1147–1161.
- 37. M. Molyneux, W. N. Jones, and F. Samuels, "Can cash transfer programmes have 'transformative' effects?" *Journal of Development Studies* 52/8 (2016), pp. 1087–1098.
- 38. G. K. Ryan, M. Semrau, E. Nkurunungi, and R. S. Mpango, "Service user involvement in global mental health: What have we learned from recent research in low and middle-income countries?" *Current Opinion in Psychiatry* 32/4 (2019), pp. 355–360; R. Douwes, M. Stuttaford, and L. London, "Social solidarity, human rights, and collective action: Considerations in the implementation of the national health insurance in South Africa," *Health and Human Rights Journal* 20/2 (2018), pp. 185–196.
 - 39. Ryan et al. (see note 38).
- 40. S. Abimbola, "The foreign gaze: Authorship in academic global health," *BMJ Global Health* 4/5 (2019); K. Tsey, *Re-thinking development in Africa: An oral history approach from Botoku, rural Ghana* (Mankon, Bamenda: Langaa Research and Publishing Common Initiative Group, 2011).
- 41. C. Campbell, "Social capital, social movements and global public health: Fighting for health-enabling contexts in marginalised settings," *Social Science and Medicine* (2019).
- 42. Ibid.; M. Mulumba, L. London, J. Nantaba, and C. Ngwena, "Using health committees to promote community participation as a social determinant of the right to health: Lessons from Uganda and South Africa," *Health and Human Rights Journal* 20/2 (2018), pp. 11–17.
- 43. R. Horton, "Offline: A perilous birthday party for mental health," *Lancet* 394/10210 (2019), p. 1696.
- 44. Lancet Global Mental Health Group, "Scale up services for mental disorders: A call for action," *Lancet* 370/9594 (2007), pp. 1241–1252.
- 45. Committee on the Rights of Persons with Disabilities (see note 26).
- 46. R. Burgess and K. Mathias, "Community mental health competencies: A new vision for Global Mental Health," in R. G. White, S. Jain, D. M. Orr, and U. M. Read (eds), *The Palgrave handbook of sociocultural perspectives on global mental health* (London: Palgrave Macmillan, 2017), pp. 211–235.
 - 47. Ibid.; Campbell (see note 41).