



Action on Children's Harmful
Work in African Agriculture

Working Paper 7

Disabled children and work: an overview of a neglected topic with a specific focus on Ghana

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About ACHA:

The research informing this Working Paper as well as its publication was made possible thanks to the Foreign, Commonwealth & Development Office (FCDO)-funded research on **Action on Children's Harmful Work in African Agriculture (ACHA)**. The aim of the programme is to build evidence on:

- the forms, drivers, and experiences of children's harmful work in African agriculture; and
- interventions that are effective in preventing harm that arises in the course of children's work.

It is currently assumed that the majority of children's work in Africa is within the agricultural sector. However, the evidence base is very poor in regard to: the prevalence of children's harmful work in African agriculture; the distribution of children's harmful work across different agricultural value chains, farming systems and agro-ecologies; the effects of different types of value chains and models of value chain coordination on the prevalence of harmful children's work; and the efficacy of different

interventions to address harmful children's work. These are the areas that ACHA will address.

ACHA is a collaborative programme led by the Institute of Development Studies (IDS), Brighton, UK. Partners include:

- University of Ghana, Legon
- University of Development Studies, Tamale
- African Rights Initiative International (ARII)
- University of Sussex
- University of Bath
- University of Bristol
- Fairtrade Foundation
- ISEAL Alliance
- Rainforest Alliance
- Food Systems Planning and Healthy Communities Lab, University at Buffalo
- International Cocoa Initiative (ICI)
- Sustainable Trade Initiative (IDH).

ACHA is directed by **Professor Rachel Sabates-Wheeler** (r.sabates-wheeler@ids.ac.uk) and **Dr James Sumberg**.

About this report:

This paper provides an overview of issues related to disabled children and work. This is a very unexplored topic and the literature is scant, so the paper first provides an overview of some key relevant background information on: disability globally and in Ghana, disability and employment, disabled children and relevant human rights approaches – the UNCRC and UNCRPD. Next examples of research on disabled children and work are presented and lastly some suggested hypotheses and possible research questions are proposed.

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Author notes

Mary Wickenden leads the Disability Research team, part of the Participation, Inclusion and Social Change Cluster, at IDS. She is a social/medical anthropologist and is interested in the perceptions and experiences of people with disabilities in high-income, middle-income and low-income settings. She has a particular interest in exploring the lives of children with disabilities and their families, and has worked on developing inclusive methodologies for participatory research, mainly in low-resource settings in the global South. Her regional experience is mainly in South Asia, southern Africa and East Africa. Currently, research interests include: community understandings of disability; the relationship between disability and poverty; participatory evaluation of disability programmes; sexuality/sexual abuse of disabled people; the wellbeing of carers; and the mainstreaming of disability components into broader research agendas. Mary is passionate about developing better dialogues across disciplines and with other actors such as governments, non-governmental organisations (NGOs) and organisations of people with disabilities (OPDs), working with disabled children and adults, their families and allies.

1 Introduction

This paper is part of a series of Working Papers coming out of the ACHA (Action on Children's Harmful Work in African Agriculture) programme, funded by the former UK Department for International Development (DFID)¹ aiming to explore issues around children and harmful work, initially in Ghana with a focus on the agricultural sector (Sabates-Wheeler and Sumberg 2020). As part of this series, this paper contributes a thematic literature review and reflections on disability as it is currently conceptualised, as well as on disabled children as a subgroup of children and on their involvement in work – a topic that has been only scantily explored so far in Ghana, Africa or globally. The paper reviews the limited literature on the topic and provides some reflections on the possible involvement of disabled children in work, their routes into work, its potential causes and consequences. (For detailed discussion about other focus areas of ACHA, please see **the other Working Papers in the series.**) The paper ends with some proposed research questions that need to be answered in relation to disabled children and work. Until recently, disability has been a neglected topic in international development. Focus on the lives of both adults and children with disabilities² has been viewed as only of minority or specialist interest, and this population has generally not been included or considered in either research or interventions on the ordinary, diverse aspects of daily life that are perceived as of importance within the rest of the community.

However, since the launch of the ground-breaking United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (UN 2006), this situation has gradually changed. In parallel to growing recognition of their rights, evidence about the numbers of people who make up this large global minority and their persistent and relative marginalisation is now increasingly available. The World Health Organization (WHO) World Report on Disability in 2011 – the first document to provide a comprehensive review on the topic (WHO and World Bank 2011) – synthesised the available data, showing that a best 'guestimate' (although still a partial picture) is that 15 per cent of the global population has a disability. Given uniform and systematic identification and measurement, it

was hypothesised that this figure would be more or less consistent across cultures and contexts. In recent years, a new method has been developed for identifying people with 'functional difficulties' of five broad types, which put them at risk of being disabled, and this is being rolled out extensively (Washington Group 2017). More consistent figures are emerging with the use of the Washington Group questions (short or extended sets) in surveys and censuses in many countries. There is now some evidence that the 15 per cent figure is an overestimate and that the true figure is probably around 7 per cent to 9 per cent. However, there will never be one definitive figure, as conceptualisations of disability vary across cultures, as do ways of measuring it, how to define the cut-off point (between disabled and non-disabled status), and other factors (Mont 2019; Mitra 2018).

Fifteen per cent is a bigger minority group than had previously been recognised and acknowledgement of the need to recognise this substantial minority has been driven by the very active lobbying of the disability movement, made up of organisations of people with disabilities (OPDs) themselves. (These organisations were previously called disabled people's organisations – DPOs.) There has followed increased acknowledgement of the need to consider disabled people in all community and development initiatives and across sectors, and at local, national, regional and global levels.

Thus, disability (and inclusion, which is a related but broader concept) are mentioned specifically in the Sustainable Development Goals (SDGs) (UN 2015) in a number of key areas (e.g. SDG 4 on education, SDG 8 on growth and employment, SDG 10 on inequity, SDG 11 on accessible human settlements, and SDG 17 on data collection and monitoring). Recognition of disability, as an important characteristic and identity for people, is implied more generally throughout the SDGs – for example, with the extensive use of the word 'inclusion', which is often used to emphasise the participation of people with a range of diverse identities (gender, sexuality, age, ethnicity, beliefs, living situation, etc.) across sectors. Disability clearly comes under this banner, referring to a group of people who are often particularly excluded. However, the term 'disability inclusion' is sometimes used to emphasise the

1 Unfortunately funding for this programme has subsequently been withdrawn at the end of the inception phase, during which these Working Papers were produced.

2 There is an ongoing discussion in the disability community about language use. The UK disability movement and academic community favour 'disabled people' in recognition that people are disabled **by** society (as per the social model of disability). In contrast, in many other international contexts, 'people with disabilities' is favoured, with a rationalisation that this puts the **person first**. The United Nations (UN) bodies use the latter. They also use 'persons' rather than 'people' in the UN Convention (UNCRPD 2006), a term that is used for legalistic reasons and is usually not preferred when talking about people's experiences more generally. In this paper I will use the two versions 'disabled people' and 'people with disabilities' interchangeably with no particular significance.

specific considerations needed to ensure equal rights for this group. There is now acceptance of their particular exclusion and an aspiration that the rights and needs of people with disabilities will be addressed more explicitly and actively across all sectors in development endeavours.

The most effective way to ensure that development programmes do not exclude persons with disabilities is by adopting 'disability mainstreaming' as a matter of policy and practice (UN DESA 2013). This implies including a disability component and lens as part of all activities being rolled out with the 'mainstream' population, be they in health, education, poverty alleviation, justice or whatever. This inclusive mainstreaming approach then contrasts with the now outdated idea that disability issues should be dealt with in separate and segregated ways. Many governments and funders now recognise a need for measurement, monitoring and evaluation of disability inclusion through the use of specific targets and indicators of inclusion. This will gradually incentivise agencies – whether governmental or non-governmental – to embrace a truly disability inclusive approach. In relation to the topic of children and work then, disabled children should be considered alongside their non-disabled peers.

Many global funders do now favour or demand a disability component or perspective as part of their 'mainstream' programmes and projects. This change is sometimes seen to echo changes that started 30 years ago in relation to gender mainstreaming. Leaving out a gender perspective from development efforts would now be regarded as unthinkable. In relation to disability, this journey is only just gaining traction and many development actors are still learning about what this might mean and how to accomplish disability inclusive development.

1.1 Structure of the paper

This review sets the scene with brief background information about the major shifts in concepts around disability that have occurred in the past 20–30 years to orientate the reader who may not be familiar with this arena. It includes current

definitions and terminology, which are important to understand when considering the lives of disabled adults and children and how they might want things to change. There is an overview of issues related to disabled people and work – the promotion of inclusive employment for adults with disabilities being a key topic for research and intervention currently. Then follows a short overview about disability and Ghana, as this was the country proposed for the initial phase of the ACHA programme.

The paper then focuses on children with disabilities, including global facts about them as a large minority group. I discuss the particular 'double bind' of exclusion that often affects them (both as children and as disabled people). Although theoretically protected by two UN conventions (the United Nations Convention on the Rights of the Child (UNCRC) 1989 and the UNCRPD 2006), they are arguably an overlooked and neglected group, both as a population of interest and materially. The paper highlights the paucity of research that proactively includes disabled children, especially in low- and middle-income country (LMIC) contexts, where a disability inclusive approach is particularly rare. The paper will not explore the large literature on children and work more generally as this is covered extensively in other Working Papers in the series and elsewhere. Suffice to say that the issue of disabled children and work is, to a large extent, not addressed in this broader body of work.

Next, I explore how and why disabled children (and their families) frequently experience extreme disadvantage, which arguably may incentivise them to work and moreover put them at risk of involvement in harmful work. Lastly, I review the small amount of evidence that is available about disabled children and work, and suggest – in the absence of substantive evidence – reasons why disabled children might be disproportionately working in harmful work settings. The evidence on this topic is very scant at present, although there is more in Asia than in Africa. Additionally, I propose some possible research questions that arguably need addressing and might be answered as part of a larger project aiming to explore the experiences of children who are working in agriculture and potentially harmful situations in Africa or indeed elsewhere.

2 Disability: some history and changing concepts

Disability is about difference. However, the way that it is understood has gone through fundamental conceptual shifts over the past 30–40 years (Shakespeare 2013). Humans have always noticed and responded to sameness and difference in others. However, some sorts of difference precipitate more particular patterns of response and, in the case of disability, these reactions have been almost universally negative and pejorative, although this does vary with cultural context to some extent.

Before the 1980s, disability was mainly seen as a matter of individual 'deviance' from a supposed norm in relation to the functioning of the physical body, the senses (hearing and vision) and/or the mind (cognitive function and mental state). This was a predominantly health-related, medical perspective, which sought to discover the cause and preferably a cure for the 'defect', so that the person could be restored to normal as far as possible. This approach is called the 'medical' or 'individual' model. Given that most types of impairment are not curable and that they are inherent unchangeable features of the person, this view was rejected by disabled people themselves (Oliver and Barnes 2012). They argued that these differences are merely common variations of the human condition.

Disabled people saw the roots of their disadvantage and marginalisation as being not in their individual bodily differences but in how society responds to those differences. Thus, the idea that disability is socially constructed evolved. It has since been elaborated and combined with a more human rights-focused approach, so the terms 'social model' and, more recently, 'human rights model' are both used and are espoused – albeit in different iterations – quite widely across the world.

A model developed by WHO in 2001 in response to these changes in perspective attempted to combine the different elements that contribute to a person being regarded as disabled (WHO 2001). Claiming to be 'biopsychosocial', the International Classification of Functioning, Disability and Health (ICF) has been helpful in promoting a more relational and interactive model, where different aspects at an individual and societal level combine to generate a person who is more or less disabled. Their disability status then depends on various factors – the type and severity of their impairment being only part of the picture.

This change in the way that impairment (the individual difference or difficulty) and disability (society's response to the person) interact is

important because it shifts the onus for change from the person (no longer expecting them to be or become 'normal') to society. It is then others who need to adapt the environment (physical, attitudinal, communication, structural) to enable people who are different to be included in all aspects of everyday life alongside their peers.

This shift towards an inclusive approach, where everyone accesses the same services and opportunities (e.g. health, education, work opportunities) is the logical follow-on from the 'social model' described earlier. Strengthened by human rights and equity perspectives, there has been a strong move away from 'segregated' provisions such as special schools or hospitals for disabled people or 'sheltered workshops' where they would do a restricted range of types of work. In the work arena, 'inclusive employment' is the current approach of choice of disabled people themselves, and is supported by global treaties (Hashemi, Kuper and Wickenden 2017; UNCRPD 2006) and national disability policies in many countries. However, implementation of these ideas lags behind the launch of treaties and policies but has gained momentum since the adoption of the UNCRPD in 2006.

As noted in the introduction, the prevalence of disabled people globally has been a matter of conjecture up until the most recent decade (WHO and World Bank 2011). This uncertainty can be accounted for by a number of factors, including: lack of consensus on definitions and terminology; variability in ways of identifying impairments; lack of interest and commitment from governments and other agencies to identify, register and count people; cultural beliefs and attitudes that reinforce stigma and discourage identification; and lack of resources to provide services once people are identified. Although we now have a regularly quoted ballpark figure of 15 per cent of any population being likely to have an impairment of some sort, national censuses and other surveys (including general instruments such as multiple indicator cluster surveys (MICS) and demographic and health surveys (DHS)) have not necessarily generated this figure in many countries. It is unlikely that the 'real' figures vary much from this suggested percentage, so the differences must be accounted for by methodological, cultural and political variations in how the prevalence figures are collected and calculated.

More recently, as awareness about the variety of ways in which people with disabilities are excluded and could be included has developed,

Table 1. Some disability statistics about Ghana

	With disabilities	Without disability	Source
Disability prevalence	12.8%		WHO World Health Survey 2002–2004
Primary school completion	54%	64%	The Disability Data Portal
	Male 51% Female 57%	Male 63% Female 65%	
Secondary school completion	23%	34%	
Participation rate of youth in formal and non-formal education and training in previous 12 months	37%	47%	
	Male 42% Female 33%	Male 52% Female 41%	
% employed in informal sectors	69%	64%	
% living below the national poverty line	67%	60%	

the importance of applying an intersectional lens is emphasised. There is now more recognition of the need to think about how different identities combine to produce relative advantage and disadvantage. Evidence is building that gender and disability often combine to produce cumulative disadvantage: disabled women usually have less access to education, employment and health care compared with disabled men. There is also a clear interaction with age, so that as people age, they tend to acquire impairments (e.g. deafness, blindness, mobility difficulties, dementia) and so the percentage of the population who could be described as disabled increases dramatically with age. Additionally, it should be remembered that within each of the major broad types of functional difficulty (impairment) – mobility, hearing and communication, vision and cognitive – there is a range of severities. In fact, like gender, the category ‘disabled’ is not a binary; it is both culturally constructed and variable in context, so that an individual person may feel disabled in one situation but not in another, depending on various aspects of that environment. Many medical diagnoses can also lead to several impairments so that (for example) someone who has had a stroke or an accident might have mobility, cognitive and communication difficulties. Impairments can, of course, be present from birth (congenital), although not necessarily identified initially, or acquired at any stage of the life course. The age at which someone acquires an impairment impacts greatly on the impact this change has on their wellbeing and life chances.

2.1 A brief overview on disability in Ghana

Demographic data and research evidence about the situation for disabled people in Ghana is scant. There have been few empirical studies to date and a search found none specifically about work or disabled children working. Ghana has been regarded as a particularly harsh and unaccepting environment for disabled children and adults, although whether it is really more so than other West African or LMICs in different regions is unclear. Table 1 presents the available statistics on some key disability-related indicators taken from a data bank that collated information on many countries in preparation for the World Summit on Disability in 2018. However, it is not exhaustive, as it draws on very few sources with little elaboration or qualitative data to support or explain the patterns emerging.

Ghana has several legal and constitutional provisions that protect socially disadvantaged people. Perhaps in anticipation of the imminent adoption of the UNCRPD in 2006, Ghana passed a Disability Act that same year (Act 715) (Asante and Sasu 2015). There are also anti-discrimination clauses on disability in the Constitution (WHO and World Bank 2011). Ghana signed up to the UNCRPD in 2007 and took the further step of ratifying it in 2012. Signing the Convention is viewed as indication of a country’s commitment to protecting the rights of disabled people but

does not always lead to change in practice on the ground.

Like most other countries, there are a number of OPDs in Ghana, although detailed information is not reviewed here. Again, like other countries, there is a national 'umbrella' entity, the Ghana Federation of Disability Organizations. These are normally active in bringing together the views of the various membership groups, who have more focused interests (e.g. representing specific impairment groups, parents of disabled children

and others). The national body usually plays a major role in advocacy and lobbying government and influencing policy on major aspects of people's lives such as human rights issues, access to services, and combating discrimination. Importantly, DPOs are normally viewed as being made up of members who are people with disabilities themselves (so 'of them') rather than organisations who might be working 'for them' such as non-governmental organisations (NGOs). This is an important distinction.

3 Disabled people and work

As part of the movement towards a more disability inclusive approach across all sectors, 'inclusive employment' has recently started to grow as an idea among both the disability community and with employers and business communities. There has, for a long time, been anecdotal evidence that families with a disabled member tended to be poorer than others in their neighbourhood, though empirical evidence is now mounting (Groce et al. 2011). There are complex and interwoven reasons for this, but one key cause is that disabled people have much lower rates of employment everywhere it has been measured, and they are unevenly distributed across types of work settings. When they do get work, this is predominantly in informal, low-paid, insecure and low status sectors, such as in small family businesses, agriculture, small-scale craft work, and daily waged labour (Mizunoya and Mitra 2012). One explanation often given for this is the low school enrolment and completion rates of disabled children and young people, which result in low literacy and other skills for work. Many never enter school or may drop out because of lack of support from families or inaccessible facilities and negative attitudes at school. However, even for those who do attain qualifications, including up to degree level, their levels of employment are disproportionately low, and they tend to have particular difficulty entering the formal work sector and higher status jobs (Mitra, Posarac and Vick 2013).

There is often a lack of expectation, both from families and from employers, that a disabled person can or should work. For the person themselves, there may be low self-esteem and reduced aspirations because of negative attitudes from others, and a lack of encouragement to find work. Many disabled people who would be able to work either do not work or may be employed in an occupation that is well below their potential capability, or are not doing work that is their choice

or interest. It is accepted that being in work is good for individuals' health and wellbeing and that the reverse is also true (WHO and World Bank 2011). Disabled people, with high unemployment and underemployment rates and lack of career advice and progression, are therefore at risk of additional health problems, including mental illness. They are easily regarded as burdensome to their families, rather as net contributors and active citizens in their communities (Hashemi et al. 2017). Once labelled disabled (either as a child or when acquiring impairment later), they very often start on a lifetime journey of stigma, discrimination and marginalisation.

It is only recently that a movement of employers who recognise the positive business case for employing disabled people has emerged globally (Global Business Disability Network). In its most progressive form, this is not driven by charitable motivations or wanting to 'look good' as a company doing corporate social responsibility (CSR), but by seeing that disabled people have the skills to work, that diversity within the workforce is a positive influence, and that disabled people comprise a substantial part of the market as consumers. So, a disability-friendly company might realise that it will do more business by demonstrating that it is disability aware and inclusive and that this is a matter of equity and rights. This kind of approach is on the increase in many countries, as are research and interventions about improving disabled people's employment opportunities (Wickenden et al. 2020).

In theory, most or indeed arguably all jobs should be accessible for disabled people, if the individual's skills are matched to the job and the appropriate adaptations are made. In parallel, most disabled people could work, all other factors being equal (WHO and World Bank 2011). Clearly, the kind of work that someone could do, if exclusion and

discrimination were removed, is still to some extent dictated by their impairment type and severity and the particular adaptations and 'reasonable accommodations' (the technical term for supportive changes to the environment) that might be needed. It should also be work that they are interested in and want to do. The UNCRPD dictates that disabled people should not be prevented from working because of lack of adaptations (e.g. lift for a wheelchair user, sign language interpreter for a deaf person, brailled documents or an adapted computer screen with text-to-speech software for a blind person, and so on).

There are various types of barriers that need to be removed to enable disabled people to have the same opportunities as others, mainly environmental, attitudinal, communication-related and institutional/structural barriers (Van Ek and Schot 2017). Often, 'accessibility' is assumed to be about physical infrastructure, visible practical aspects to adapt for those with mobility impairments (e.g. ramp, rails, lifts, toilets). Although these are often the most obvious and easy adaptations to understand and provide, there are others. Needs for changes in communication modes and format (e.g. sign language, Easyread, pictures, slower pace) or attitudinal changes are more invisible and can be hard for others to recognise as necessary and to embed in practice.

The relative disadvantage experienced by people with different impairments can result in a 'hierarchy of impairments' (Deal 2007). Commonly, people with physical and visual impairments are relatively less disadvantaged than other disabled people in many spheres of life. Impairment group identities also intersect with gender so that often, men with physical or visual impairments are to be found as leaders of DPOs at local, national and international levels. Disabled women are less likely to be seen in prominent positions. People with cognitive, psycho-emotional and communication difficulties and those with multiple impairments (e.g. deafblind) are consistently the most excluded from society, including from the labour market (Mitra 2018). Overcoming these various kinds of discrimination can be very difficult.

Hence most disabled people who work, do so informally for their families' small businesses, in agriculture and very locally to home. Here a form of 'natural inclusion' can sometimes be seen, where the person is well known, understood, supported as necessary and a role that suits their strengths evolves. Someone with no mobility impairments (but who has a sensory impairment such as deafness or blindness, or a cognitive impairment such as learning difficulty) may be included in a physical job with no apparent difficulty, so long as access needs in relation to communication, guidance, etc. are met. However, such a positive outcome is not always the case,

and there may often be no safety, protection or appropriate support in place in these informal work arrangements.

Unfortunately, there are reportedly high rates of neglect and abuse of disabled people (particularly of women and girls), so some will not be experiencing positive inclusion in their communities at all. They may be forced to do work that is difficult for them or be bullied and maltreated (Mizunoya and Mitra 2012). However, those who have been successful by their own definition often mention the specific support of an individual or community resource that enabled them to access education and then work (Shakespeare et al. 2019).

3.1 From segregation to inclusion

Before the present era of active promotion of 'inclusive employment' (the idea that disabled people should and can find work within the open labour market and be supported to do so), many disabled youth and adults were placed in separate and protected work settings – for example, in 'sheltered workshops'. These provided work of a limited range of types – e.g. arts and crafts, carpentry, basket weaving, etc., and often young people would join these, perhaps as a late alternative to or having dropped out of school, and might remain there for many years into adulthood. More latterly, some have moved to more contemporarily relevant skills such as computing, desktop publishing, etc. However, there was little choice for people about which trade or specialism they would do and virtually no career progression or personal development beyond perhaps initial on-the-job training. These segregated workplaces are now regarded as counter to the UNCRPD and although some still exist, they are gradually closing. Some people are being supported or mentored into 'real' jobs in the open market. This transition can be tricky, as some people will have worked in these protected environments for many years and will naturally feel anxious about moving to a new workplace.

Evidence about work conditions for people with disabilities is increasingly becoming available but most studies are from global North contexts. We know that most disabled people who do work, mainly do so in the informal sectors including in agriculture, family business, micro-enterprises and the like. 'Livelihoods' projects are a popular strand of the grassroots multisectoral approach to supporting disabled people called CBR (community-based rehabilitation) or CBID (community-based inclusive development) (WHO 2010). They are seen to address the poverty–disability vicious circle (discussed in section 4.4), with small-scale

loans, skill building, entrepreneurship and business development training, etc. Disabled people themselves (evidence from adults) are becoming more vocal in self-advocating about their right to decent work as laid out by the UNCRPD in article 27 on work and employment.

States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. (UNCRPD 2006: 19)

There is a paucity of information about disabled people's involvement in agricultural work although we know anecdotally that many people do work or 'help out' on family farms and businesses in informal ways. The Food and Agriculture Organization of the United Nations (FAO) has highlighted this lack of information (FAO 2018, cited by IDA 2018).

An intervention study by Bruijn (2013) in Bangladesh focused on disabled and non-disabled women who were ultra-poor, involving them in food security-targeted income generation, including agriculture, beef and other livestock rearing, and homestead gardening. There were some very positive outcomes of this as the women reported increased social acceptance and improved respect and power within the family. There were also other social benefits for them in the wider community. The study emphasised that assumptions should not be made about what types of work the women would be able to do and that schemes should be responsive to their skills and interests. Some of the international NGOs who work specifically on disability have focused on increasing employment rates of people with disabilities, and in the past have concentrated on training people to work in small-scale local businesses in rural areas in activities such as horticulture, agriculture and crafts (e.g. Leonard Cheshire International 2020; Baart and Maarse 2017).

4 Disabled children: an overview of a neglected group

The difficulties described earlier in collecting accurate disability figures for adults are exacerbated for children because of the interaction with their evolving skills as they develop over time. Using a definition of children as people under 18 years of age, disabled children make up about 7 per cent to 10 per cent of all children globally (UNICEF 2013). An estimated 95 million girls and boys have a functional moderate or severe difficulty or disability, of whom 13 million have a severe disability (WHO and World Bank 2011). Thus, percentages for younger children (under five years) are particularly uncertain and variable, and in many countries developmental surveillance is poor or non-existent. Children can have a range of impairments falling broadly into the main categories already mentioned: mobility/physical, cognitive/learning, vision, hearing and communication, and behavioural/psychosocial. These vary in severity and cause, depending on the underlying health condition, and some children have several types of impairments. For example, children with cerebral palsy (which is a neurological condition and, in its pure form, causes physical difficulties) often have other associated difficulties such as learning and sensory impairments.

Most children with impairments will have had these from birth. However, not all impairments are

identified or indeed possible to spot at birth or in the early years. Additionally, in many countries early check-ups (for example, of vision, hearing, physical, social and cognitive development) are not available. Many children's difficulties may only emerge and be noticed by families later in childhood as the child fails to reach expected developmental milestones.

A smaller number of children will acquire an impairment, through illness or an accident (e.g. head injury/ poisoning/landmines, etc.). It is unclear whether and how many children become disabled in work contexts. Very broadly, the pattern of types of difficulties globally is similar, although some impairment types may not be identified or have significance in some contexts (e.g. dyslexia). Some may be more common because of the lack of health care or a disadvantageous structural or environmental situation (e.g. weak perinatal surveillance, lack of immunisation, malnutrition, poor water and sanitation, or where there is a natural disaster or ongoing conflict). These latter factors will increase the proportion of disabled children in the population. Mortality rates for disabled children, however, may also be increased as survival is more precarious, and their needs may not be prioritised over those of other family members (Kuper et al. 2014).

The numbers of children with impairments is skewed towards the mild end of the range, so there are many more children with a single mild impairment than there are children with severe and multiple difficulties. For children with mild difficulties, a label of 'disabled' may not be used, either by the family or the child. Care must be taken in using such labels, when it may not be recognised or useful for them and may be stigmatising. In parallel with the development of a systematic method of measuring adult disability prevalence, mentioned earlier, there is ongoing development of a parallel tool for identifying children with disabilities more accurately (Washington Group 2016 child functioning module). This tool is gradually being rolled out and used in many countries and contexts. We expect the statistics about disabled children, disaggregated by type and severity of difficulty and gender, to improve markedly in the next few years (Zia et al. 2020).

4.1 Parallels between disability theory and childhood studies

There are some clear parallels between the discourses over the past 20–30 years or so in the multidisciplinary arenas of childhood studies and disability studies. The new 'sociology of childhood' kick-started the idea that children are a socially constructed group of people whose agency is often overlooked and about whom assumptions of incompetence and vulnerability are often made (Tisdall and Punch 2012; Skelton 2008; James and Prout 1998). These ideas have then been applied, but not without controversy in various 'global South' settings, where concepts of children and childhood may be very different and vary with context (White and Choudhury 2007). However, there has been increasing recognition in the global South of the importance of engaging with children about matters that concern them, just as is happening in the North (Hart 2008). This recognises them as being competent and having agency (Hunleth 2011). Notwithstanding this progress towards more empowering views of children, it is still often the case that children have a lower status than others in their families or in the community, and have a lack of choice about what happens, their voices being muted and drowned out by others. Sometimes children's opinions and voices are gathered but in ways which look tokenistic (James 2007). Participatory and inclusive approaches to doing research with children in a variety of global contexts have gathered pace in the past decade or so (Ansell et al. 2012).

Similar observations about the lack of recognition of voice and worth are made about disabled people

and in both cases the rights agenda has gradually influenced and changed this (Burman, Greenstein and Kumar 2015). Both children and those with disabilities are now consulted more, given space to express their views and to emphasise that their own perspectives are not always what others close to them believe them to be. So, for children, asking them directly rather than their parents or teachers has become accepted as a good practice; similarly, in the disability movement, the mantra 'nothing about us without us' highlights the need to consult this population directly about their priorities and experiences. Hearing from people directly can have a powerful effect, as it humanises them and brings into focus the real lives being lived.

4.2 Disabled children and rights

As noted earlier, disabled children come under the purview of two UN Conventions, the UNCRC (1989) and the UNCRPD (2006). However, it has been argued that disabled children are poorly served by both (Lansdown 2012). The UNCRC only mentions disability very briefly and in what now seems an outdated way (rather partial in its support for disabled children as able to be included in society). In turn, the UNCRPD only mentions children briefly, having more of a focus on adults with disabilities than children.

Thus, disabled children are arguably easily overlooked and remain substantially unprotected and uncatered for in relation to recognition of their needs and rights. They are easily forgotten and exploited, and evidence suggests that they are often excluded from education, health care, social support and so on (UNICEF 2013). Their parents and families are often among the poorest in communities, the additional costs incurred in having a disabled child (such as medical needs, care, and loss of one parent's income) often pushing them into catastrophic expenditure, impacting on the whole family (Mitra 2018). Disabled children and their families are sometimes referred to as experiencing a 'double disadvantage', due to the combination of difficulties that they experience, despite their theoretical protection from two UN treaties (Lansdown 2012). They are recognised now to be an overlooked group who are often to be found at the bottom of a number of population metrics, including for wealth centiles, educational enrolment and completion, and health status. Perhaps surprisingly there has been very little work on measuring wellbeing among disabled children specifically. As Sabatello (2013) puts it, they are 'invisible citizens'.

In childhood research, there is often only a cursory or tokenistic mention of disability as being one of the intersecting identities that might confer disadvantage on a child. Often, the causes of and mechanisms for this cumulative exclusion are not explored or dissected. There is also habitually an assumption that disability means physical difficulties, so that the other categories of impairment (deaf, blind, cognitive, psychosocial) are not discussed or explored, and these individuals' marginalisation is not recognised (Wickenden and Kembhavi 2014). In fact, the 'hierarchy of impairments' mentioned above plays out with children as well as with adults and leads those with physical or visual impairments to be proportionately less excluded than those with hearing, communication or behavioural difficulties. The more extreme discrimination that is experienced by some groups compared with others can be seen in the proportions of disabled children who attend school, for example.

4.3 Research about and with disabled children

Most research about disabled children has so far taken place in high-income countries and, to a large extent, focuses on aspects of the child's impairment rather than their lived experiences (Singal 2010). For example, there are numerous 'clinical' studies about different types of treatments and interventions, or service evaluations. Researchers are beginning to ask the children themselves what they think of such provisions, but the trend that is seen within childhood studies of asking children directly about more diverse and perhaps 'ordinary' aspects of their lives (e.g. transport, food, climate change, poverty, leisure, etc.) has not yet been extended to disabled children. It tends to be assumed by adults that the child's impairment is the most important aspect of their identity, whereas the few studies that have consulted them show that this is not usually the case. They see themselves as 'normal kids' with a range of interests and concerns beyond their disability. They tend to talk about their impairment in rather pragmatic and undramatic ways and do not like this aspect of them to be privileged over their identities as young people, who have perspectives on their lives and aspirations just as other children do. To date, there are very few studies with or about disabled children in the global South, which really engage them directly and ask for their views about their lives and what influences their wellbeing or could improve it (Zuurmond et al. 2016; Wickenden and Kembhavi 2014).

4.4 Inclusive research methodologies

Methodologically, the same kinds of debates take place about how to do research with disabled children as occur about children more broadly. However, there is the added need to consider how to make studies inclusive enough to enable disabled children to participate in meaningful and equal ways to their peers and alongside them. Arguments about participation of children generally centre around seeing them as agentic, having optimistic expectations of what they can do, providing choice, and using methods that will appeal to them in their cultural context. There is also potential to include them as 'peer researchers' in some or all aspects of studies (including design, data collection, analysis and dissemination of findings), and giving them recognition and support to enable this (Kellett 2010). Discussions have also centred on whether the same methods can be used with children as are used with adults, and when and why these methods might need adapting (Punch 2002).

All these aspects are applicable and perhaps amplified for disabled children (Witchger Hansen, Siame and van der Veen 2014). Judgements about competence are similarly relevant, although rigid age-based stipulations are even more likely to be problematic than with other children. It is important not to either patronise children by underestimating their skills or put them off by expecting too much of them without providing appropriate levels of support and so inadvertently excluding them. Disabled children are highly sensitive to both these possibilities and, given the chance, will say what they can and cannot do, what they are interested in and what help they need from others in order to join in (Thompson, Cannon and Wickenden 2020).

The specific adaptations to create accessibility (called reasonable adjustments) that might be needed to make an activity inclusive of all children are many and various. This will depend on the type of functional difficulty that the children have (for example, an adapted physical environment, special equipment, sign language interpretation, braille/large print, use of pictures and symbols to aid understanding, use of simple, clear spoken and written language (Easyread), repetition, extra time and others). Access needs should be anticipated, enquired about and provided for as a basic right and as part of the planning and budgeting of activities. If this is not done then accidental, unwitting exclusion can happen and this risks exacerbating the marginalisation already experienced by disabled children and young people. They are regularly not included in consultations with the 'mainstream' population of children, who are increasingly asked for their views on a variety of topics including work, school, home life and their

hopes for the future (Wickenden and Elphick 2016; National Children's Bureau 2012).

There is plenty of evidence globally that families who have a disabled member in their household are disproportionately likely to be poorer than their neighbours (Trani and Loeb 2012). This seems to hold true across contexts and cultures, in both high- and low-income settings (Groce et al. 2011). The mechanisms for and nuances of this interrelationship are still not entirely clear and will vary culturally, but certainly there is a 'vicious cycle', where being poor increases the chances of being disabled and, conversely, being disabled increases the chances of being poor. Mediating factors are likely to include: the extra costs if someone in the family has a chronic health condition or impairment (such as health and care costs); opportunity costs in relation to lost earnings for the person themselves and for others (often women) not being able to work outside the home because they are a carer; missed educational opportunities (disabled children are disproportionately out of school); and smaller social networks and reduced social capital (because of stigma and discrimination driven by negative beliefs and attitudes about disability). There is some evidence that in the very poorest communities, disabled households are not much poorer than others (because everyone is very poor). However, when economic development happens and countries or communities move out of poverty, disabled people and their families are often left behind. This has been called the 'disability development gap' (Groce and Kett 2019). So, families with a disabled member are disproportionately likely to be in the lowest wealth quintiles in a given community.

When they are asked about their lives, disabled children often focus on aspects such as poverty rather than on their disability per se. However, not many studies have explored this in depth, so we do not know if they are talking about poverty more broadly that they experience in their community, or whether this is specific to being disabled; probably it is a mixture (Feldman et al. 2013). Sometimes they are only vaguely aware that they are labelled 'disabled' by others. It is not until older childhood (possibly 8–10 years plus) that they start to realise they are categorised by others in this way or that this has a social meaning, and usually a negative one. Within their families they are, to a large extent, treated like everyone else, although there is some evidence of differential treatment by parents sometimes (e.g. in relation to food, paying for health care or school fees). Disabled children want to be treated like their siblings and have the same opportunities as them, and this may or may not happen. It is quite common to hear of a disabled child being taken out of the parental home to be looked after by a grandparent or other relative, or for one parent to refuse to support the child. In a context of poverty, this is evidence of the parents

making what for them is a pragmatic choice about who is 'worthy' of investment. Responses within and outside families vary greatly from very supportive to rejecting and cruel (Wickenden and Elphick 2016).

Rates of neglect and abuse of disabled children are universally found to be higher than for other children, sometimes as much as four times higher, although extensive data is hard to find (Coe 2013; Jones et al. 2012; Ellery, Lansdowne and Csáky 2011). This maltreatment can occur inside the family home, or outside in the community and, indeed, in schools. Girls with disabilities are at particular risk of abuse, including sexual abuse as they reach puberty. They may be regarded as an 'easy target' as their ability to report may be assumed (often wrongly) to be limited. Perpetrators can continue this behaviour with impunity, sometimes with families colluding in it or feeling unable to intervene. Because of the increased risks for disabled children, some parents may be very (overly) protective of them, and this can be a reason why they do not go to school, thus exacerbating their isolation and potential for social exclusion and lack of work in later life.

Disabled children themselves are aware of some of these risks to realising their full citizenship. If asked, they express the desire to feel safe, to go to school, to have friends and to join in with community activities – in short, to be 'normal' children or young people. They see other people's attitudes to their differences as a hindrance to them being seen as ordinary; in fact, they usually emphasise that they are 'normal' in more ways than they are different and would like to be treated as such (Wickenden and Elphick 2016).

4.5 Disabled children in Ghana

Only one study about disabled children in Ghana has been identified, although because several international NGOs work on disability issues in the country, there may be more grey literature about them, but this has not been found. Kassah, Kassah and Agbota (2012), in a small qualitative study, explore the various types of abuse experienced by disabled children. They find four types of abuse: social, capital (killing), physical and emotional. They suggest a key reason for the prevalence of these is that in Ghanaian traditional belief systems, disabled children are regarded as non-human or supernatural beings and are thus 'othered' by society, both within families and in the community. Therefore, the children are regarded with suspicion and it would be flouting social norms to 'challenge the dangerous and pervasive notion that lives of disabled peoples are not worth living' (*ibid.*: 700).

Ghana is often cited as one of the countries that practices killing of disabled children, and anecdotal stories abound, although there is scant evidence about the extent to which this actually happens (Oppong-Ansah 2011).

4.6 Disabled children and work

There is a large body of literature on child labour, the various types of work that children do globally and whether this should be regarded as unacceptable under any circumstances or whether a more nuanced and conditional view of these activities should be taken (Bourdillon and Carothers 2018; ILO 2017; Boyden and Ling 1998). This literature will not be interrogated here, apart from to say that rates of child employment in Africa are much higher than in other regions and progress in reducing this has stalled. Estimates in 2016 suggest that one-fifth of African children are involved in child labour, which is more than twice the proportion in any other region. The vast majority of child workers are young (typically under 12) and mostly work in agriculture (ILO 2018). The age at which work is permitted varies across countries and there are also varying definitions such as for 'hazardous' work or 'light' work, for example. It is noticeable that consideration of disabled children and work is almost completely missing. However, this does not mean that these children are not working. It is likely that many of them do work, but that data is not collected on disability status, for some of the reasons mentioned earlier in relation to collecting disability statistics.

Given what we know about disabled children, as outlined earlier, and remembering that this is not actually a binary category but a spectrum of difference (Wickenden 2019), what can we say about disabled children and work? To date, there is extremely little evidence or data of any sort on this topic. There is some literature on children and injuries in the workplace, but this does not make explicit links with permanent disabling consequences of such injuries (e.g. Rhaman 2018; Salminen 2004). Thus, ironically, the marginalisation and exclusion of disabled children in many societies is echoed in the research arena, where they are largely invisible. They are generally regarded as a vulnerable group, although children themselves may reject this category. Two examples of studies that do address the issue follow; these were the only ones to come up in a search on disabled children and work.

Villalobos and colleagues (2017) in Mexico carried out a large quantitative study, which shows that children with functional difficulties (often used as a proxy for disability) are disproportionately more

likely to be working than other children. They find that children who have psychosocial/ emotional difficulties are the most likely to be working. This is not very surprising as these children are likely to be physically unimpaired (and so arguably more able to do physical work) and also may have been excluded from school because of their behaviour or may have been considered difficult to teach or include in the classroom. In their analysis, the authors express uncertainty about the direction of causation of their findings but reflect on the links between poverty, school enrolment and child labour. They suggest 'worrisome indications of a vicious cycle of limited education and poverty for those who do child labor, perhaps especially for children who have a functioning difficulty or disability' (Villalobos et al. 2017: 381). They conclude that 'Guaranteeing educational opportunities and respect for the rights of children with severe functioning difficulties and disability is essential to achieve development of their full potential' (Villalobos et al. 2017: 387).

Secondly, Rakshit et al. (2019) conducted an econometric analysis of educational attainment and child labour status among disabled children in Tamil Nadu, India. The findings make a similar link to that suggested above between poverty and disability, suggesting that whether a child is given work depends on the type of impairment they have. The research shows that children who are physically and mentally disabled are more likely to attend school than those with other impairments and, rather surprisingly, to participate less in the child labour force compared with children with multiple disabilities. This finding is quite difficult to interpret. Urban disabled children are more likely to go to school and are less likely to drop out compared to their rural counterparts. No gender difference in workforce participation was found but more boys go to school. The study also found an interaction with child marriage, revealing that those who were married were more likely to be working; thus they also suggest a vulnerability of disabled children to child marriage as well as working rather than attending school. It is suggested that the Tamil Nadu Disabled Persons Act (2007) has not made a marked difference to the educational achievements of learning-disabled children. This is not very surprising, as there is plenty of evidence from international NGO reports that these children are usually the most excluded.

Rakshit et al. (2019) also point to some converse evidence from the ILO, which reports that disabled children who are not in school are not doing income-generating activities or household tasks, but the authors argue that in contexts of poverty (in India), disabled children are working rather than going to school. It is not clear whether their lack of school attendance is linked to the other reasons often cited for disabled children's non-attendance (as well as economic ones) such as stigma and discrimination and the lack of a welcoming and

inclusive approach by schools. Given the lack of research in this area, there are several assumptions and tentative hypotheses we can make about disabled children and work, especially in view of the likelihood of these children being part of poor and disadvantaged households. There may be a number of drivers that would encourage and perpetuate disabled children working.

- 1 Given that disabled children are quite likely to be out of school, they may well be working (perhaps instead of going to school rather than alongside school attendance, which is common for other children).
- 2 If their families are working in agriculture and/or their own business, disabled children are likely to accompany their parents to these places (while other siblings are at school) and so may choose, be encouraged or be forced to work.
- 3 Families know well what their children's capacities are, and so are likely to identify and adapt work to what the child can do. They may adapt tasks, equipment/machinery or a process to enable the child to join in. However, a disabled child might need more supervision than other children.
- 4 Families who are poor are more likely to be doing hazardous work, and so there is an increased chance that disabled children will do this kind of work too.
- 5 The perception that the disabled child 'is a burden' may provide an extra incentive or motivation for them to involve themselves in work wherever and however they can, in order to 'prove their worth' by earning money and thus being seen as a net contributor (we know that adults with disabilities express this motivation to work).
- 6 Negative attitudes and assumptions of incompetence may encourage the child to 'prove themselves' able to contribute, in ways which might be dangerous or harmful.
- 7 The lack of worth accorded to some disabled children by adults may put them at increased risk of danger and with reduced protection.
- 8 Disabled children who are at home when their siblings go to school may do disproportionately more housework than other children in the household.

Potential research questions about the nexus between children labelled as disabled and being involved in work and harmful work are as follows.

- How do others' (e.g. parents, employers) perceptions of competence/incompetence affect what children are expected or allowed to do?
- What does having a different body or mind represent or signal to families or employers? What kind of body (or mind) can do work and what kind of work?
- Are perceptions and actions in relation to safety and protection the same or different for disabled children who are working compared with other children? (e.g. what is the attitude towards them experiencing temporary or permanent harm or injury?)
- Does being a 'working child' counteract the negative connotations of being labelled disabled and allow the child recognition as a worthy person or a citizen?
- How are children with different impairment types viewed in relation to work? (e.g. physical impairment vs blind vs deaf vs intellectually impaired vs psychosocial impairment?) Who is seen as employable and what kinds of work are they offered?
- How is a working child seen to be embodied? What kind of body and mind should they have, do they have? Are some children seen as unemployable? How is that judgement made and by whom?
- How are reasonable adjustments/accessibility provisions for children viewed in the workplace by employers?
- What is the response of families/employers to a child who becomes disabled at work?
- How are disabled children's economic, educational and social activities viewed compared with other children?
- How many children with mild, moderate or severe impairments, and of which types, are working in agriculture in Ghana?
- Is there any consideration of disabled children as workers in policy development about children and work more broadly, at either the international or national levels? If not, then what recommendations could be made in relation to making policies and laws more disability inclusive?

Some of these may be interesting questions for researchers to explore.

5 Conclusion

We can see in the small amount of empirical data presented here on disabled children in the global South generally and on disabled children as part of the workforce, a pattern often noted in disability research. This is that most countries have signed human rights conventions and have national laws and policies in place to promote the rights and protection of disabled people (adults and children usually), but often these are not enacted or implemented. Thus, there is a contrast and uneasy relationship between international treaties, national laws and policies, and what happens in practice on the ground. Traditional attitudes and beliefs that have tended to define people with disabilities as abnormal, deficient, sometimes as not human and as of reduced worth, still prevail. Disability activists and practitioners often cite this as a major frustration, where people's lived experience is very different and much more inequitable than the rhetoric of human rights and inclusion.

We know that families with a disabled member are usually poor and that disabled children often do not attend or complete school. There is also a potential paradox, in that disabled adults have difficulty getting into employment, but disabled children

may in contrast be working and possibly in harmful work. It seems likely that at least some of them may be working in the informal sector, perhaps alongside their siblings and peers, but possibly with worse conditions, or less attention to their welfare and protection in these work settings. They may be working instead of going to school, rather than in parallel with school attendance as their non-disabled peers often do. However, the facts are extremely sparse.

The global promise of the two relevant human rights treaties, the UNCRPD and the UNCRC, is that disabled children should be regarded as like other children, as citizens with rights and as people who should be considered in the mainstream development agenda (UNICEF 2011). There is a need for empirical data about the lives of disabled children, including about whether they work as much as, in the same way as and under similar conditions as other children in their context. We need more information about their lives in order to inform policymaking, planning and resourcing of initiatives that might be designed to benefit all children, but which currently regularly exclude disabled children.

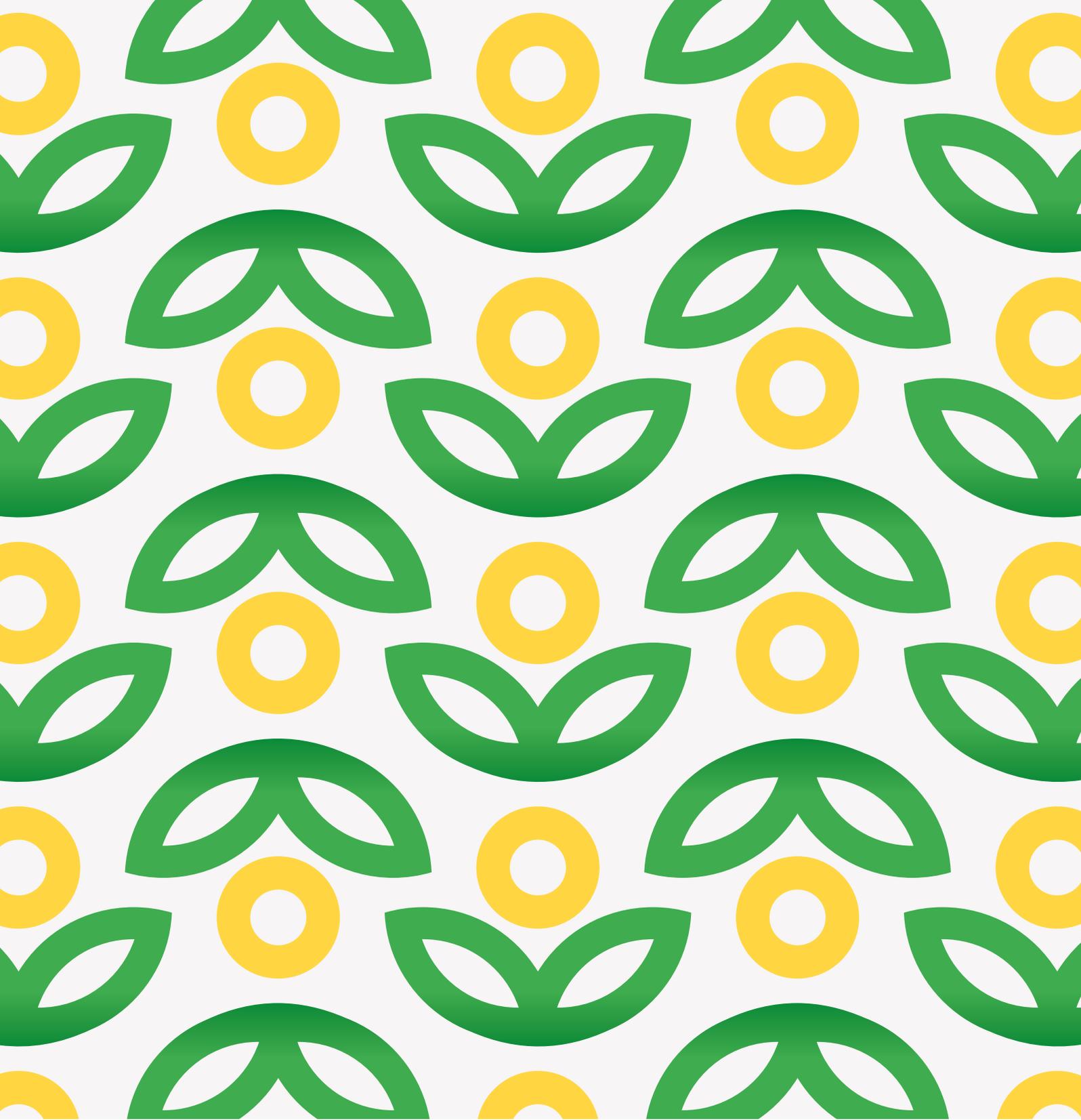
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