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# INTELLECTUAL DISABILITY AND ASSISTIVE TECHNOLOGY

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The capacity of assistive technology (AT) to improve the lives of individuals with disabilities is well documented. Although promising, it is not without challenges. Historically, devices that provide mobility aids and physical supports dominate the world of AT; however, AT solution that specifically aims to address cognitive needs is scarce. The inequality of AT accessibility has left populations such as individuals with intellectual disability (ID) behind these potential benefits. This book presents six articles that highlight the need, impact, and possibilities of AT for people with ID. With the emphasis on the multidisciplinary perspectives, the objective of the book is to facilitate a better understanding of the needs of people with ID and the potential AT influences. Ultimately, we hope this book will shed some lights on this important topic and provoke more discussions and efforts devoted to improving the lives of individuals with ID through the use of AT.

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# Editorial: Intellectual Disability and Assistive Technology

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**Keywords:** assistive technology, assistive products, intellectual disability, health inequity, cognitive functioning

## Editorial on the Research Topic

### Intellectual Disability and Assistive Technology

People with intellectual disabilities (ID) need assistive technology (AT) to maintain and improve their levels of functioning and independence, which in turn promotes well-being. AT enhances the ability of people with cognitive limitations to participate in and integrate into an inclusive society. AT can also be used to better manage comorbidities, and people with ID have a higher prevalence of comorbidity compared to the general population. With the current growth of aging populations, the prevalence of older people with ID is likely to increase along with the demand for access to AT. Nevertheless, people with ID are disproportionately affected by disparities in healthcare services and in the acquisition of AT.

Although AT offers great opportunities for improving quality of life, it's people with ID who remain an underexplored focus for research and practice. This Research Topic compiles six articles that highlight the need, impact, and possibilities of AT for people with ID. Through the lens of multidisciplinary perspectives, the objective of the Research Topic is to facilitate a better understanding of the needs of people with ID. Specifically, it focuses on how to close the gap between services and outcomes and also to increase the inclusion of this population in society. The articles shed light on three broad themes related to AT. The first theme (O'Brolcháin; Boot et al.) offers perspectives on the importance of ethical considerations regarding ID and AT, and how the challenges that ID presents should be considered. The second theme (Lancioni et al.; Robb et al.; Lee et al.) reports on results and outcomes of three original empirical studies that include a smart-phone intervention, a computerized cognitive training method, and an assessment on cognitive functioning among children. The third theme (Ngomwa) illustrates the impact of policy on AT use in the context of Malawi, Africa.

The first article (O'Brolcháin) describes the right to autonomy and the associated risks of AT for people with ID. The article argues that AT can both promote and undermine autonomy, specifically in the areas of knowledge, authenticity, and liberty. Undermining the autonomy of people with ID is most pronounced in those with severe to profound ID, because it is difficult to determine their preferences and the degree of autonomy in these cases. Ethical oversight should be included when developing AT for people with ID, according to the author.

The second article (Boot et al.) provides insights into the value of including people with ID in global initiatives related to AT and improving access to AT. It focuses on the factors related to the need for and provisions of AT that are critical to serving people with ID and discusses ways to address these factors.

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The third article, an empirical study (Lancioni et al.) demonstrates the use of smartphones to help people with ID and sensory impairments to perform daily living activities. In this study, each participant was given a smartphone, which was set up to deliver verbal or vibratory and visual reminders at the times when activities were planned and to present verbal or pictorial instructions for the steps of these activities. This intervention study is an example of how AT can be adapted and used for people with ID to enhance their independence.

The fourth article, an empirical study by Robb et al. examines the attitudes of parents to support the use of computerized cognitive training to improve executive functioning in children with neurodevelopmental disorders. Children often depend on parental support to use such computerized cognitive training. The findings show that parents see the potential of such training, especially to improve social skills, motor skills, cognitive skills, and quality of life.

In the fifth article, Lee et al. explain how interactive block games are used in relation to AT to assess children's cognitive functioning. Although many validated tests are available to assess cognitive functioning, these tests often have inherent problems such as high costs associated with testing, limited availability of appropriately trained clinicians, and susceptibility to human error. This study compares the use of the interactive block games method with the traditional intellectual assessments.

In the sixth article, Ngomwa provides mini reviews on ID and improved access to AT in Malawi. The article presents the barriers faced by Malawian people with ID and examines the policies and legislation that can positively influence access to AT for this group. The article also discusses and recommends ways to remove barriers and enhance access to AT.

The functional limitations of ID vary greatly from one individual to another. The uncertainty of functional limitations is further complicated by the high comorbidity rate. This makes managing the activities of daily living more challenging, and also increases the cost for the professional health care. With the

increased prevalence rate of the ID population and the need for long-term care, it is anticipated that the challenges will only become more serious. AT has provided some promising results. It is our hope that this Research Topic will shed some lights on this important but often overlooked topic, and thus spark more discussion and support for the ID population and AT solutions.

## AUTHOR CONTRIBUTIONS

JL, RC, HK, and FB: substantial contributions to the conception and design of the work, drafting the work, revising the work critically for important intellectual content, final approval of the version to be published, and agreement to be accountable for all aspects of the work in ensuring questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. The authors alone are responsible for the views expressed in this article and they do not necessarily represent the views, decisions or policies of the institutions with which they are affiliated.

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# Autonomy Benefits and Risks of Assistive Technologies for Persons With Intellectual and Developmental Disabilities

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This paper explores the ways in which assistive technologies (ATs) can both promote and undermine the autonomy of Persons with Intellectual and Developmental Disabilities (PIDD). Following an initial discussion of ATs for PIDD, I examine the specific issues of autonomy for PIDD. I outline the ways in which ATs can boost autonomy, of PIDD, focusing on knowledge, authenticity, and liberty. Following that I suggest that ATs are not necessarily beneficial in terms of autonomy and examine ways that they might be used to undermine the autonomy of PIDD, specifically the categories of knowledge, authenticity, and liberty. I conclude by suggesting that the development of ATs requires ethical oversight.

**Keywords:** assistive technology, intellectual disability disorders, autonomy, ethics, philosophy, medical ethics

## INTRODUCTION

Assistive technologies (ATs) offer much potential to improve the lives of persons with intellectual disabilities. These technologies,<sup>1</sup> which can range from the simple (handheld digital magnifiers) to the extremely sophisticated (e.g., brain-computer interfaces), are being designed to help persons with disabilities of all sorts to function more easily in the world. The range of persons with disabilities is extensive and the number is increasing. It can include persons with physical disabilities, intellectual disabilities, and cognitive impairments.

This paper focuses on the subset of ATs being designed for persons with intellectual and developmental disabilities (PIDD). Intellectual disabilities are a multifaceted phenomenon with many variations, and there is a wide range of ATs being developed. While ATs are designed with many goals in mind, many are ultimately intended to increase the user's autonomy.

Within Western philosophical thought, respect for individual autonomy is a core principle. Within Western medical ethics, there is a broad consensus that respecting patient autonomy is required for good practice. That autonomy is a goal of those developing ATs should not surprise us then, as it is becoming a cornerstone of ethical thinking in medical contexts. Nonetheless, it is worth examining what is meant by autonomy in the context of ATs. Few people will argue against the goal of promoting the autonomy of PIDD, making this goal a useful claim for tech developers wishing to promote their products. This paper intends to examine the ways in which ATs can both

<sup>1</sup> If we adopt a very broad definition of ATs, canes and crutches, spectacles, and wheelchairs, and other venerable and familiar technologies count as ATs.

promote and undermine the autonomy of PIDD. This involves providing a more detailed account of what is meant by autonomy and exploring the ways ATs will interact with the conditions essential to it.

This discussion is emblematic of a larger discussion regarding the development of novel technologies. New technological developments, such as Big Data, nudging, internet-of-things, are better able to attract our attention (which is considered to be a finite resource). The more privacy we surrender, the more information those with access to technology have about us, and the easier it is for them to nudge us to behave in certain ways. As well as raising deep philosophical questions about the nature of human freedom (which, unfortunately, is not addressed here due to lack of space), this raises political questions about the control of and access to novel technologies. The positive outcomes of assistive technologies are a major justificatory reason for developing such technologies. However, as we see in this paper, there also exist hidden dangers. As such, the discussion of the impacts of ATs for PIDD has implications for the wider population. While the technologies might first be used to help PIDD, they are likely to become more widely available; and while the vulnerabilities of PIDD are more obvious, similar vulnerabilities exist in us all. Technological companies thrive by attracting people's attention, which enable them to more easily sell to those people. PIDD are in a number of ways more attentionally vulnerable, but the issue is not theirs alone. This is an ethical issue for everyone.

The structure of the paper is as follows. First, a brief outline of the goals of autonomy is provided, followed by an introduction to PIDD and the types of ATs being developed for PIDD. Following this, the issues of autonomy in relation to PIDD is introduced. The next section outlines the ways in which ATs might promote or boost the autonomy of PIDD. The following section suggests some ways in which the ATs might undermine the autonomy of PIDD. There is then a brief discussion and conclusion.

As a philosophical paper, this paper relies on conditionals. ATs *may* bring benefits and *may* bring harms. The future is not set and the overall result of ATs is and will be dependent on numerous factors, ranging from technological developments to policy makers, regulators, and users. This paper aims to elucidate the philosophical concept of autonomy and explore the possible real impacts of ATs on autonomy, so that developers, policy makers, regulators, and users will have a better understanding of the impact of ATs.

## THE GOAL OF AUTONOMY

ATs are frequently advocated as aids to increase the autonomy of people with intellectual disabilities (PIDD). Increasing or improving the autonomy of PIDD is a goal of the United Nations Convention on the Rights of Persons with Disabilities [(1): Preamble (n)]. The same convention obliges signatories to “undertake or promote research and development” of “assistive technologies” [(1), 4, g, h]. The Convention does not make a link between the use of assistive technologies and autonomy, but this connection is prevalent in the literature about the use of ATs and

PIDD (2, 3). For instance, a person's autonomy is one of the factors measured in determining an individual's predisposition to use AT (4). A good example of this is the University of Victoria's CanAssist program which focuses on developing and deploying assistive technologies for students with disabilities and aims to remove barriers to inclusion and to create tools that will provide persons with disabilities with greater autonomy and independence [(5), p. 57].

## PERSONS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES AND ASSISTIVE TECHNOLOGIES

Intellectual and developmental disabilities cover a wide range of conditions. The US National Institute of Health defines intellectual disability as starting before a person turns 18 and consisting of “intellectual functioning or intelligence, which includes the ability to learn, reason, problem solve, and other skills”; and “problems with adaptive behavior, which includes everyday social and life skills” (6), while developmental disabilities might encompass a broader range of disabilities, both physical and intellectual. Intellectual disability can range from mild to severe or radical. While mild cognitive disability would include learning difficulties or attentional disorders, severe cognitive disability might “limit or preclude the development of ... the consciousness of oneself as a temporally-extended being; practical rationality—the capacity to govern one's actions by reasoning about how to act; and the capacity to make and respond to moral demands” (7). These latter attributes are sometimes considered essential if a person is to be considered to have full moral status (7), and thus are of much theoretical, practical, and emotional importance. Thus, cognitive disability is best viewed as being a spectrum. Similarly, being autonomous is, as will be discussed in the next section, also predicated on certain attributes, and similarly autonomy can be viewed as being on a spectrum.

Technological aids are therefore of immense importance as they may bring people up to a certain threshold, whereby they will be better able to communicate, interact, or be part of their society. There is, understandably, much excitement about this potential. Assistive technologies similarly cover a wide-range of devices and equipment that facilitates teaching new skills, augments existing skills, or otherwise reduces the impact of disability on daily functioning [(8), p. 157]. It may be extremely high-tech (making use of virtual reality, robotics, or brain-computer interfaces) or low-tech (pencil grips, slant boards, pictures for communication). In between are technologies such as microswitches, which facilitate persons with certain disabilities to communicate via very simple responses (e.g., small movements of their hands/fingers, lips, or eyelids). This allows PIDD to “(a) access a computer system and choose and activate different program options or (b) activate simple environmental stimulation (i.e., depending on their levels of intellectual functioning and engagement interests)” (9).

Different ATs are likely to be used for people with mild, moderate, and severe disabilities. For people with mild



disabilities, reminders, and guides would be applicable; it is similar for people with moderate disabilities, who might also make use of ATs that help with communication, emotional skills, or adaptive skills in daily living. Communication devices might also be useful for people with severe ID. Other ATs for people with moderate or severe ID might be used to control impulses or discern their preferences. As technologies advance, it should be possible to develop technologies that will be personalized and more precise. These may be better able to help those with severe ID.

## AUTONOMY OF PEOPLE WITH INTELLECTUAL DISABILITIES

Personal autonomy, according to Beauchamp and Childress [(10), p. 101] “encompasses self-rule that is free from both controlling interference by others and limitations that prevent meaningful choice, such as inadequate understanding”. We can think of autonomy in the sense of being free from the control of other people or groups, e.g., autonomy in the political and social sense, or we can think of autonomy in a more personal sense intimately connected with notions of authenticity. Autonomy in the political and social sense, i.e., autonomy as it relates to a person's choices, is not the primary concern of this paper, although there are connections between political autonomy and autonomy in the sense of it being a feature of a person's self. Suffice it to say that if we assume the basic principles of liberalism, our aim will be to remove as many limitations on choices as possible. ATs can benefit this type of autonomy in relation to PIDD, as will be discussed below. ATs can certainly improve some aspects of personal autonomy, i.e., autonomy as it relates to authenticity and self-rule, but in other ways might undermine it. ATs will alter the conditions in which values, choices, and plans are made and the media through which they are facilitated and communicated. The question that is worth asking concerns the impact ATs will have on the autonomy of people, including PIDD.

This is not to say that a PIDD or the choices, values, and plans of PIDD should be afforded any less respect or ethical value. However, there will be reason for concern if those choices, values, and plans are not “theirs.” The normative judgements about the autonomy of PIDD using ATs may be especially relevant in relation to PIDD for a number of reasons as follows:

- 1) There is a push, as we have seen, for ATs to be developed for PIDD (carers and others want to see PIDD live more autonomously; grand claims are being made regarding the promise of ATs).
- 2) PIDD may be unlikely to be able to evaluate as fully the risks and benefits of ATs for their autonomy, depending on the level, and severity of their ID.
- 3) carers and others who are emotionally involved with PIDD may be blinded by the promise of the ATs.
- 4) If PIDD are considered to be closer to full autonomy, they ought to be autonomous in a political sense as well [c.f. (11)]. That they vote according to their own conscience is of the utmost importance.

None of this is to suggest that ATs should not be developed for PIDD nor that PIDD should not be permitted to vote or have any other civil and political rights. While Feinberg (12) has identified four different variations of autonomy in moral and political philosophy, central to all of them “is a conception of the person able to act, reflect, and choose on the basis of factors that are somehow her own (authentic in some sense)” (13). Certain types of ATs pose a threat to this type of autonomy. This will be discussed in more detail below.

Given the different understandings surrounding the concept of autonomy, it will be useful to start with a working definition. We can then say that at minimum, autonomy consists of self-rule, of deciding for oneself what one would like to be able to do. As such three components stand out: (1) knowledge, (2), authenticity, and (3) liberty. Knowledge will be required in order for a person to make decisions about what he or she values, as well as being essential if one is to determine what one wants to do in pursuit of their values. Authenticity is then required if the person is to be the initiator of his or her own actions—if a person is merely following someone else's plan or is brainwashed, then he or she is not fully autonomous. Here, liberty means political autonomy or having rights over themselves.

## ASSISTIVE TECHNOLOGIES AND THE PROMOTION OF AUTONOMY

In relation to ATs, Leslie Francis notes that people with physical disabilities use assistive devices, but his or her actions involving these devices are still considered to be his or her own; she also correctly notes that people without intellectual disabilities also use assistive devices. So, the fact that someone might use an assistive device does not necessarily mean that they have diminished autonomy. Francis contends that

“...the significance of prostheses and other forms of assistance is normative. The judgement that a value, or a choice, or a plan of action is not sufficiently or appropriately a matter of my individual psychological processing to be regarded as ‘mine’ is a normative conclusion about how that value, or choice, of plan of action is to be regarded, whether it is to be respected, how I am to be treated in light of it” [(14), p. 208].

Clearly, using assistive technologies does not mean that a value, choice, or a plan is insufficiently a matter of a person's individual psychological processing to be regarded as theirs. Francis is arguing against a perception that PIDD lack autonomy and is pointing out that a person's use of ATs should not be held against him or her. Nonetheless questions over whether someone's values, choices, or plans of action are a matter of their individual psychological processing is of great ethical importance including in terms of assistive technologies, and including (more specifically) assistive technologies for PIDD.

Let us first examine the many ways in which ATs could promote autonomy. Take for example the number of deficits faced by at least some PIDD that relate to autonomy listed by Francis: difficulty with abstract reasoning, difficulty with impulse control, difficulty in planning ahead and in pursuing developed

plans, problems in social adaptation that might manifest as gullibility, naiveté, and increased and potentially problematic dependency on others [(14), p. 204]. Technological aids could help PIDD overcome or manage a number of these deficits, thus promoting autonomy.

Francis points out that, “that what it is to have autonomy in some relevant senses is a complex matter and that judgements about the autonomy of people with intellectual disabilities must be complex as well” [(14), p. 200–201]. She provides a more extensive list of attributes of autonomy: “being able to value, being able to reason, being able to resist impulses, being able to imagine an ordered life, being able to order one’s life being able to put one’s plans into practice, being able to participate in moral deliberation of an idealized kind, and being politically free” [(14), p. 202]<sup>2</sup>. In what follows, the ways in which ATs may be able to promote three subsets of autonomy—knowledge, authenticity, and liberty—are outlined.

## Knowledge

A number of PIDD have difficulty retaining information, so technological aids that supply knowledge in an easily digestible form will be of immense use. Maps and guides are obvious examples, but technology that informs PIDD of what various signs and signals do will also be important, e.g., a device that reminds PIDD about the meaning of road signals might help PIDD walk about a city by themselves. ATs might be used to provide reminders of what their long-term goals are, thus nudging them to align their current desires with previous plans or preferences (possibly made in conjunction with family members or carers). As such, ATs could help with impulse control. ATs might also help with abstract reasoning, by making abstract concepts comprehensible to PIDD.

## Authenticity

Many people with severe ID struggle to “formulate, articulate, or communicate complex ideas” [(15), p. 313]; some are arguably incapable of formulating, articulating, and communicating complex ideas. As such, it is extremely difficult to determine what, if any, their preferences are. In some cases, it will be difficult to determine the authentic desires of people with severe cognitive impairments. For example, a person with severe apraxia might struggle to communicate a sentence, perhaps taking an hour to complete the sentence. While ATs could help, they could also easily distort what the person is likely to say. ATs that aid their communication or that are able to interpret their preferences (e.g., using eye-tracking or emotion recognition software) will help in allowing these people to pursue their authentic goals. If they are able to communicate, then the goals they are given or that they choose are likely to reflect their interests and preferences.

This presupposes that they can be said to have preferences from which interests can be generated. ATs might also be useful in helping PIDD (particularly those with moderate or mild

impairments) determine their preferences and order their lives. Assistive devices can be used to make up for deficits in planning ahead and pursuing goals.

Some PIDD have poor impulse control—ATs may be able to promote being one’s own person by helping people choose courses of action that should help them achieve their goals in life rather than being led by their intuitive and emotional responses to things. ATs could be used to nudge PIDD toward certain goals (ideally worked out in conjunction with the user). Nudging works by appealing to people’s automatic affective systems (i.e., the systems governed by emotional and intuitive reactions to things) in order to promote goals that people would (ideally) choose if they had time to reflect on their longer-term, strategic goals (16). This is relatively easy to illustrate—suppose a person’s long-term goal is to eat more healthily in order to live longer, but his or her affective self responds to a cake at the counter by buying the cake. A nudge in such a scenario would arrange the presentation of food so that the cake is not as tempting; an AT might remind the person of their longer-term goal of not eating the cake, thus helping the person achieve this goal; or might suggest lunches; or might calculate the calories of the items that the person buys. Interesting research has been done, for instance, on the links between harmful use of alcohol and tobacco and the density of outlets supplying such products (17, 18).

In terms of PIDD, this sort of nudging is trickier as in some cases of intellectual disability the capacity to form long-term strategic goals might not exist. However, Francis and Silvers have suggested “the possibility of constructing individualized conceptions of their good by, with, and for people with lifelong intellectual disabilities” (14). They argue further “people with intellectual disabilities can participate in practices that are centered on their own ideas of the good, even though they cannot formulate, articulate, or communicate complex ideas” [(15), p. 313]. There is an earlier argument advanced by Francis together with Silvers that “To the extent that people with intellectual disabilities have recognizable preferences, and interests that can be generated from these preferences, other people can collaborate with them to construct individualized, subjective conceptions of the good” [(15), p. 325].

## Liberty

Regarding the liberty condition of autonomy, ATs should reduce PIDD’s dependency on others and render them slightly less naïve and gullible in practice (by reminding them how to interact with others, for instance). Moreover, insofar as ATs promoting the autonomy of PIDD in the sense of character or personality, i.e., giving PIDD more knowledge and facilitating their independent pursuit of their own conceptions of the good, there will be a stronger argument for them to enlarge the scope of rights over themselves. For instance, Nussbaum points out that regarding political entitlements, “People with limited ability to read, people who easily become confused or fearful in a new setting, may be excluded from voting and jury service de facto, even though sensitive thought about how to include them could prove just as successful in these settings as it has in education” [(11), p. 344]. By helping PIDD communicate,

<sup>2</sup>She also outlines a number of deficits faced by at least some PIDD that relate to autonomy, such as difficulty with abstract reasoning, difficulty with impulse control, difficulty in planning ahead and in pursuing developed plans, problems in social adaptation that might be manifest as gullibility, naiveté, and increased and potentially problematic dependency on others [(14): p. 204].

understand information, and deal with new scenarios and new people, the range of choices available in social and political spheres is increased and thus this aspect of his or her autonomy is increased.

For those who argue for relational autonomy, having normative authority over one's central values and commitments is seen as being of utmost importance, i.e., being the validating source of these values, if not necessarily the origin [(19), p. 375]. In this case, then, so long as PIDD validated the values being promoted by the ATs, they would be seen as autonomous in the relational sense. ATs, by helping PIDD interact with the rest of society more easily, will facilitate their social recognition, and thus promote self-respect and dignity.

## ASSISTIVE TECHNOLOGIES UNDERMINING THE AUTONOMY OF USERS

ATs might undermine the authenticity of PIDD. Let us focus on the ways in which ATs might impact the knowledge, authenticity, and liberty conditions of autonomy. While “compulsion, temporary or protracted mental disability, and addiction are most often mentioned as examples” of ways in which autonomy can be undermined, “brainwashing and manipulation of the psychic economy of the agent” are also threats as they “undercut the person's ability to reflectively accept her first-order motives and/or the way that she has come to develop them” [(19), p. 375]. This is not to say that all interference or suggestion undermines autonomy. Persons with IDD can be naïve and not well-informed regarding their use of technologies, making them especially vulnerable. For instance, a study on the use of IT by PIDD found that “privacy breaches were revealed to be a major risk for persons with IDD, who did not seem to consistently understand that they should protect their personal information and *how* it could be used by third parties” (20).

### Knowledge

Electronic ATs (i.e., apps on mobile devices) might distort or misrepresent information being made available for users. Often the information being made available for PIDD will necessarily be simplified so as to make it comprehensible. Depending on the degree of simplification, this could result in misrepresentations of knowledge. The choices made in terms of what information to omit or what to emphasize could be seen as distortion. Designers of ATs will also need to ensure they minimize their own biases.

### Authenticity

The addition of a layer of technology to the relationship between PIDD and the world around them might complicate matters as much as simplify them. We mentioned that some apps might help PIDD communicate their inner psychological states to others. There are potential drawbacks to this ostensible benefit—the risk that the user's inner psychological state will be misrepresented. It may be distorted

or manipulated in translation. In cases of people with profound cognitive impairments, it might be extremely difficult to determine if the AT is in error or if their preferences have changed.

Secondly, if an app—for instance—offers the user a range of options from which to choose, the choice architecture [c.f. (21)] will nudge them in one way or another. The degree of nudging, which is unavoidable, risks undermining their autonomy.

Of course, this is not only the case for PIDD. Recent psychological research suggests that “the palatability of certain kinds of mental stimulation seems to be hard-wired, just as our taste for sugar, fat, and salt is” [(22), p. 16]. Companies in possession of huge amounts of data about a person that develops apps for that person will be easily able to provide us with stimulation that we crave, thereby undermining capacities for self-regulation (which is said to be finite) as well making claims on our attention. Novel technologies are being designed to target the “attentional resources” of people, resources that are considered finite [(22), p. 11]. Moreover, the ability to allocate attention is linked with self-regulation, meaning that “To the extent that the power of concentration is widely attenuated, so too is the power of self-regulation” [(22), p. 16]. The less attentional resources we are able to muster at any time, the more pliable we become and the more vulnerable we are to manipulation. Novel technologies, by gathering data about us, are better able to determine which nudges and techniques will grab our attention. The less we are able to focus on ourselves, the more easily manipulated our decisions and choices will be—the less “authentic.” This impacts on autonomy, including the autonomy of PIDD. So, while ATs might provide more knowledge and better ability to communicate, it will be essential to ensure that they do not reduce PIDD's “attentional resources.”

ATs might be used either to help determine what a PIDD's preference are, or to create those preferences. If some third party creates the preferences, it becomes difficult to claim that the PIDD is autonomous.

### Liberty

If a PIDD has no (or severely reduced) personal autonomy in the sense of them initiating their own actions, developing, and following their own plans, or choosing their own values, then they cannot be said to have very much autonomy. As such, there would be severe problems with political autonomy. If they were not authentically choosing how to vote, for instance, but were instead voting according to preferences suggested to them by an AT, or making jury-deliberations, there would be a risk to the legitimacy of those processed. A major risk of ATs then is that they might be used to manipulate PIDD for legal or political ends. If this were to happen it would set back the cause of obtaining equal civil and political rights for PIDD.

Less individualistic accounts of autonomy such as relational accounts (23) of autonomy do not necessarily help in this case either. Relational accounts of autonomy focus on recognition of the person's autonomy, and on the importance of a person validating their own values. However, this simply shifts the problem—ATs could nudge the person toward validating the

values the AT suggests. The user might be seen not as the origin of these values but as validating them. If they have been nudged toward validating them, then the problem remains.

## DISCUSSION

Our notions of autonomy emphasize the importance of individuals making choices according to their own individual preferences. Indeed, a core tenet of political liberalism is that people should be allowed to pursue their own subjective account of the good. Recent developments in big data technologies, alongside developments in “nudging” techniques, mean that our preferences themselves are increasingly subject to social engineering.

In developing ATs for PIDD, we must be extremely careful to ensure that novel technologies do not in fact create preferences based on the interests of technology designers, engineers, or carers. Francis and Silvers argue that a conception of the good “can be carried on, and indeed often is carried on, in dependency” [(15), p. 313] (e.g., with others) and seem to envisage carers or other trusted people helping PIDD develop conceptions of the good. They note that “For a conception of the good to be individually scripted, it must be tailored to the individual in a way that reflects the individual’s subjective experiences and personal characteristics” [(15), p. 322]. ATs can help carers understand and interpret the preferences of PIDD and help PIDD communicate those preferences [c.f. (24, 25)]. As such, they are useful, but they also risk misrepresenting an individual’s subjective experiences, or constructing preferences (by framing responses to certain things or directing their attention in specific ways) that are in fact in the interests of the developer. In scenarios where the PIDD has a profound impairment, they will struggle to correct it; or ATs will be able to impact on the PIDD’s subjective experiences. Although ATs will bring benefits then, they will also present PIDD and carers with novel problems and threats.

The issue of ATs undermining the autonomy of PIDD will be most pronounced in cases of profound cognitive impairment, as it is in these cases that it is difficult to determine the preferences of PIDD and their degree of autonomy. ATs are likely to promote the autonomy of PIDD at the mild or moderate end of the spectrum. They are likely to facilitate greater independence by serving as memory aids, guides, and planners. They will certainly promote autonomy in this sense. They may help people develop and pursue life goals. In terms of people with moderate or severe ID, they can promote autonomy in the sense of providing means to communicate and to control impulses.

In all cases there remains a risk that they will also make users biased toward or against particular goals. The degree to which nudging undermines autonomy is pressing then.

ATs insert an extra-layer into decision making for people with severe ID. While Silvers and Francis have argued that it might be possible to determine someone’s subjective good, this relies on others to do so. ATs may help in this quest,

but they also complicate the matter, as they can be used to interpret the preferences of the user. Given the epistemological uncertainty regarding the preferences of a person with severe ID, a reliance on ATs will still require the involvement of guardians or carers.

This suggests the need for strict controls on the development of ATs, at least for those involved in certain stages of AT development, just as people working in care are strictly vetted. At the very least, increased ethical oversight is required. The aim of promoting the autonomy of PIDD is commendable and ATs are, at first glance, immensely appealing. However, if we are to actually promote autonomy, we need to analyze carefully what is meant by autonomy, and ensure that those conditions are not undermined by the very technologies designed to increase autonomy.

## CONCLUSION

This paper discusses the ways in which ATs can both promote and undermine the autonomy of PIDD. Following an initial discussion of ATs for PIDD, issues of autonomy for PIDD were addressed. The ways in which ATs can boost autonomy of PIDD, focusing on knowledge, authenticity, and liberty, were outlined. It was then suggested that ATs are not necessarily beneficial in terms of autonomy and that they might be used to undermine the autonomy of PIDD, specifically the categories of knowledge, authenticity, and liberty. It can be concluded by suggesting that the development of ATs requires ethical oversight.

However, this discussion touches on broader issues that pose ethical issues for every facet of society, not just for PIDD and those who care for them. Threats to our attentional resources are becoming more apparent and risk making people more pliable and threatening their individual autonomy. Given the centrality of individual autonomy to democracy, this is an issue that all democratic governments should be addressing. A blinkered focus on the positive potential of new technologies, for instance the potential of ATs to promote the autonomy of PIDD, risks blinding us to their dangers. The financial incentives associated with the creation of novel technologies mean they are inevitable, but if we are to avoid the risks and maximize the benefits, more ethical oversight and (probably) regulation will be needed.

## AUTHOR CONTRIBUTIONS

The author confirms being the sole contributor of this work and has approved it for publication.

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# Intellectual Disability and Assistive Technology: Opening the GATE Wider

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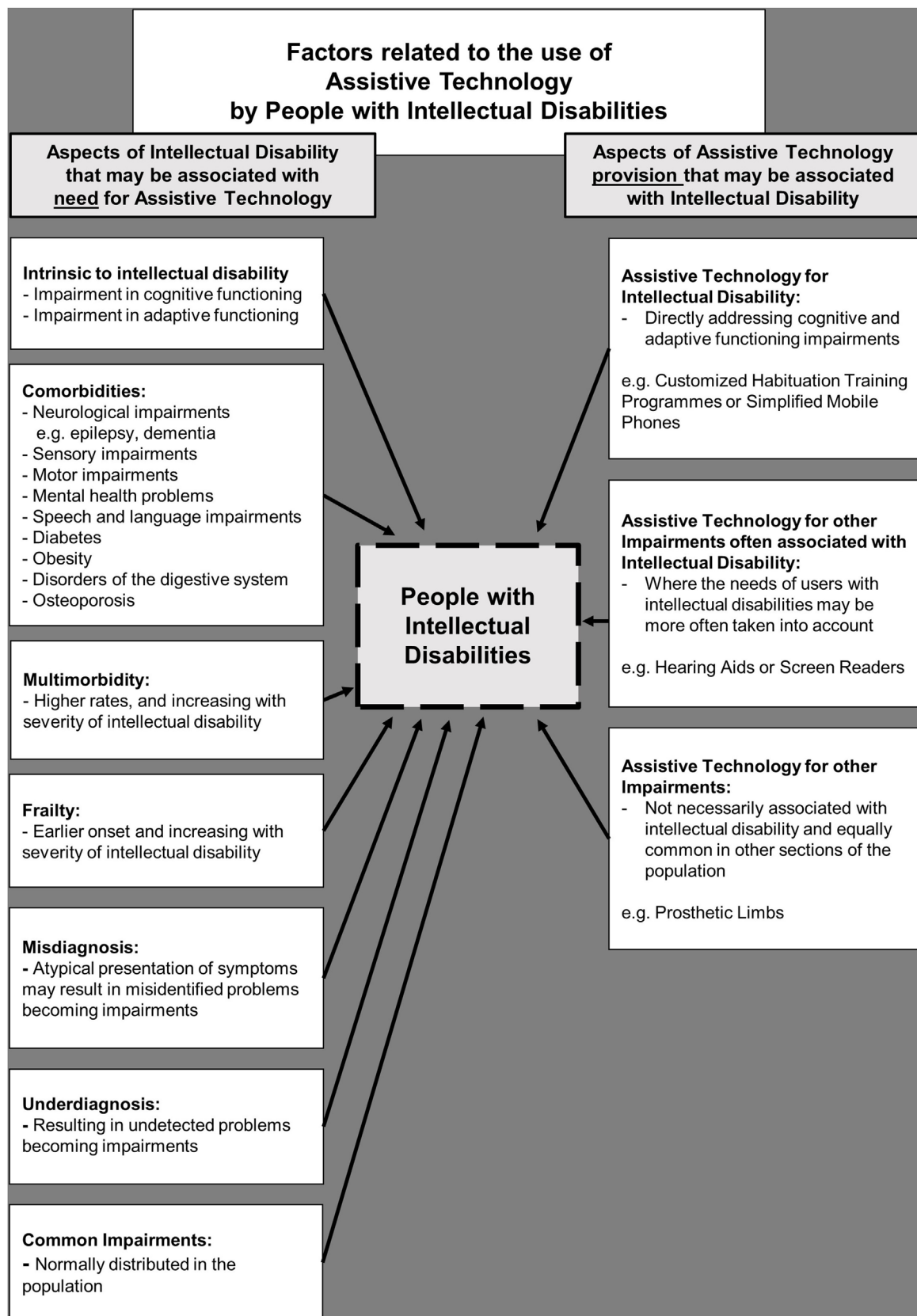
The World Health Organization has launched a program to promote Global Cooperation on Assistive Technology (GATE). The objective of the GATE program is to improve access to high quality, affordable assistive technology for people with varying disabilities, diseases, and age-related conditions. As a first step, GATE has developed the assistive products list, a list of priority assistive products based on addressing the greatest need at population level. A specific group of people who can benefit from user appropriate assistive technology are people with intellectual disabilities. However, the use of assistive products by people with intellectual disabilities is a neglected area of research and practice, and offers considerable opportunities for the advancement of population health and the realization of basic human rights. It is unknown how many people with intellectual disabilities globally have access to appropriate assistive products and which factors influence their access. We call for a much greater focus on people with intellectual disabilities within the GATE program. We present a framework for understanding the complex interaction between intellectual disability, health and wellbeing, and assistive technology.

**Keywords:** intellectual disabilities, assistive technology, assistive devices, global health, public health policy, health inequality, World Health Organization

Only 10% of the people who are in need of assistive products actually have access to them, despite such access being claimed to be a human right (1, 2). An assistive product is any product (including devices, equipment, instruments, and software), either specially designed and produced or generally available, whose primary purpose is to maintain or improve an individual's functioning and independence and thereby promote their wellbeing (3). Common examples of assistive products are spectacles, hearing aids, wheelchairs, prosthetics, communication boards, incontinence products, pill organizers, and therapeutic footwear. Assistive products can improve the quality of life for people with impairments, including the extent of their inclusion and participation in society. However, the use of assistive products by people with an intellectual disability (ID) is a neglected area of research and practice and offers considerable opportunities for the advancement of population health and the realization of basic human rights. About 1% of the total population have ID, with higher prevalence rates in low- and middle income countries (4). ID is defined by the American Association on Intellectual and Developmental Disabilities, the Diagnostic and Statistical Manual of Mental Disorders V, and the International Classifications of Diseases 10 (mental retardation) as an IQ below 70, manifested during the developmental period (<18 years of age), with impairments in adaptive functioning, such as communication skills, social skills, personal independence, school, or work functioning (5–7).

The World Health Organization has launched a program to promote Global Cooperation on Assistive Technology (GATE) to implement those parts of the United Nations Convention on the Rights of Persons with Disabilities referring to assistive technology (3, 8, 9). The GATE program's





**FIGURE 1 |** Factors related to the use of assistive technology by people with intellectual disabilities.

objective is to improve access to high quality, affordable assistive products for people with varying disabilities, diseases, and age-related conditions. As a first step, GATE has developed the assistive products list (APL) of priority assistive products to address the greatest needs at population level (10). To be effective, the APL will require countries to develop national assistive technology policies; source appropriate products; train specialized personnel; and develop effective and efficient systems of provision (10).

However, barriers that people with ID experience regarding access to assistive products have not yet been sufficiently considered. Worldwide, people with ID are still generally regarded as a devalued and stigmatized group, and at least part of their relatively poor health status is due to health inequities. People with ID are still often disadvantaged when attempting to access or secure health services and assistive products (11, 12). It is unknown what proportion of people with ID globally actually has access to appropriate assistive products. It has been suggested that for people with ID there is a high rate of underdiagnosis and misdiagnosis; so that too often they do not receive the correct treatment and that the need for rehabilitation arises as a result of absent or ineffective health care (13). The atypical presentation of symptoms by people with ID is often a challenge for their care system. With accurate assessment and appropriate interventions, the use of assistive products can be not only enabling and empowering, but also transformative in facilitating new life skills and opportunities for people with ID.

Compared to the general population, people with ID have a higher prevalence of comorbidities which could be better managed with assistive products (see **Figure 1**). For instance, motor disabilities are present in a significant proportion (26%) of people with ID (14). Visual impairment has a prevalence of 19.2% in adults with ID compared to 1.9% in adults of the general population. For hearing impairment, the prevalence is 30 vs 17%, respectively; and for dementia, it is 13.1 vs 5.4%, respectively (15). People with ID are now recognized as a group with a disproportionately greater need for assistive products due to higher rates of frailty and multimorbidity (including increased severity and earlier onset) than the general population (16, 17). The result is a greater prevalence of disabilities in daily functioning and mobility with increased care needs and support required (18–20). Multimorbidity (the presence of two or more chronic conditions) is of particular concern with an 80% prevalence rate in adults >50 years with ID (17). Besides the association with age, multimorbidity, and frailty are also associated with a severe and profound level of ID (16, 17). The life expectancy of people with ID is increasing in line with the general population trends. Therefore, the prevalence of older people with ID is also likely to increase along with the demand for access to assistive products (21).

Access to assistive products presents three distinct challenges if people with ID are going to benefit from the increased provision aspired by GATE (see **Figure 1**). First, impairments in cognitive and adaptive functioning intrinsic to ID should be adequately catered for within population-level systems of assistive technology policy, products, health care personnel, caregivers, and provision. That means, communication skills and physical examinations by health care personnel need to be adapted to the intellectual and

emotional level of the person with ID, to get the correct diagnosis and ensure the appropriate assistive product(s) are prescribed. The use of assistive products requires information, instruction, and support that are both accessible and understandable to the person with ID, if it is to be used effectively. In addition, a multidisciplinary approach to develop protocols for the training and support of people with ID is needed in order to direct the effective use and evaluation of the assistive products. For example, hearing aids require a customized habituation training program adjusted to an individual's level of ID. This needs to be implemented in collaboration with the speech and language therapist, behaviorist, and caregiver together to help the person with ID to accept and benefit from the use of the new product.

A second challenge for people with ID to benefit from the APL is increased awareness among caregivers and health personnel of comorbidities that people with ID often experience; such as sensory impairments and dementia. These comorbidities may require the use of assistive products, and so the needs of the users with ID must be more often taken into account.

Third, people with ID will experience physical impairments not necessarily associated with ID, which are equally common in other sections of the population. For instance, a person with ID may need to learn to use a prosthesis or walking aids and—as above—the effective use of such products requires information, instruction, and support that is as accessible and understandable as possible. While it is known that the use of assistive products, such as a prosthesis, is influenced by a range of psychosocial factors, such research derives almost exclusively from users of assistive products without ID (22, 23).

Without a concerted and systematic approach to consider the challenges that ID presents, for the users, caregivers, and providers of assistive products, profound inequities in health, in life opportunities, and therefore in the quality of life for people with ID will persist. We call for a much greater focus on people with ID within the GATE program and in particular regarding national initiatives to adopt the APL.

## AUTHOR CONTRIBUTIONS

FB: substantial contributions to the conception and design of the work; drafting the work; final approval of the version to be published; agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. JD, CK, and MM: substantial contributions to the conception and design of the work; revising the work critically for important intellectual content; final approval of the version to be published; agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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# Using Smartphones to Help People with Intellectual and Sensory Disabilities Perform Daily Activities

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**Background:** People with mild-to-moderate intellectual disability and sensory impairments often fail to take initiative in starting and carrying out daily activities, with negative consequences for their occupational condition and social status. Their failure seems due to their inability to determine the right time for the activities and to remember all the activity steps.

**Aim:** This study assessed a smartphone intervention, which was designed to help eight participants (four presenting with intellectual disability and blindness and four presenting with intellectual disability and hearing impairment) to independently start and carry out daily activities at appropriate times.

**Method:** The intervention was introduced according to a non-concurrent multiple baseline design across participants. During the intervention, each participant was provided with a smartphone, which was fitted with the time schedule of his or her activities and the verbal or pictorial instructions for the single steps of those activities. When the time for an activity was reached, the participant was automatically reminded to start that activity and, thereafter, he or she was presented with the instructions for it.

**Results:** The use of the smartphone intervention promoted great improvement over the baseline for all participants. That is, the participants managed to (a) independently start the activities at the scheduled times and (b) carry out those activities with high levels of accuracy.

**Conclusion:** A smartphone intervention, such as that used in this study, may help people with mild-to-moderate intellectual disability and sensory impairments to successfully engage in daily activities.

**Keywords:** technology, smartphone, activities, intellectual disability, blindness, hearing impairment

## INTRODUCTION

People with mild-to-moderate intellectual disability and sensory impairments (i.e., blindness or hearing loss) may experience major difficulties engaging in functional daily activities independently (1–6). Indeed, they may be unable to determine the right time for the activities and fail to take initiative and start to perform them (7–9). Their situation can also be complicated by their

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apparent inability to remember all the steps of the activities and/or the steps' correct sequence (10, 11). As a consequence of the aforementioned challenges, people with intellectual and sensory disabilities tend to be largely sedentary and passive with negative implications for their self-confidence, constructive engagement time, environmental sensory input, and social status (6, 12).

This negative perspective has created strong consensus on the need to find strategies to help them reach a more active and functional role within their daily contexts (11–15). It is also increasingly clear that aiming to enhance their activity engagement through extended staff assistance may not be feasible or desirable. In fact, staff resources are known to be generally limited and probably insufficient to guarantee the necessary level of supervision. Moreover, an increase in the level of staff support/supervision would counter the people's personal development in terms of self-determination, self-regulated engagement, and social image, and thus might prove detrimental (16–18).

In light of the above, efforts to increase people's activity engagement have largely focused on providing them with activity support tools suited to their conditions (i.e., tools encompassing the step instructions of the activities to be performed) and teaching them to use those tools independently (15–20). The most basic tools consist of booklets with pictorial representations of objects related to the activity steps (i.e., with visual cues the people can use to help themselves remember the steps and their sequence) (20, 21). Other tools involve the use of technological devices (often modified for the purpose of the studies) such as (a) verbal recording devices that the people can use to obtain verbal instructions concerning the activity steps (5, 22–24), (b) simplified computer-aided systems, iPods, or video devices that the people can use to obtain static or dynamic visual instructions (i.e., pictures/photos or video clips illustrating the activity steps) (25–28), and (c) simplified computer-aided systems that automatically show (i.e., at preset time intervals) static or dynamic visual instructions for the activity steps (29).

Studies assessing the effectiveness of the aforementioned tools have reported encouraging results, that is, people appeared generally capable of using the tools to carry out multistep activities independently. It is noteworthy that, in contrast with the efforts to support the people's independent performance of complex/functional activities, almost no attention has been paid to investigating whether they could also be helped to start those complex activities on their own, at the appropriate times (i.e., with a further enhancement of their active role) (30, 31).

In a recent, preliminary study aimed at pursuing both the aforementioned goals (i.e., enabling people to perform relevant multistep activities and also start those activities independently at the appropriate times), Lancioni et al. (32) compiled a technology-aided intervention relying on a smartphone and a tablet. The smartphone was set up to deliver timely reminders about the activities the participants were to carry out and the tablet served to present the participants the pictorial instructions for the steps of those activities. The results showed that all three participants managed to start the activities at the right times and carry them out correctly, thus suggesting that the intervention was suitable to achieve both target goals.

Notwithstanding the positive results of the study, caution is required in drawing conclusions given the small number of participants involved and the fact that the technology arrangement and instructions used would not be suitable for persons with blindness (33, 34). New research efforts to overcome these limitations and confirm the plausibility of targeting both goals (i.e., independent timely start and independent performance of relevant activities) are warranted. The present study was one such effort involving eight participants with intellectual disability, four presenting with blindness and the other four with hearing impairment. A smartphone intervention was used with each of them. In practice, each participant was provided with a smartphone, which was set up to (a) deliver verbal or vibratory and visual reminders at the times in which the activities were due and (b) present verbal or pictorial instructions for the single steps of those activities.

## MATERIALS AND METHODS

### Participants

**Table 1** reports the participants' chronological ages and their Vineland age equivalences for receptive communication and personal and domestic daily living skills (35, 36). The participants, for whom pseudonyms are used, attended rehabilitation and care centers for persons with multiple disabilities and represented a convenience sample (37). They were divided into two groups, based on their sensory condition. Group 1 included the participants with total blindness (i.e., Sophie, Fergus, and Brady) or light/darkness discrimination (i.e., Nigel). Group 2 included the participants with severe hearing impairment and typical/functional sight (i.e., Owen, Karen, Loris, and Betty). The psychological records of the centers that the participants attended described their levels of intellectual disability to be in the mild/moderate or moderate ranges. Their Vineland age equivalences varied between 4 years and 3 months and 6 years and 6 months for receptive communication; between 3 years and 2 months and 4 years and 7 months for personal daily living skills; and between 4 years and 3 months and 7 years for domestic daily living skills (see **Table 1**).

**TABLE 1 |** Participants' chronological ages and Vineland age equivalences for receptive communication (RC) and Personal and Domestic Daily Living Skills (P/DLS and D/DLS).

Participants <sup>a</sup>	Chronological ages (years)	Vineland age equivalences <sup>b,c</sup>		
		RC	P/DLS	D/DLS
Sophie	18	4;3	3;2	4;3
Nigel	49	6;6	4;0	6;5
Fergus	43	6;6	3;10	6;5
Brady	45	6;2	3;11	4;7
Owen	25	5;1	4;7	7;0
Karen	57	5;10	4;7	6;9
Loris	19	4;8	3;6	6;5
Betty	32	5;6	4;7	7;0

<sup>a</sup>The dotted line separates the participants of Group 1 and Group 2.

<sup>b</sup>Vineland age equivalences are reported in "years" (numbers before the semicolon) and "months" (numbers after the semicolon).

<sup>c</sup>The age equivalences are based on the Italian standardization of the scales (35).

Staff and caregivers' reports and direct observations had indicated that the participants had difficulties with daily activities (i.e., failing to remember the times at which they were due and the steps involved). In practice, participants tended to be dependent on external assistance. Staff and caregivers had expressed interest for a technology-aided approach that would encompass both reminders and verbal or pictorial instructions (i.e., to alert the participants about the activities to perform at the appropriate times and indicate the steps of those activities, respectively). Moreover, participants had shown willingness to use a smartphone such as that adopted in this study (i.e., after the functioning of that smartphone had been demonstrated to them by staff). In spite of this willingness, the participants were unable to give informed consent to the study. Thus, written informed consent was obtained from their legal representatives. The consent agreement allowed the legal representatives to withdraw the participants from the study at any time if they perceived the participants did not benefit from or were unhappy within the study. (None of the participants dropped out.) The study complied with the 1964 Helsinki declaration and its later amendments and was approved by the Ethics Committee of the Lega F. D'Oro, Osimo, Italy.

## Setting, Technology, and Activities

The study was conducted in the centers that the participants attended. The technology involved a Samsung Galaxy A3 smartphone with Android 5.1 Operating System, which included standard functions such as Bluetooth connection and Alarm and was fitted with the Easy Alarm YouTube application as well as with audio and video files. Audio files were used for the participants with visual impairment and typical hearing and consisted of the verbal reminders and instructions concerning the activity steps. There was one file for each of the activities included. The time for the performance of each of the activities was scheduled by the research assistant by linking the activity-related audio file with the alarm tone of the smartphone. As soon as such time was reached, the smartphone emitted a verbal reminder with the name of the activity to be performed. The reminder was then followed by each of the step instructions arranged for the activity. The research assistant scheduled the intervals between the reminder and the first activity instruction as well as between any pair of the following instructions of the sequence, based on preliminary observations of the participant's performance speed. Longer intervals were scheduled following instructions related to more demanding steps, and vice-versa. The intervals could be readjusted in line with the participant's progress. The instructions were conveyed directly *via* the smartphone that the participant carried with him or her or through a wireless Bluetooth earpiece that the participant wore during the sessions (thus avoiding to carry the smartphone).

Video files were used for the participants with hearing impairment and typical visual ability and consisted of static pictorial instructions, that is, photos of the object(s) involved in the single steps of the activities. As with the audio files, there was one video file for each activity included. The time for the performance of each activity was arranged through the Easy Alarm YouTube application. In essence, as the time for an activity was reached,

the Easy Alarm YouTube application activated a reminder consisting of a vibratory signal and a general (preliminary/global) picture of the activity. This reminder was then automatically followed by the visual instructions for the single activity steps, which were separated by intervals scheduled according to the rules described for the verbal instructions. Again, the time intervals separating the instructions could be readjusted based on the participants' progress. The participants carried the smartphone with them. The smartphone, which was hanging around their neck and reached their waist, was protected inside a transparent box (so the participants could handle it freely while watching the instructions without interfering with the preset functioning arrangements).

Pools of 10 or 12 daily activities of practical relevance were available for the participants (e.g., preparing coffee, setting the table for lunch, setting the table for recess, reordering the bathroom, reordering the bedroom, preparing material for the occupational room, putting away kitchen items, and preparing a service tray). The activities, which could vary across participants, included 20–25 steps. **Table 2** lists the steps for one of those activities, that is, setting the table for recess. Six activities were scheduled for each session (i.e., a morning or afternoon period of 1.5–2 h). One or two daily sessions were typically available for the participants.

## Research Assistants and Data Recording

Four college-graduate, research assistants experienced in the use of technology-aided programs with persons with multiple disabilities were in charge of the sessions across the different phases of the study, arranged the technology (smartphones) with verbal or vibratory and pictorial reminders and instructions, provided prompting in case of need, and carried out data recording (see below). Research assistants were involved in preliminary preparation meetings on each aspect of their role. Moreover, they were in communication among themselves during the study so as to clarify questions and ensure consistency across them.

**TABLE 2 |** Setting the table for recess.

1	Take the fruit from the refrigerator
2	Bring the fruit to the table
3	Take the instant coffee from the cupboard
4	Bring the coffee to the table
5	Take a bottle of water
6	Put the bottle on the table next to the water boiler
7	Take two cups
8	Put the cups on the table
9	Take the pitcher from the cupboard
10	Put the pitcher on the table
11	Take ice cubes from the freezer
12	Put the ice cubes into the pitcher
13	Take a bottle of lemonade
14	Put the bottle on the table next to the pitcher
15	Take two glasses
16	Put the glasses on the table
17	Take a dish with knives and spoons
18	Put the dish on the table
19	Take the napkins from the cabinet
20	Put the napkins on the table
21	Tell the research assistant you are finished



Data recording concerned (a) the activities that the participants started correctly (i.e., at the appropriate time and independently) and (b) the activity steps they carried out correctly. A step was considered correct if the action required for it was performed independent of any prompting from the research assistant. Interrater agreement was checked in over 20% of the sessions (i.e., during which the research assistant and a reliability observer recorded the data) and was computed on groups of 10 activities for the first measure and single activities for the second measure. The percentages of agreement (which were determined by dividing the number of activities or steps with the same correct or incorrect score by the total number of activities or steps and multiplying by 100%) were in the 80–100 range, with means above 90 on both measures for all participants.

## Experimental Conditions and Data Analysis

The study was carried out according to a non-concurrent multiple baseline design across participants within each of the two groups of participants (38). Specifically, two baseline phases were implemented prior to the start of the intervention with the smartphone. Each of the two baseline phases included different numbers of sessions for the different participants of the groups. The number of baseline sessions for the single participants was preset. Yet, sessions would be added if the participants' percentages of activities started correctly or activity steps carried out correctly were above 30 and the value of the last session exceeded those of previous sessions (this condition never applied). The intervention sessions served to determine the effects of the smartphone on each of the two measures. The baseline and intervention percentages of activities started correctly and activity steps carried out correctly were summarized/graphed as means per session over blocks of sessions, and their difference was analyzed *via* the "percentage of nonoverlapping data" (PND) method (39, 40).

### Baseline I

Baseline I was to assess whether the participants started the activities correctly and included two to five sessions. The participant did not have any smartphone input and sat at a desk where conventional occupational material was available (e.g., jigsaws, family pictures, objects to be assembled, sorted or sanded, cardboards, and glue). Each session started with the participant receiving a list of the six activities scheduled for the session and the times at which the activities were due. The list consisted of (a) a paper sheet with small object replicas indicating the activities attached to the left column, and clock replicas with the times for the activities attached to the right column (Group 1) and (b) a paper sheet with the pictorial images of the activities on the left column and of clocks with the times for the activities on the right column (Group 2). A research assistant read those activities and times (Group 1) or pointed to those activities and times (Group 2) and ensured that the participant had the sheet in front of him or her.

### Baseline II

Baseline II was to assess the participants' level of correct activity performance (i.e., the number of activity steps that they performed correctly) and included three to five sessions. During each session,

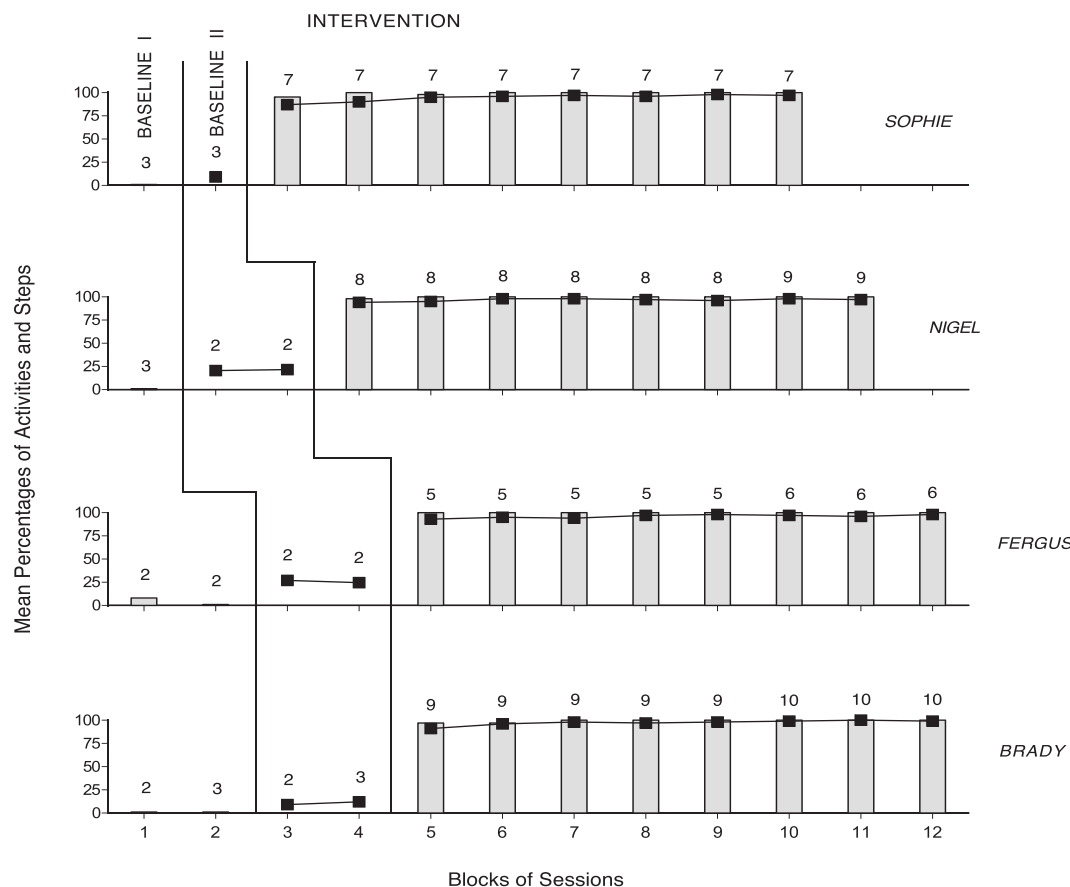
the research assistant asked the participant to carry out six activities (i.e., one at a time). The research assistant provided verbal or physical prompting (encouragement) if the participant did not make any progress for about 1 min and corrected a step error if that precluded the adequate continuation of the activity. An activity would be interrupted after three consecutive prompting occasions, if the participant indicated that he or she did not know how to proceed. The steps not performed were scored incorrect. The participant would receive social approval for his or her efforts after each activity.

### Intervention

The intervention phase was to assess the effects of the smartphone on the participants' independent and timely start of the activities and correct performance of the activity steps and included 43–75 sessions. The participants had the smartphone with verbal instructions (Group 1) or pictorial instructions (Group 2), which worked as described in the *Setting, Technology, and Activities* section. Nigel and Brady (Group 1) received the verbal instruction *via* a wireless Bluetooth earpiece. Prior to the start of the intervention phase, the participants received five to seven practice sessions. During every practice session, the research assistant provided the participant with the verbal or physical prompting needed for an appropriate use of the technology (i.e., for responding to the smartphone's reminders and following the smartphone's activity instructions). During the regular intervention sessions that followed, the research assistant intervened with prompting if the participant did not respond to an activity reminder within about 30 s or made step errors during the performance of an activity that would interfere with its accurate completion. The participants received social approval after the performance of the activities (i.e., the last step instruction for each activity was to report to the research assistant; see **Table 2**) and at the end of the session.

## RESULTS

The panels of **Figures 1** and **2** summarize the baseline and intervention data of the four members of Group 1 and the four members of Group 2, respectively. During Baseline I, the participants' mean percentages of activities started correctly were 0 or close to 0. During Baseline II, the participants' mean percentages of activity steps carried out correctly were below 30. During the intervention phase (i.e., following the five to seven practice sessions that are not reported in the figures), the participants' mean percentages of activities started correctly per session were (nearly) 100. That is, the participants responded to all smartphone-regulated activity reminders or missed only very few of them (i.e., five or less in total). The mean percentages of correct activity steps per session (i.e., across all the activities available within the session) increased to near or above 95 for all participants, with no apparent difference between Group 1 and Group 2. Comparisons of the intervention with the Baseline I and Baseline II session data on correctly started activities and correct activity steps, according to the PND method, showed indices of 1.0 for all participants (i.e., all their intervention data points on each measure exceeded their baseline levels).



**FIGURE 1 |** The four panels summarize the baseline and intervention data of the four members of Group 1 (i.e., Sophie, Nigel, Fergus, and Brady). The bars and black squares represent mean percentages of activities started correctly and mean percentages of activity steps carried out correctly per session, respectively, over blocks of sessions. The number of sessions included in the blocks is indicated by the numerals above the bars, squares, or bar-square combinations.

## DISCUSSION

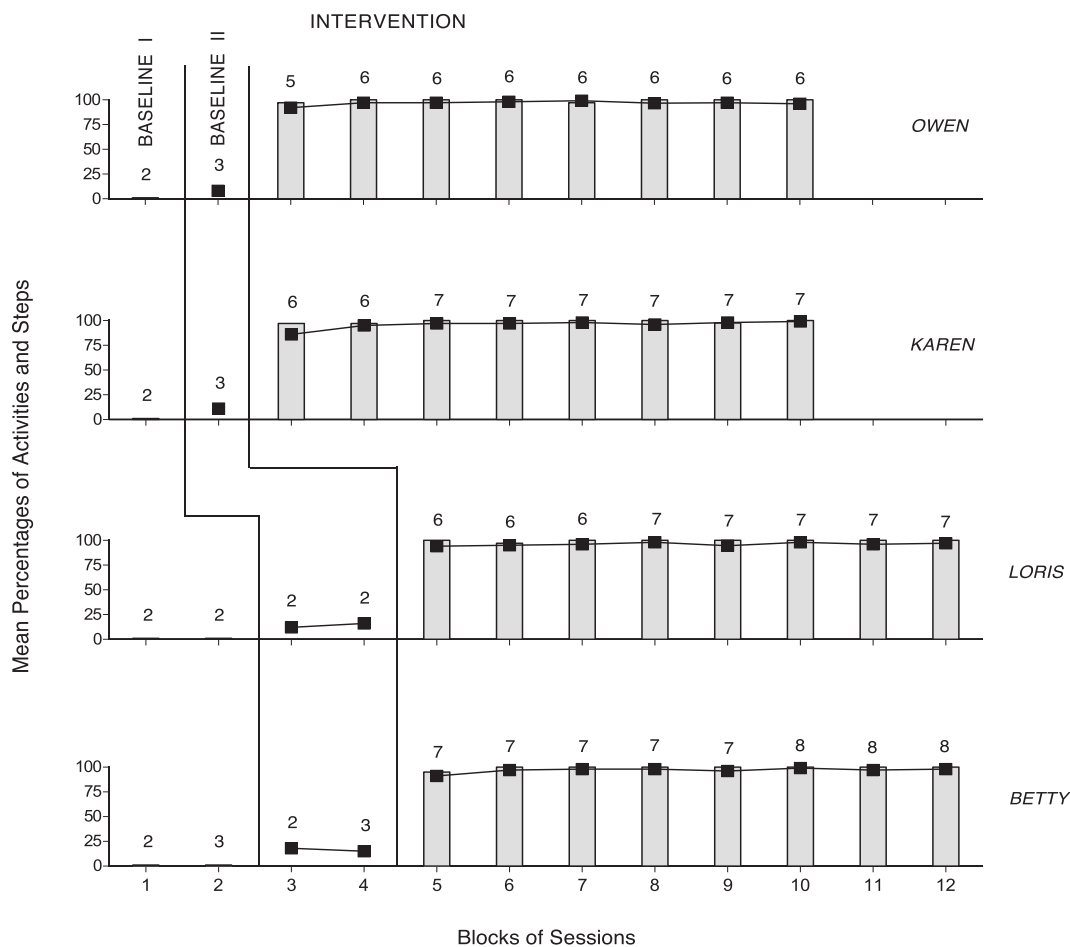
The results of this study indicate that the smartphone intervention was effective in helping both groups of participants to correctly start and carry out the activities scheduled during the sessions. Indeed, all participants seemed to respond successfully to the reminders and activity instructions presented by the smartphone, thus showing clear performance improvement compared to the baseline periods. Moreover, the participants seemed to enjoy the sessions and their activity management (i.e., start and execution) with the support of the smartphone, as indicated by a number of informal reports, which underlined their eagerness to be involved in the sessions and their satisfaction with their activity engagement. In light of the above, a number of considerations may be in order.

First, these data confirm preliminary, pilot findings and show that persons with mild and moderate intellectual disabilities and sensory impairments can manage the independent and timely start and correct performance of relevant activities through the support of technology (32). Although caution is needed in drawing general conclusions given the relatively small number of participants involved in this study, one could still argue that the

data reported here add considerably to the evidence previously available (33, 34). Indeed, these data might be taken as a new, encouraging reference for education and rehabilitation contexts in charge of people like the participants of this study.

Second, the smartphone intervention allowed one to arrange verbal stimuli or combinations of vibratory and visual stimuli as activity reminders. Those reminders, which were deemed suitable for individuals with blindness and hearing impairment, respectively, proved highly effective with the two groups of participants involved in this study. Similarly, the smartphone could be fitted with audio or visual files and thus serve as an effective instruction tool for all participants irrespective of their type of sensory impairment. This versatility of the technology, and its accessibility (commercial availability) and affordability can be considered great practical advantages that may enable education and rehabilitation contexts to successfully set up intervention programs for persons with different requirements.

Third, in addition to being flexible and affordable, the smartphone intervention is also practical to use for participants and staff. Participants who rely on verbal reminders and verbal instructions may not need to carry the smartphone with them. It is sufficient that they wear a wireless Bluetooth earpiece during



**FIGURE 2 |** The four panels summarize the baseline and intervention data of the four members of Group 2 (i.e., Owen, Karen, Loris, and Betty). The data are plotted as in **Figure 1**.

the sessions (as it was done by two participants in this study). Participants with hearing impairment need to carry the smartphone with them. Carrying it enables them to readily perceive the reminders and see the visual instructions. The smartphone can be hanging around their neck or can be attached to their belt, in line with their preference. Staff can easily modify audio or video files in terms of content or time intervals and thus can make intervention adjustments in relation to participants' general skills and progress.

Fourth, successful performance with the smartphone intervention probably increases the participants' levels of self-confidence and satisfaction (41, 42). These aspects may contribute (together with the social approval following the performance of the activities) to ensure maintenance of positive activity engagement (43, 44). The participants' new performance skills might also be seen as instrumental in facilitating a higher level of approval and appreciation from their education/rehabilitation and social context with potentially beneficial consequences for their mood and overall quality of life (45–47). While all these statements appear quite reasonable in light of previous literature and informal observations, research still needs to address them directly to determine their accuracy (42, 45).

Fifth, a main limitation of the study is the relatively small number of participants involved. Obviously, new studies with additional participants are required to verify the suitability of the smartphone intervention, the reliability of the findings, as well as the maintenance and generalization of the activity skills (33, 34). A second limitation is the lack of a social validation assessment aimed at determining the opinion of staff personnel about the smartphone's impact and usability within everyday contexts (48, 49). Such an opinion might significantly add to the data and partly predict the future adoption of smartphones within those contexts (50, 51). Another apparent limitation is the lack of reliability (procedural fidelity) checks on the research assistants' performance. In this study, research assistants' experience and preliminary preparation were considered the best guarantee of procedural fidelity. Notwithstanding the directness of this view, the use of reliability checks remains a basic methodological requirement (52).

In conclusion, the results indicate that the smartphone intervention was suitable to support correct start and accurate performance of daily activities by persons with intellectual and sensory disabilities. Before general statements can be made about the usability of smartphones, new research would need to address the main limitations of the present study and determine

the dependability of the results reported. New research efforts may also focus on (a) gathering formal evidence about participants' satisfaction with the intervention conditions and their performance (i.e., by recording their preferences or indices of happiness) (53, 54) and (b) determining the overall acceptability of smartphones within everyday contexts (51).

## ETHICS STATEMENT

Appropriate institutional board approval and written informed consent were obtained for the study. All procedures performed

were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

## AUTHOR CONTRIBUTIONS

GL, NS, MO, and JS were responsible for setting up the study, acquiring/analyzing the data, and writing/editing the manuscript. GA, CZ, and VC contributed in acquiring and analyzing the data and editing the manuscript.

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# Parental Intention to Support the Use of Computerized Cognitive Training for Children With Genetic Neurodevelopmental Disorders

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Children with genetic neurodevelopmental disorders (NDDs) such as Down syndrome, Prader-Willi syndrome, and Fragile X syndrome may show a range of cognitive impairments, including impairments in executive functions (EF). EF are related to general intelligence, academic achievement, and literacy and mathematical skills. EF deficits are linked to a variety of clinically and socially important behaviors. Therefore, methods for improving EF in children with NDDs could be beneficial. One method for improving EF is through cognitive training. Research on commercial brain training programmes and video games suggests that EF can be improved through training, both in healthy adults and in children with NDDs. Computerized cognitive training (CCT) therefore represents a potentially viable intervention for children with NDDs. For training to be effective, it is important that an appropriate regimen is followed. Since children are likely to engage with training at home, the intentions of their parents to support them are therefore important. However, no research has investigated the attitudes of parents of children with NDDs to CCT. To address this, we developed a questionnaire based on the theory of planned behavior, which states that a person's intention to engage in a behavior is predicted by (1) their attitude toward the behavior, (2) their perception of subjective norms regarding the behavior (i.e., perceived social pressure), and (3) their perceived control over the behavior. The questionnaire was completed by parents of children with NDDs; 58 unique responses were retained for analyses. Parents reported low levels of knowledge of CCTs, and low levels of experience with CCTs (both their own experience and their child's experience). However, our results also show that parents of children with NDDs have positive beliefs about the potential of CCT to benefit their children and intend to support the use of CCT by their children. Linear modeling showed that, of the three constructs of the theory of planned behavior, only attitudes significantly predicted intention. Finally, parents' beliefs about the benefits of CCT correlated positively with positive attitudes toward such training. We also found limited evidence that parents of boys have more positive attitudes regarding CCT than parents of girls.

**Keywords:** intellectual disability, cognitive training, developmental disabilities, theory of planned behavior, assistive technology



## INTRODUCTION

During early life, the typical child's brain develops rapidly. In response to both genes and the environment, neural connections develop that will play a role in every aspect of life: sensing, reasoning, language, motor skills, personality, and memory. Of particular importance is the development of executive functions, such as working memory, inhibition, and task switching (1, 2). Executive functions are high-level cognitive processes which control how and when lower-level cognitive processes operate, such as when we are multitasking or regulating our behavior (e.g., forcing ourselves to eat healthily when we would rather eat cake). Executive functions are essential for success in almost every aspect of our lives; they are related to school readiness (3), the development of academic skills (4), social-emotional competence (5), and psychological well-being (6). Deficits in executive function are associated with clinically significant behaviors such as externalizing behavior (7) and temper outbursts (8). In addition, executive functions are highly adversely affected by stress, sleep deprivation, and poor physical health (9).

Given their importance for success in so many aspects of life, the prospect of improving executive functions through training has recently received a great deal of attention. While far from conclusive, evidence from some randomized controlled trials shows the potential of a variety of training programs (9). Note that executive function training need not necessarily be provided via computer software. For example, Lakes and Hoyt (10) found that 3 months of Tae Kwon Do training improved self-regulation skills in children. However, a large proportion of research in this area has focused on a software-based approach. In such computerized cognitive training (CCT), trainees use a computer or touchscreen device to complete tasks which are designed to engage the target cognitive skills. For example, trainees may be required to categorize objects according to their color, then be asked to switch to categorizing the same objects in terms of their shape (11). This would—it is claimed—improve the trainees' ability to switch between different cognitive tasks, which is an example of an executive function ability (1). There may be several reasons why most research on cognitive training programmes has focused on a software-based approach. For example, the ubiquity of smartphones and other mobile devices, which makes computerized cognitive training more accessible and affordable by being distributed via apps or mobile games (12). In addition, companies like Cogmed<sup>1</sup> and Lumos Labs<sup>2</sup> are already delivering CCT to large numbers of paying customers (13), despite the fact that there is still no scientific consensus on their effectiveness (14, 15). This means that understanding if and how CCT is effective is research which can benefit a large number of consumers.

Children with neurodevelopmental disorders (NDDs) stand to benefit greatly from the development of effective CCT. There is evidence that children whose executive functioning is poorest show greatest improvement after training (9), and many NDDs are associated with deficits in executive functioning (16). In addition, we know that children with NDDs are at least as

capable of, and interested in, using mobile apps and games as typically developing children (17, 18). Finally, research on specific neurodevelopmental disorders has established clear links between atypical neural development and real-world problems faced by children with NDDs and their families, *via deficits in executive function*. For example, children with the NDD Prader-Willi syndrome often display challenging behaviors (such as temper outbursts and repetitive questioning) following changes to their plans or routines (19). Empirical research has established that this phenomenon is partly caused by an impaired ability to switch between tasks (i.e., impaired executive functioning), which correlates with atypical neural activation during task switching in children with the syndrome (20, 21). More generally, this research on Prader-Willi syndrome demonstrates an approach to modeling the relationship between specific cognitive deficits and behavioral profiles in NDDs in a way which can aid the development of targeted interventions (8, 22), including the development of targeted CCT programs (11). There is therefore compelling evidence that, if CCT of executive functions can be effective, this would be especially beneficial to children with NDDs (16).

However, there are still many issues to be addressed to understand if and how CCT can be effective, both for the general population and for children with NDDs. Here we focus on a specific issue which has so far received limited attention. It is obvious that, for CCT to be effective, participants must actually take part in the training; a CCT app cannot benefit the child who does not download and use it. Yet, for a variety of reasons, ensuring engagement with CCT may not be straightforward. Firstly, during some trials of CCT programmes, researchers note that it can be difficult for trainees to adhere to the training over the required period, and therefore they feel they need to incorporate a parent or other facilitator into the process to ensure adherence (23, 24). In fact, one widely-used commercial program assigns users a coach who monitors their engagement with the software and assists with ensuring motivation and training adherence throughout.<sup>3</sup> Secondly, beliefs that apps and games may have negative implications for children's health, development, or safety could impact on parents' willingness to allow their children to use CCTs (25, 26). In both these cases, we can see that parents will have a role to play in supporting the use of CCT by their children with NDDs. As such, it is important to understand the factors which may influence if and how parents of children with NDDs would support the use of CCT by their children.

The theory of planned behavior (27) may provide a systematic way to understand these behavioral intentions. The theory states that an individual's intention to perform (or refrain from performing) a behavior is predicted by (1) their attitudes toward the behavior, (2) their perception of social norms regarding the behavior, and (3) their perceived control over the behavior (27, 28). The theory provides a formal framework for the intuitive idea that the extent to which we engage in an activity (such as playing video games) is linked to our attitudes (e.g., playing video games is good for you), our perceptions of what others think

<sup>1</sup><https://www.cogmed.com/>

<sup>2</sup><https://lumosity.com/>

<sup>3</sup><https://www.cogmed.com/how-is-cogmed-different>

(e.g., other people think it's okay to play video games), and our perceived ability to control the activity (e.g., I think I can stop myself from playing games too often). The theory has been used in a broad range of contexts and is widely regarded to provide a robust model of how an individual's behavioral intentions are determined (29). Importantly, the theory of planned behavior has also been used to successfully examine the behavioral intentions of parents and carers of people with cognitive disabilities (18, 30). Finke et al. (18) investigated the intention of parents of children with the NDD autism spectrum disorder to support video game play by their children. The authors found that parents' attitudes toward video games most strongly predicted their intention to support game play. They also showed that these attitudes were significantly positively correlated with positive behavioral beliefs regarding the effects of gameplay on their children's development, including cognitive development. While these results may have some applicability to the issue of parental intention to support CCT by children with NDD, some important caveats should be noted. Firstly, the focus of this previous study is solely on video games. While it is highly plausible that playing such games may have positive effects on cognitive processes (31), our focus is on the beliefs and intentions of parents toward software that is explicitly marketed and distributed with the intention of providing cognitive training. Most popular video games are not marketed and distributed in this way. Secondly, and most importantly, this previous study is focused only on parents of children with autism, and the cognitive profile of autism is complex: there is evidence that many individuals with autism have average intellectual ability (32), and that executive function deficits, although they may occur, are not universal in autism (32, 33). In addition, by focusing on autism, one would expect (and this was the case) more responses from parents of boys than girls, as autism is more prevalent in males (32).

In the present study we measured the attitudes, knowledge, and experience of parents of children with NDDs associated with intellectual disability regarding CCT. Our primary aim was to investigate if the constructs of the theory of planned behavior predicted parental intention to support the use of CCT. In addition, we aimed to investigate potential correlations between attitudes, knowledge, or experience regarding CCT, and correlations between the constructs of the theory of planned behavior. Our final aim was to investigate if there are differences in these attitudes, knowledge, and experience between parents of children with different identified gender or a different diagnosis of NDD.

## MATERIALS AND METHODS

### Questionnaire

An online questionnaire was developed for this study (see **Supplemental Material** for the full questionnaire). Introductory pages explained the research to respondents, making clear that their responses would be recorded anonymously and that they were not obliged to take part. This introductory section also included a brief explanation of CCT, including images showing examples of a variety of CCT programs. The images used were all obtained from the websites of CCTs; only images designated

as freely-available for press use were used in the questionnaire. As in previous similar research investigating parental attitudes to technology use (18), the questionnaire incorporated items designed to determine respondents' *behavioral intention* to support CCT, *attitudes* toward CCT, their perceptions of *behavioral control* over the use of CCT and their perceptions of *social norms* regarding CCT (i.e., the constructs of the theory of planned behavior). The questionnaire also incorporated items related to behavioral beliefs about how CCT may affect their child's cognitive skills (e.g., "I believe that cognitive training programmes would help my child develop his/her problem-solving skills"), items relating to parents' knowledge of CCT, their level of experience (and their child's level of experience) with CCT, and demographic questions, including the specific NDD the respondent's child had been diagnosed with, the age of diagnosis, and their child's age and gender. Apart from demographic questions, all items were 7-point Likert-style ratings (see **Supplemental Material** for the labels used for each item).

### Participants and Recruitment

The questionnaire was completed by parents of children with NDDs. A total of 62 responses were received. We removed 3 responses which we suspected to be duplicates. We suspected they were duplicates because each response was identical to another response and submitted very close in time to the other response. We also removed 1 response as it was unclear if the child had in fact been diagnosed with a genetic syndrome associated with ID. Participants were recruited by firstly contacting organizations that support children with NDDs. Once an organization agreed to assist with recruitment, they were asked to circulate a link to the questionnaire via email, social media, and organizations' own websites. All data was collected anonymously. All recruitment and data collection procedures were approved by the Human Research Ethics Committee at University College Dublin.

### Data Preparation

Data were analyzed using IBM SPSS v. 24. To determine internal consistency of the theory of planned behavior constructs, we calculated Cronbach's alpha for each construct. A value of  $\alpha > 0.70$  shows an acceptable level of internal consistency (34). Cronbach's Alpha was acceptable for attitude ( $\alpha = 0.933$ ), subjective norms ( $\alpha = 0.936$ ), and perceived behavioral control ( $\alpha = 0.736$ ). Cronbach's Alpha was also acceptable for the additional behavioral beliefs construct ( $\alpha = 0.963$ ). For each individual parent's responses, we then calculated the mean score for each of the constructs and used these means in our analyses.

## RESULTS

The final sample consisted of 58 participants (34 female; mean age 9.38 years, std. dev. 5.94 years). The NDDs represented among the sample are shown in **Table 1**. Means and standard deviations for the main constructs/items are shown in **Table 2**: overall, parents intend to support the use of CCT by their children; their behavioral beliefs about CCT are positive, as

**TABLE 1 |** Genetic neurodevelopmental disorders (NDDs) with which respondents' children had been diagnosed.

NDD	n (%)
Down syndrome	16 (27.59)
Williams syndrome	14 (24.14)
22q11.2 deletion syndrome	14 (24.14)
Prader-Willi syndrome	8 (13.79)
Fragile X syndrome	3 (5.17)
Other	3 (5.17)

**TABLE 2 |** Means and standard deviations for the main items/constructs.

Item/construct	Mean	Standard deviation
Parents' knowledge of CCT	2.66	1.57
Parents' experience with CCT	1.91	1.34
Children's experience with CCT	1.90	1.63
Parents' behavioral beliefs regarding CCT	5.57	1.25
Parents' perceived social norms regarding CCT	5.18	1.40
Parents' perceived behavioral control of the use of CCT	5.60	1.30
Parents' attitudes toward CCT	5.81	0.99
Parents' intention to support the use of CCT	6.17	1.05

CCT, Computerized cognitive training.

are their attitudes toward CCT; parents perceive that social norms regarding CCT are positive; they also believe that they could control how often their child uses CCT. However, parents reported that both they and their child have limited experience with CCT. Parents also reported that they have low levels of knowledge about CCT.

To determine if parents of children with different genetic syndromes offered different responses, we ran Kruskal-Wallis *H*-tests. We used 5 groups: Prader-Willi syndrome, Down syndrome, 22q11.2 deletion syndrome, Williams syndrome, and Other. We found no significant differences between these groups in any of the constructs of the theory of planned behavior, nor in terms of parents' knowledge of CCT, parents' experience of CCT, or children's experience of CCT.

Next, we ran Mann-Whitney *U*-tests to determine if there were differences in terms of child's gender. Only the attitude construct was statistically significantly different; in this case, the distributions were judged to be similar (based on visual inspection of a population pyramid), and median attitudes scores were higher in parents of males (6.33) than females (5.66),  $U = 571$ ,  $z = 2.584$ ,  $p = 0.01$ .

Automatic linear modeling in SPSS version 24 was used to determine the direct predictors of parents' intention to support the use of CCT, based on the theory of planned behavior. Automatic data preparation was disabled, meaning that all 58 cases were included in the model and no variables were transformed. The three constructs of the theory of planned behavior (attitudes, perceived social norms, and perceived control) were included in the model. The variable selection

**TABLE 3 |** Model summary.

Factors	Coefficient	P-value	95% confidence interval		Importance
			Lower	Upper	
Intercept	1.282	0.026	0.161	2.402	
Attitudes	0.718	<0.001	0.508	0.928	0.947

Attitudes toward computerized cognitive training (CCT) predict parental intention to support the use of CCT with their children.

method was forward stepwise regression. The model was significant [adjusted  $R^2 = 0.575$ ,  $F_{(2,55)} = 39.585$ ,  $p < 0.001$ ]. Only attitudes significantly predicted intention to support CCT, as shown in the model summary in **Table 3**.

Finally, we considered correlations between variables using Spearman's Rank-Order correlation. We found a strong positive correlation between behavioral beliefs and attitudes,  $r_{s(56)} = 0.715$ ,  $p < 0.001$ . We also considered if behavioral beliefs or attitudes correlated with any of the following three variables: parents' knowledge of CCT; parents' experience of CCT; children's experience of CCT. None of these correlations were significant.

## DISCUSSION

Even though cognitive training receives much attention in the media, and many such apps are widely available both online and via mobile app stores, the parents in our sample reported low knowledge of CCT. Additionally, both parents and children had limited experience with CCT. One possible explanation for this finding is that CCT programmes are typically not marketed toward children with genetic NDDs. It may be that parents of children with these syndromes—i.e., children who stand to benefit greatly from CCTs—are simply not very well informed about the applicability of such software as interventions for their children. This, in turn, may be because most current research and development on CCT is not in fact focused on children with genetic NDDs such as those exhibited in our sample. For example, Lumosity, which is one of the most widely used commercial CCT programmes (12) is only intended to be used by adults<sup>4</sup>, while research focusing on the application of CCT as executive function training for children with disabilities primarily focuses on attention deficit hyperactivity disorder (16).

However, despite limited knowledge of, and experience with, CCT, parents do believe that such training could potentially benefit their children, across a broad range of areas, including social skills, motor skills, cognitive skills, and quality of life. In line with previous research, we found that the theory of planned behavior can be used to model how these positive beliefs influence parents' intention to support the use of CCT: as expected, we found that attitudes were the strongest predictor of behavioral intention. In fact, in our model, the attitudes construct was the only significant predictor of intention. Furthermore,

<sup>4</sup><https://help.lumosity.com/hc/en-us/articles/202173060-Is-Lumosity-designed-for-children->

these positive attitudes are strongly correlated with parents' positive beliefs about the effects of CCT on the range of skills mentioned above. As such, our study shows that parents' intention to support the use of CCT is based primarily on positive beliefs about what CCT can achieve and positive attitudes about CCT in general.

Interestingly, our research suggests the possibility that parents' beliefs about the benefits of CCT are not necessarily based on practical experience or awareness of such programs, since knowledge of and experience with CCT were low, while beliefs and attitudes regarding CCT were high. We were unable to establish significant correlations between knowledge or experience and the variables related to planned behavior. Therefore, while it is encouraging to know that the parents in our sample believe CCT to be potentially beneficial, a crucial open question remains about what these beliefs are in turn based on.

Unexpectedly, we found limited evidence that parents of boys had significantly more positive attitudes regarding CCT than parents of girls. It would be unwise to draw conclusions based on this limited finding in a small sample. However, if parental attitudes regarding CCT were different for parents of boys and girls, this would be an important issue, as research suggests that parents' (35) and teachers' (36) gender stereotypes regarding children's abilities can negatively impact differences in attitudes and abilities of children to their education.

Our study also adds to previous research by providing evidence that the theory of planned behavior may be used to model how parents of children with NDDs *other* than autism make decisions about software use. This is important because children with NDDs linked to the genetic syndromes found in our sample will undoubtedly have different cognitive profiles to children with autism.

## Limitations

It is important to be cautious when drawing conclusions from this study due to some limitations. As our questionnaire was delivered online, our results are therefore subject to the inherent limitations of this approach. Specifically, it is recognized that technical problems can affect online questionnaires (37). It is possible that such technical problems led to the possible duplicate responses which were removed, as explained in section Participants and Recruitment. Additionally, our sample size is small, and so we should be careful about generalizing our findings. However, it is worth noting that the syndromes featured in our sample are all considered to be rare [e.g., Whittington et al. (38) estimated that the population prevalence of Prader-Willi syndrome could be as low as 1:52,000], and, as far as we are aware, our study is the first to investigate the attitudes of parents of children with NDDs to CCT. As such, it provides an important starting point for future research in this area. The final limitation is more complex. As our findings show, parents had limited knowledge of CCT. As we expected this, we prefaced our questionnaire with a brief description of CCT, including pictures illustrating specific programs. While we aimed to ensure that (1) we did not encourage parents to answer the questionnaire with a specific CCT program in mind, and (2) we did not predispose parents to have positive or negative attitudes to CCT, it is nevertheless possible that parents were influenced

to some extent by this description. However, given the limited knowledge parents have of CCT, it is difficult to see how we could have avoided providing some description. This limitation could be partly addressed by conducting a similar study with parents of children with NDDs who have significant experience of CCT; such parents would presumably not require a pre-questionnaire explanation, and so it may be that the issue of influencing parents' beliefs in these introductory explanations could be avoided.

## Future Work

Perhaps the clearest avenue for future work arising from our study is the open question of what exactly parents' positive beliefs about CCT are based on. It is conceivable, for example, that parents may be influenced by the claims of developers of commercialized CCT about the effectiveness of their products. This would be a concern, as Lumos Labs, a major developer of CCT, has previously been fined a substantial amount by the Federal Trade Commission for deceptive advertising<sup>5</sup>. In this context, it would also be interesting to carry out further research on families for which knowledge of, and experience with, CCT is higher, to determine if increased awareness of CCT impacts parental attitudes, beliefs, and intentions. It is important that parents of children with NDDs can make informed decisions about any intervention they choose to use for their child. As such, increasing the availability of clear, simple information about the effectiveness (or otherwise) of CCT, and ensuring that developers of commercial CCTs do not mislead parents of children with NDDs should be recognized as an important issue to be addressed alongside the development of potentially more effective CCT programs in the future.

## DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this manuscript will be made available by the authors, without undue reservation, to any qualified researcher.

## AUTHOR CONTRIBUTIONS

NR led the study, conceived the study idea and design, developed the questionnaire, carried out statistical analyses, interpreted results, and prepared the final manuscript. JN contributed material for the literature review, helped with recruitment, contributed to the development of the methods section and reviewed the manuscript. YP contributed material for the literature review, processed the experimental data, carried out some of the statistical analysis, aided in interpreting the results and reviewed the manuscript. BZ contributed to questionnaire construction, ethical approval, and the literature review.

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<sup>5</sup><https://www.ftc.gov/news-events/press-releases/2016/01/lumosity-pay-2-million-settle-ftc-deceptive-advertising-charges/>



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# Interactive Block Games for Assessing Children's Cognitive Skills: Design and Preliminary Evaluation

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**Background:** This paper presents design and results from preliminary evaluation of Tangible Geometric Games (TAG-Games) for cognitive assessment in young children. The TAG-Games technology employs a set of sensor-integrated cube blocks, called SIG-Blocks, and graphical user interfaces for test administration and real-time performance monitoring. TAG-Games were administered to children from 4 to 8 years of age for evaluating preliminary efficacy of this new technology-based approach.

**Methods:** Five different sets of SIG-Blocks comprised of geometric shapes, segmented human faces, segmented animal faces, emoticons, and colors, were used for three types of TAG-Games, including Assembly, Shape Matching, and Sequence Memory. Computational task difficulty measures were defined for each game and used to generate items with varying difficulty. For preliminary evaluation, TAG-Games were tested on 40 children. To explore the clinical utility of the information assessed by TAG-Games, three subtests of the age-appropriate Wechsler tests (i.e., Block Design, Matrix Reasoning, and Picture Concept) were also administered.

**Results:** Internal consistency of TAG-Games was evaluated by the split-half reliability test. Weak to moderate correlations between Assembly and Block Design, Shape Matching and Matrix Reasoning, and Sequence Memory and Picture Concept were found. The computational measure of task complexity for each TAG-Game showed a significant correlation with participants' performance. In addition, age-correlations on TAG-Game scores were found, implying its potential use for assessing children's cognitive skills autonomously.

**Keywords:** block games, cognitive assessment, block design test, technology-based assessment, child development

## 1. INTRODUCTION

The development of cognitive skills begins at birth and continues throughout adulthood (1, 2). Optimizing development and identifying cognitive issues that place children at risk for developmental delays has been the mission of pediatricians, psychologists, and educators alike (3, 4). More recently, politicians have joined the movement mandating the use of standardized

cognitive assessment tests at frequent intervals throughout a student's academic career. A plethora of tests are available to be used for periodic assessment and their reliability and validity are well established. However, the standardized nature often requires an unvarying set of problems, presented in a prescribed sequence, and a trained specialist to administer the test. Among the earliest and most frequently used assessment instruments, the Wechsler series (5, 6) is considered to be the "gold standard" (7). The Wechsler series has two age standardized variants, exclusively designed for children: the Wechsler Preschool and Primary Scale of Intelligence – 4th Edition (WPPSI-IV) for ages 2:6–7:7 and Wechsler Intelligence Scale for Children-5th Edition (WISC-V) for ages 6:0–16:11. To minimize language bias, Raven's Progressive Matrices (RPM) are sometimes used in place of the Wechsler tests (8, 9). RPM involves a series of perceptual analytic reasoning problems presented in a matrix format, which do not rely on language usage and thus appear to reduce cultural bias (10, 11). Pediatricians and psychologists often use these standardized tests in conjunction with parental interviews and clinical observations to pinpoint a child's strengths and weaknesses and thereby develop an appropriate developmental/educational intervention plan (12, 13).

While cognition, attention, memory, and language are strong components of traditional intellectual assessments, motor skills have played less of a role. Nonetheless, motor control and hand-eye coordination skills are found to be closely linked with child development as well as general cognitive and learning abilities (14–17). Only a few instruments target these skills directly. The two such examples are Block Design (BD) in the Wechsler test series and the Beery Visual-Motor Integration (VMI) test. BD uses a set of red-and-white blocks where the examinee must copy an abstract image by assembling these blocks. This test, designed to measure spatial visualization and motor skills, is considered the best single predictor of Performance IQ (18–20). VMI measures both cognitive processing and motor response by asking the individual to trace geometric drawings using a pencil (21).

The reliability and validity of standardized measures, such as the Wechsler series, RPM, and the VMI, are well established; however, the challenges associated with obtaining accurate, objective, and timely assessment of cognitive skills are still formidable. The most pressing challenges include the costs associated with testing (22), limited availability of appropriately trained clinicians (23), and difficulties in addressing individual differences in age and cognitive status (24). Cognitive tests require trained professionals to administer and manually record the performance of the examinees in terms of speed and accuracy. Aside from high operation costs, this process is also susceptible to human errors. For children, administration of standardized tests become more challenging because of language demands, attentional fluctuations, and lack of comfort (25).

In an attempt to address the above challenges, researchers have been investigating computerized approaches for cognitive assessment in children. Many traditional forms of paper-pencil tests have been converted into computerized forms. For example, Pearson's Q-interactive allows iPad-mediated administration

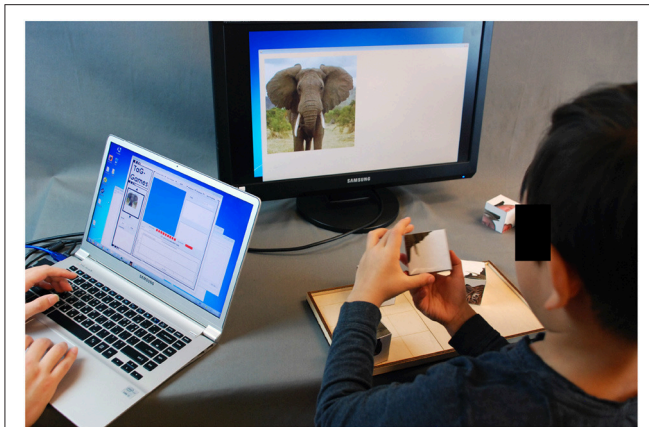
of cognitive tests, including WISC-V and WPPSI-IV (26). While Q-interactive reduces clinician's workload and increases engagement in examinees, the level of automation is still limited and requires a professional for administration (26, 27). Computerized psychomotor tests, including finger tapping test, simple reaction time, choice reaction time, choice discrimination test, digit picture substitution test, and card sorting test, were employed for cognitive assessment in children with learning disabilities (28). A recent review reported that gamified cognitive tests, using a computer or other technical tools, were highly engaging and reduced anxiety and thus improved motivation (29). Despite the potential, most of computer-based methods have been focused on automating scoring, rather than automating administration (30). In addition, there is no clinically valid computerized tool that can fully automate tasks, involving physical object manipulation, such as the Wechsler's BD subtest. There exist some studies on technology-assisted approaches, but the technical functionality in these works was quite primitive, such as a tabletop interface with a stereo camera providing limited assessment data on the user performance (31).

In this paper, a technology-based approach using sensor-integrated geometric blocks (SIG-Blocks) was employed for cognitive assessment in young children (See **Figure 1**) (32–34). The computerized tests using SIG-Blocks are called TAG-Games. Building on our previous work involving 98 university students (32), this technology-based instrument has been redesigned for the target age group and tested on 40 participants at the ages of 4–8. The system employs a set of SIG-Blocks and an interfacing computing device, such as a laptop computer with two screens (or two computers) for TAG-Game administration. One screen is used for real-time administration and monitoring of the process and the other for displaying test items to the examinee. Three sets of TAG-Games, including Assembly (TAG-Game<sup>A</sup>), Shape-Matching (TAG-Game<sup>S</sup>), and Memory (TAG-Game<sup>M</sup>), were developed for preliminary reliability and validity evaluation. While requiring further evaluation studies building on the preliminary, yet important, outcomes presented in this paper, this system is equipped and designed for automating both administration and scoring.

## 2. MATERIALS AND METHODS

### 2.1. Technology Overview

TAG-Games are an integrated tangible game technology for automated test administration, visualization, and data collection (**Figure 1**). The games are designed to measure cognitive problem solving, working memory, and spatial reasoning skills coupled with motor responses through three sets of games, i.e., TAG-Game<sup>A</sup>, TAG-Game<sup>S</sup>, and TAG-Game<sup>M</sup>, using SIG-Blocks. In addition to overall accuracy and speed typically measured in existing cognitive tests, this technology-based system also assesses step-by-step procedural accuracy and speed information throughout the problem solving process. The user interface allows the administrator to monitor the examinee's real-time performance locally or remotely through a wireless network.



**FIGURE 1 |** Study setting: The TAG-Games technology consists of a set of SIG-Blocks, an interfacing computing device (e.g., a laptop) for administration and monitoring, and an extra screen for displaying test items. This picture shows a child using four SIG-Blocks with segmented animal faces to match the displayed image. Parent consent was obtained for publication of this image.

The entire technology will be available at a relatively low cost, with the estimated commercial price of the TAG-Games package to be less than \$1,000. This paper presents design and preliminary evaluation of TAG-Games for cognitive assessment in young children. TAG-Games were previously examined for the technical functionality and preliminary utility in assessing cognitive skills of adults. In keeping the overall design of TAG-Games similar to the adult version, we modified the TAG-Games tests carefully aiming to be appropriate for the target age group of 4–8. Specifically, the following modifications were made: (1) SIG-Blocks covered with segmented human and animal faces and simple emoticons were added and used in the new TAG-Games; (2) Easier items were added and harder ones were removed; and (3) Discontinuation rule was applied by stopping the test after the child fails to answer correctly on two consecutive items at the same difficulty level. More details about the hardware, game design, and computational complexity measures are followed.

### 2.1.1. Hardware Design of SIG-Blocks (32, 34)

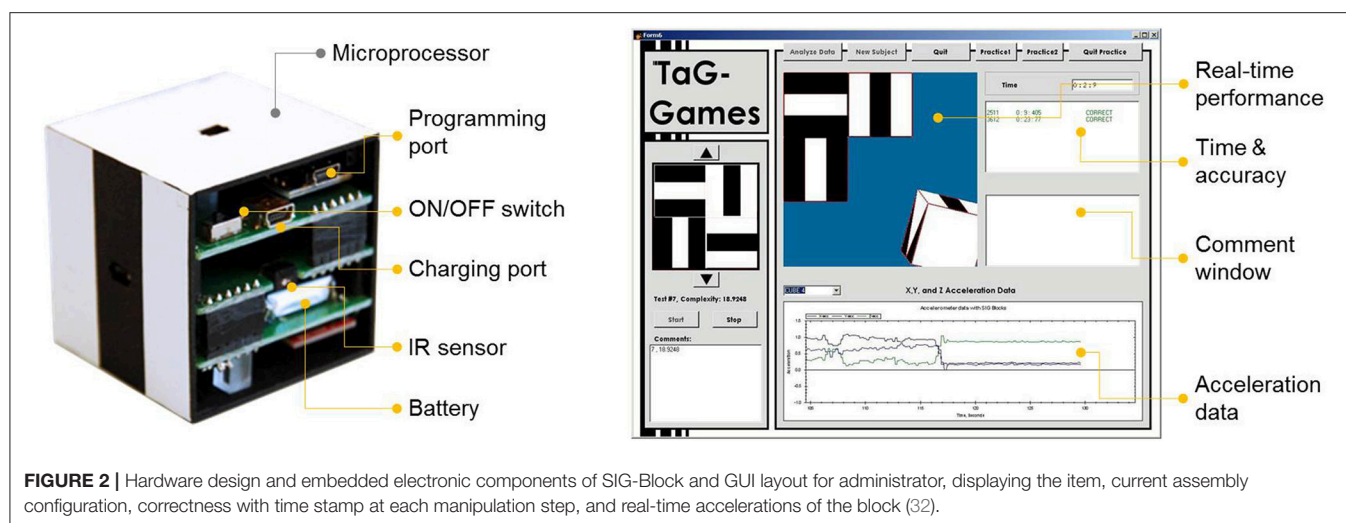
Embedded in the system are six optical sensors, a tri-axial accelerometer, a ZigBee-based wireless communication module, and a timer in the microprocessor, which are used to determine the accuracy and time for each manipulation step and wirelessly transfer to an interfacing device (Figure 2). Algorithms were developed to measure accuracy and speed at each manipulation step. A single step of manipulation refers to when any two blocks were assembled together. For example, if an item required the person to assemble four blocks to achieve a specific assembly configuration, the minimum number of manipulation steps is three; however, the person could make more than three manipulations. The system records the total number of manipulation steps, the correctness, and the time for each.

### 2.1.2. TAG-Game Design (32)

The target measures of TAG-Games are fine motor, visual-motor integration, problem solving and working memory skills. A unique feature of the presented system is the use of physical objects, i.e., SIG-Blocks. In order to capture target cognitive skills, three types of TAG-Games (i.e., TAG-Game<sup>A</sup>, TAG-Game<sup>S</sup>, and TAG-Game<sup>M</sup>) were designed to selectively measure subsets of these domains. Table 1 shows three types of TAG-Games and the cognitive skills which are expected to be associated with each game. TAG-Game<sup>A</sup> is an assembly construction game in which the user recreates a displayed image by assembling the SIG-Blocks. The displayed item is an arrangement of the images on the block faces. The player must rotate and rearrange the blocks in order to create the displayed pattern. TAG-Games<sup>S</sup> involves the presentation of assembly patterns with a missing piece displayed. The participant is prompted to fill in the missing image by placing a SIG-Block with the matching image. For all items, the system records the time it takes for the participant to complete the pattern and whether it is completed correctly or not. As with TAG-Game<sup>A</sup>, TAG-Game<sup>S</sup> requires fine-motor control, as well as visuospatial reasoning (i.e., ability to see the relationships between block rotations and face images) and problem-solving skills (i.e., finding the relations within the pattern and predicting the missing image). TAG-Game<sup>M</sup> requires the participant to remember a sequence of images and repeat it back using a SIG-Block. The images within the sequence are flashed one at a time on a screen, and the participant repeats the sequence by placing the SIG-Blocks with the correct image face up in the order that they appeared. TAG-Game<sup>M</sup> is designed to test a participant's fine motor control, working memory, and attention span. Fine motor control is reflected in the speed and accuracy with which the participant can rotate the block to find the right face image. Working memory is reflected in how well the participant remembers the sequence of images. Attention span is reflected in the ability to maintain focus when the sequences become longer.

### 2.1.3. Computational Complexity Measures (32)

Computational measures of play complexity ( $C^{play}$ ) were defined for each TAG-Game.  $C^{play}$  measures relative complexity of the items used in each game, based on the number of blocks and their geometric properties (including rotational symmetry and color). We hypothesized that these complexity measures were correlated to the performance and by adjusting these factors affecting  $C^{play}$ , the administrator could fine-tune the test difficulty for a target population or individual. For TAG-Game<sup>A</sup>,  $C_A^{play}$  was defined as a configurational entropy change during an assembly task. The change was found from the difference between the entropy before ( $H^{initial}$ ) and after ( $H^{final}$ ) the task. For TAG-Game<sup>S</sup>,  $C_S^{play}$  increased as the number of blocks ( $N$ ), the number of distinctive images used in the item ( $N_d$ ), and/or the pattern length ( $L$ ) increased and decreased as the number of pattern repeats ( $R$ ) and/or the number of symmetry axes ( $S$ ) increased. For TAG-Game<sup>M</sup>,  $C_M^{play}$  was calculated by counting the total number of possible arrangements for the images used in the item ( $Q$ ) and the



**FIGURE 2 |** Hardware design and embedded electronic components of SIG-Block and GUI layout for administrator, displaying the item, current assembly configuration, correctness with time stamp at each manipulation step, and real-time accelerations of the block (32).

**TABLE 1 |** Three types of TAG-Games and cognitive skills expected to be associated with each game.

Type	Associated cognitive and motor skills
TAG-Game <sup>A</sup>	Fine-motor proficiency Visual-motor integration Low-level working memory
TAG-Game <sup>S</sup>	Fine-motor proficiency Visual-motor integration Low-level working memory Spatial reasoning
TAG-Game <sup>M</sup>	Fine-motor proficiency Visual-motor integration High-level working memory

length of the sequence ( $L$ ) and then taking the base-2 logarithm. Specific formulas used for each TAG-Game are provided below:

$$C_A^{play} = H^{initial} - H^{final}; \quad C_S^{play} = \frac{N \cdot N_d \cdot L}{R(S+1)};$$

$$C_M^{play} = \log_2 Q + \log_2 L \quad (1)$$

Figure 3 shows a set of SIG-Blocks and example TAG-Game items and their corresponding  $C^{play}$  values calculated using the above formulas.

## 2.2. Study Design and Method

Evaluation of children's TAG-Games focused on technical functionality, validity of the proposed complexity measures that were previously verified for adults' data, and preliminary validity of the collected data in terms of assessing children's cognitive skills in comparison with a selected standardized instrument. This study was reviewed and approved by Case Western Reserve University's Institutional Review Board. Informed

consent was obtained from parents of all participants. Oral assent was obtained from each child participant after a brief description of the study provided by the research team.

### 2.2.1. Participants

Forty typically developing children (28 males), aged 4–8, participated in this study. Children were recruited for this study from an advertisement placed on the community message board at a local university in the Cleveland Area. All parents were informed of the voluntary nature of the study. Parents were thanked for their participation with a brief report about the study and children received a small educational toy of their choosing for participation.

### 2.2.2. Protocol

TAG-Games for children employed five different designs of SIG-Blocks: geometric shapes (GS), segmented human faces (HF), segmented animal faces (AF), emoticons (EM), and colors (CL) (Figure 4). TAG-Game<sup>A</sup> included three subtests, using the blocks covered with GS (20 items), HF (6 items), and AF (6 items). GS used two to four blocks while HF and AF used four blocks (Figures 5–7). For HF and AF items, if a child fails to assemble four blocks to reconstruct a displayed face image correctly, the second trial displays the same image with grid lines to separate each segment, as shown in Figures 6, 7. Two subtests were designed for TAG-Game<sup>S</sup>: one set of items using GS (12 items) and the other set using EM (6 items) (Figure 8). TAG-Game<sup>M</sup> consisted of three subtests, each using GS, CL, or EM (Figure 9). Each subtest in TAG-Game<sup>M</sup> included 6 items. A discontinuation rule was applied for TAG-Games when a participant failed to correctly answer two consecutive items. The number of items and average time for completion for each subtest are summarized in Table 2.

For evaluating potential utility of TAG-Games as a cognitive assessment tool, three subtests of the WPPSI/WISC test, including Block Design (BD), Matrix Reasoning (MR), and

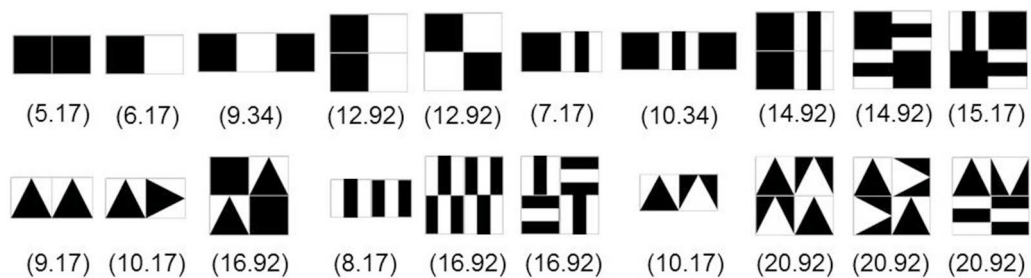




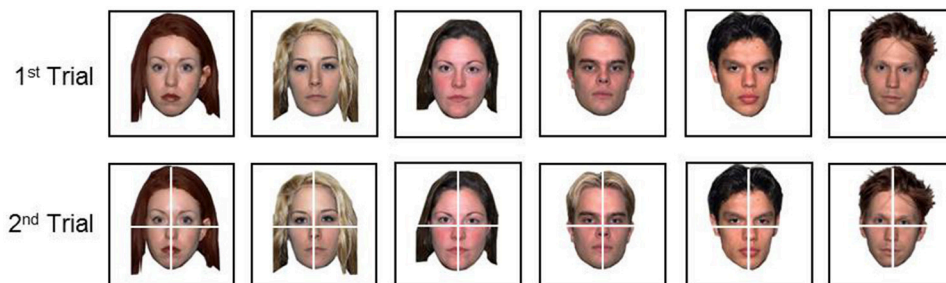
**FIGURE 3** | SIG-Block cover images: For children's TAG-Games, in addition to the geometric shapes and color blocks used in our preliminary study, SIG-Blocks with segmented human and animal face images and emoticons were also used.  $C^{play}$  values are calculated by the formula shown in Equation (1).



**FIGURE 4** | Five types of SIG-Blocks used in the study: geometric shape (GS), color (CL), emoticon (EM), segmented animal face (AF), and segmented human face (HF).

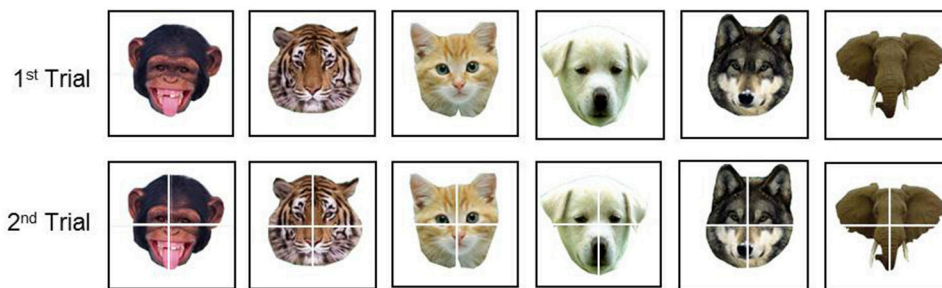


**FIGURE 5** | Twenty TAG-Game<sup>A</sup>-GS items and calculated  $C_A^{play}$  values.

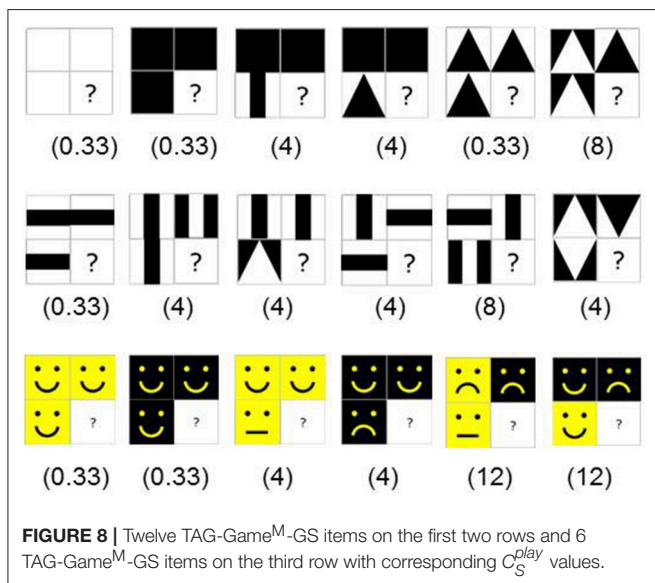


**FIGURE 6** | Six TAG-Game<sup>A</sup>-HF items. If one does not successfully assemble the blocks correctly to match the face in the first trial, the second trial shows thin grid lines to separate the image segments.  $C_A^{play} = 22.92$  for all items.





**FIGURE 7** | Six TAG-Game<sup>A</sup>-AF items. If one does not successfully assemble the blocks correctly to match the face in the first trial, the second trial shows thin grid lines to separate the image segments.  $C_A^{play} = 22.92$  for all items.



**FIGURE 8** | Twelve TAG-Game<sup>M</sup>-GS items on the first two rows and 6 TAG-Game<sup>M</sup>-GS items on the third row with corresponding  $C_S^{play}$  values.

Picture Concept (PC), were administered to investigate relationships between the well-established tests and the outcomes with the TAG-Games measures. For ease of comparison, we calculated a composite score for each TAG-Game in a similar fashion to the method used in WPPSI and WISC. The WPPSI-IV was used for participants at the ages of four and five, with the WISC-V employed for children at the ages of six to eight. The three subtests from the WPPSI-IV/WISC-V were administered using the standardized protocol (i.e., instruction, prompts, time limits, and discontinuation rules) outlined in the manuals.

Two tables were set up to allow efficient administration of both TAG-Games and WPPSI/WISC tests simultaneously. TAG-Games were administered by an engineering graduate student trained for human subject studies and the WPPSI/WISC subtests were administered by an advanced psychology graduate student. Administration of TAG-Games in the current form of the technology only requires clicking icons on a graphical user interface to start and end each game using a mouse connected to an interfacing computer and replacing the blocks after completing each game item. Transition between the

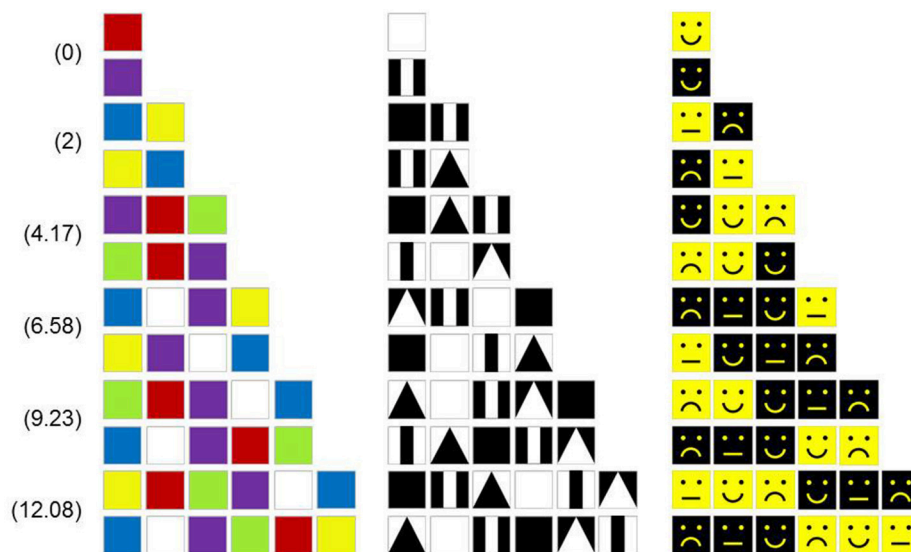
items can be easily automated, but this function was not incorporated at this early stage and we focused on evaluating sensor data accuracy and any potential technical problems. After completing each item, the blocks must be rearranged in randomized positions and orientations prior to displaying the next item. Unlike adult participants who could do this by themselves, the administrator relocated the blocks at each item completion for child participants. The order of administration between TAG-Games and WPPSI/WISC tests were altered. All participants completed both parts of the study within the same day. We note that the TAG-Games technology can support fully automated administration and data collection, while the current study involved a human administrator.

### 2.2.3. Scoring Methods

Scoring of TAG-Games considered correctness and time. For TAG-Game<sup>A</sup> and TAG-Game<sup>S</sup>, terciles were employed for allocating different points based on the completion time for producing a correct answer. Completion times for all correct answers for each item were recorded and divided into three groups: correct answers made within 33% quantile time, correct answers made in between 33 and 67% quantile times and those took longer than 67% quantile time. Children often failed to produce correct assemblies in TAG-Game<sup>A</sup>-HF and TAG-Game<sup>A</sup>-AF. This was likely due to similarity in the appearance of the individual sides of a block. In these two games, for each item, up to two trials were allowed. For correct answers made in the first trial, 4–6 points were allocated depending on completion time. Correct answers made in the second trial after failing in the first trial received 1–3 points. For TAG-Game<sup>M</sup>, only correctness was considered. This game involves two items with the length from 1 to 6, and therefore, if a person successfully remembers items up to four-image sequences, the total score would be 20 (from  $1 + 1 + 2 + 2 + 3 + 3 + 4 + 4 = 20$ ). All incorrect answers received 0 point. For WPPSI-IV and WISC-V subtests, we used the scoring methods as outlined in the manual. The total available score of each subtest was 66 for BD, 26 for MR, and 48 for PC.

### 2.2.4. Data Analysis

TAG-Game scores, computed complexity values, and the scores from the three subtests of WPPSI-IV and WISC-V were the



**FIGURE 9 |** Twelve TAG-Game<sup>M</sup>-CL items (**Left**), 12 TAG-Game<sup>M</sup>-GS items (**Middle**), and 12 TAG-Game<sup>M</sup>-EM items (**Right**) with corresponding  $C_S^{play}$  values.

**TABLE 2 |** The number of items and the average administration time for six subtests of TAG-Games.

Test	Subtest	Max. No. Items	Ave. Time [min]
TAG-Game <sup>A</sup>	GS	20	20
	HF	6	7
	AF	6	7
TAG-Game <sup>S</sup>	GS	12	10
	EM	6	5
TAG-Game <sup>M</sup>	GS	6	3
	CL	6	3
	EM	6	3

A discontinuation rule was applied to all participants to stop the test when failed to correctly answer two consecutive items at the same difficulty level.

primary outcome measures used to examine the preliminary utility of TAG-Games for cognitive assessment. For each TAG-Game, the average raw score and scaled score were calculated to enable comparisons among the tests. Scaling was performed to convert a raw score to 0–100 scale. The data analysis strategy focused on establishing the preliminary psychometric integrity and utility of the measure in young children. As the first step, split-half reliability test was conducted using Spearman's correlations with  $\alpha = 0.05$ . To evaluate the computational complexity measures defined in (1), we also investigated correlations between the complexity value computed for each item and the participant's performance based on time and correctness. For preliminary utility evaluation of TAG-Games for cognitive assessment capabilities, correlation analysis between the TAG-Games and WPPSI-IV/WISC-V were conducted.

**TABLE 3 |** Average scores of TAG-Games for each age group.

Age (No. subjects)	TAG-Game <sup>A</sup>			TAG-Game <sup>S</sup>		TAG-Game <sup>M</sup>		
	GS	HF	AF	GS	EM	CL	GS	EM
4 (7)	15.3	22.5	25.5	16.8	8.7	8.2	11.8	8.3
5 (7)	26.7	25.3	27.5	15.2	5.8	9.2	10.2	7.5
6 (11)	33.3	19.6	21.3	13.6	8	9.3	11.3	8.7
7 (8)	37.5	26.5	28.9	22.5	12.9	10.8	16.4	14.1
8 (7)	46.3	15.3	20.1	15.9	8	6.8	13	10.6
Total Ave. (40)	33.03	21.40	24.15	16.55	8.68	12.58	8.90	9.90
Total Ave. Scaled	55.05	59.44	67.08	45.97	48.22	29.95	21.19	23.57

The number inside the parenthesis indicates the total available raw score for each game. The bottom row shows the total average scores transformed to 0–100 scale for ease of comparison.

## 3. RESULTS

### 3.1. Results From TAG-Games

As detailed in section 2.2.3, total available scores vary across different TAG-Games. Therefore, the raw scores obtained from the participants were transformed to a 0–100 scale for ease of comparison. **Table 3** summarizes the results. The transformed scores for TAG-Game<sup>A</sup> were 55.05, 59.44, and 67.08 for the three subtests, respectively. The two subtests in TAG-Game<sup>S</sup> using the blocks with geometric shapes (GS) and emoticons (EM) resulted in similar average scaled scores, i.e., 45.97 and 48.22 for GS and EM, respectively. For the three TAG-Game<sup>M</sup>, the average scaled scores were 29.95, 21.19, and 23.57, respectively. As shown in the table, age correlations were found in the scores in TAG-Game<sup>A</sup>-GS. In the rest of the tests, we also found age correlations except for relatively poor performance in 8-year-olds.

For the three TAG-Game<sup>A</sup>, children showed a higher mean score using the blocks with human faces (HF) (average score = 59.44) and with animal faces (AF) (average score = 67.08) compared to GS (average score = 55.05). These data provide preliminary evidence in support of our hypothesis that typically developing children would better perform tasks using familiar images than that with unfamiliar shapes. Between AF and HF, the average score from AF was higher than that from HF. As shown in **Figure 4**, all human faces share similar geometry, size, and proportion, while the animal faces used in the test are clearly distinctive in color and shape, possibly making it easier for children to match the blocks correctly. In TAG-Game<sup>S</sup>, the scaled score from the test using EM (48.22) was higher than that using GS (45.97). Again, as shown in **Figure 4**, EM appear to be easier to process and identify the missing piece in the pattern possibly because it only involves two discriminating factors, i.e., color (black vs. yellow) and emotion (smiley vs. angry). On the other hand, six geometric shapes involve color (original vs. inverse) and shape (plane, strip, or triangle). The results from the three tests in TAG-Game<sup>M</sup> were consistent with the previous findings. Children performed the best in memorizing sequences of CL blocks where color is the only variable. The scaled score in TAG-Game<sup>M</sup>-EM was slightly higher than that in TAG-Game<sup>M</sup>-GS, also implying that sequences of EM were slightly easier to memorize than that using GS.

### 3.2. Split-Half Reliability of TAG-Games

For each TAG-Game, the items were divided into odd and even numbers and the scores were compared between the two. For TAG-Game<sup>A</sup> with geometric shapes, a high correlation was found between the odd numbered items and even numbered items, i.e.,  $r_{(10)} = 0.90$  ( $p < 0.05$ ). TAG-Game<sup>A</sup>-HF and -AF use similar types of items that are human and animal faces segmented into 4, and thus the difficulty across these items was assumed to be similar. For 6 items in each of TAG-Game<sup>A</sup>-HF/AF, split-half correlations were  $r_{(3)} = 0.64$  ( $p < 0.05$ ) and  $r_{(3)} = 0.57$  ( $p < 0.05$ ), respectively. For the two types of TAG-Game<sup>S</sup>, split-half reliability test showed that  $r_{(6)} = 0.76$  ( $p < 0.05$ ) for TAG-Game<sup>S</sup>-GS and  $r_{(3)} = 0.68$  ( $p < 0.05$ ) for TAG-Game<sup>S</sup>-EM. There were three subtests in TAG-Game<sup>M</sup>, resulting in  $r_{(3)} = 0.70$  ( $p < 0.05$ ) for color blocks (CL),  $r_{(3)} = 0.67$  ( $p < 0.05$ ) for GS, and  $r_{(3)} = 0.62$  ( $p < 0.05$ ) for EM.

### 3.3. Validity of $C^{play}$

The utility of the computational measures of play complexity for TAG-Games was evaluated by examining the correlation between play complexity and performance measures (e.g., completion time and correctness) at the item level. For TAG-Game<sup>A</sup>-GS, the mean time required for completing each item and correctness of the answer were considered to be two indices of performance and used to examine the impact that play complexity had on performance. As anticipated,  $C_A^{play}$  was strongly correlated with the completion time [ $r_{(20)} = 0.99$ ,  $p < 0.05$ ] and negatively correlated with the correctness [ $r_{(20)} = -0.73$ ,  $p < 0.05$ ]. The  $C^{play}$  values across the items in TAG-Game<sup>A</sup>-HF/AF remain the same using the proposed formula because they all involve

quadrants of face images ( $C_A^{play} = 22.92$ ). Therefore, those games were excluded from the analysis.

TAG-Game<sup>S</sup>-GS and EM employed the same performance indices, i.e., the mean time for completion and correctness, to correlate the performance with  $C_S^{play}$ . For TAG-Game<sup>S</sup>-GS, a strong correlation between  $C_S^{play}$  and the average completion time was found [ $r_{(12)} = 0.76$ ,  $p < 0.05$ ] and a negative correlation between  $C_S^{play}$  and correctness was found [ $r_{(12)} = -0.65$ ,  $p < 0.05$ ]. Similarly in TAG-Game<sup>S</sup>-EM,  $C_S^{play}$  was strongly correlated with the average completion time [ $r_{(6)} = 0.84$ ,  $p = 0.07$ ] and negatively correlated with the correctness [ $r_{(6)} = -0.91$ ,  $p < 0.05$ ]. For the three subtests of TAG-Game<sup>M</sup>-CL, GS, and EM, only correctness was used in this evaluation. Strong negative correlations were found in all three TAG-Game<sup>M</sup>, resulting in  $r_{(6)} = -1.0$  ( $p < 0.05$ ),  $r_{(6)} = -0.99$  ( $p < 0.05$ ), and  $r_{(6)} = -1.0$  ( $p < 0.05$ ) for CL, GS, and EM, respectively. Thus, the strong relationship between play complexity and our TAG-Games was found, implying the potential utility of  $C^{play}$  for personalized assessment.

### 3.4. Relationship Between TAG-Games and WPPSI/WISC

**Table 4** shows the correlations among the TAG-Games and the subtests of WPPSI/WISC scores. Within the TAG-Games, strong correlations were found between the same types of TAG-Games, i.e., TAG-Game<sup>A</sup>-GS was highly correlated with TAG-Game<sup>A</sup>-HF ( $r = 0.54$ ,  $p < 0.05$ ) and TAG-Game<sup>A</sup>-AF ( $r = 0.59$ ,  $p < 0.05$ ). Correlation between TAG-Game<sup>A</sup>-HF and TAG-Game<sup>A</sup>-AF was even higher ( $r = 0.65$ ,  $p < 0.05$ ). TAG-Game<sup>S</sup>-GS was highly correlated with TAG-Game<sup>S</sup>-EM ( $r = 0.62$ ,  $p < 0.05$ ). Three types of TAG-Game<sup>M</sup> were also correlated with each other. We also found correlations across different types of TAG-Games. TAG-Game<sup>A</sup>-GS was correlated with TAG-Game<sup>S</sup>-GS ( $r = 0.67$ ,  $p < 0.05$ ), TAG-Game<sup>S</sup>-EM ( $r = 0.71$ ,  $p < 0.05$ ), and TAG-Game<sup>M</sup>-GS ( $r = 0.63$ ,  $p < 0.05$ ). TAG-Game<sup>S</sup>-GS showed relatively strong correlations with all three TAG-Game<sup>M</sup>.

First focusing on the raw scores in WPPSI/WISC, BDR was correlated with all three types of TAG-Game<sup>A</sup> (GS:  $r = 0.49$ , HF:  $r = 0.32$ , AF:  $r = 0.46$ ;  $p < 0.05$ ). BD was also correlated with TAG-Game<sup>S</sup>-GS ( $r = 0.31$ ,  $p = 0.05$ ), but not correlated with TAG-Game<sup>S</sup>-EM. MR showed correlations with TAG-Game<sup>A</sup>-GS ( $r = 0.40$ ,  $p < 0.05$ ), TAG-Game<sup>A</sup>-AF ( $r = 0.39$ ,  $p < 0.05$ ), and the two types of TAG-Game<sup>S</sup> (GS:  $r = 0.37$ , EM:  $r = 0.36$ ;  $p < 0.05$ ). PC was correlated with TAG-Game<sup>A</sup>-HF ( $r = 0.36$ ,  $p < 0.05$ ) and TAG-Game<sup>M</sup>-CL ( $r = 0.32$ ,  $p < 0.05$ ).

While some correlations between TAG-Game scores and raw scores from the three subtests of BD, MR, and PC were observed, no significant correlations were found between the TAG-Games scores and the standardized BD, MR, or PC scores as expected. This may be due to the fact that the WPPSI/WISC are standardized measures and the scaled scores take into account the age differences, while TAG-Games has not been standardized. This is also reflected in the age correlation data shown in

**TABLE 4 |** Correlation coefficients,  $r$ , among TAG-Games and WPPSI/WISC subtests.

	TA-HF	TA-AF	TS-GS	TS-EM	TM-CL	TM-GS	TM-EM	BD	MR	PC
TA-GS	0.54 ( $< 0.05$ )	0.59 ( $< 0.05$ )	0.67 ( $< 0.05$ )	0.71 ( $< 0.05$ )	0.47 ( $< 0.05$ )	0.63 ( $< 0.05$ )	0.42 ( $< 0.05$ )	0.49 ( $< 0.05$ )	0.40 ( $< 0.05$ )	0.26 (0.11)
TA-HF	–	0.65 ( $< 0.05$ )	0.55 ( $< 0.05$ )	0.43 ( $< 0.05$ )	0.34 ( $< 0.05$ )	0.51 ( $< 0.05$ )	0.24 (0.13)	0.32 ( $< 0.05$ )	0.28 (0.08)	0.36 ( $< 0.05$ )
TA-AF	–	–	0.58 ( $< 0.05$ )	0.41 ( $< 0.05$ )	0.39 ( $< 0.05$ )	0.45 ( $< 0.05$ )	0.26 (0.11)	0.46 ( $< 0.05$ )	0.39 ( $< 0.05$ )	0.24 (0.14)
TS-GS	–	–	–	0.62 ( $< 0.05$ )	0.64 ( $< 0.05$ )	0.60 ( $< 0.05$ )	0.56 ( $< 0.05$ )	0.31 (0.05)	0.37 ( $< 0.05$ )	0.30 (0.06)
TS-EM	–	–	–	–	0.45 ( $< 0.05$ )	0.50 ( $< 0.05$ )	0.48 ( $< 0.05$ )	0.14 (0.39)	0.35 ( $< 0.05$ )	0.20 (0.21)
TM-CL	–	–	–	–	–	0.64 ( $< 0.05$ )	0.69 ( $< 0.05$ )	0.12 (0.46)	0.19 (0.25)	0.32 ( $< 0.05$ )
TM-GS	–	–	–	–	–	–	0.54 ( $< 0.05$ )	0.26 (0.10)	0.26 (0.11)	0.23 (0.15)
TM-EM	–	–	–	–	–	–	–	0.24 (0.13)	0.24 (0.14)	0.17 (0.30)
BD	–	–	–	–	–	–	–	–	0.39 ( $< 0.05$ )	0.33 ( $< 0.05$ )
MR	–	–	–	–	–	–	–	–	–	0.34 ( $< 0.05$ )

The values inside the parenthesis indicate the significance,  $p$ . For short handwriting, TA, TAG-Game<sup>A</sup>, TS, TAG-Game<sup>S</sup>, TM, TAG-Game<sup>M</sup>.

**TABLE 5 |** Age correlations for the TAG-Game scores, the raw WPPSI/WISC scores (i.e., Block Design raw score (BDR), Matrix Reasoning raw score (MRR), and Picture Concept raw score (PCR), and the standardized WPPSI/WISC scores (i.e., Block Design standardized score (BDS), Matrix Reasoning standardized score (MRS), and Picture Concept standardized score (PCS).

TA-GS	TA-HF	TA-AF	TS-GS	TS-EM	TM-CL	TM-GS	TM-EM	BDR	MRR	PCR	BDS	MRS	PCS
0.74 ( $< 0.05$ )	0.70 ( $< 0.05$ )	0.70 ( $< 0.05$ )	0.63 ( $< 0.05$ )	0.63 ( $< 0.05$ )	0.48 ( $< 0.05$ )	0.60 ( $< 0.05$ )	0.39 ( $< 0.05$ )	0.39 ( $< 0.05$ )	0.41 ( $< 0.05$ )	0.34 ( $< 0.05$ )	0.02 (0.88)	–0.17 (0.30)	0.07 (0.68)

**Table 5.** TAG-Game scores showed higher age correlations than the BD, MR, and PC raw scores, implying that TAG-Games may better capture developmental differences than the Wechsler's subtests.

## 4. DISCUSSION

### 4.1. Conclusion

Forty children aged between 4 and 8 participated in our preliminary evaluation. In TAG-Game<sup>A</sup> (block assembly tasks), the average scaled score in the test using the geometric shapes was lower than the tests using the images of human or animal faces. Between the tests using human faces and animal faces, the average scaled score in the animal face

test was significantly higher than the test with human faces. It is possibly because the animal faces used in the items were more distinctive than human faces in color and geometry. Children showed better performance in TAG-Game<sup>S</sup> (shape matching tasks) involving the emoticon images than TAG-Game<sup>S</sup> with geometric shapes as well. In TAG-Game<sup>M</sup> (sequence memory tasks), the results were consistent with the other two types of TAG-Games, showing that the children could better memorize sequences of simpler or familiar images than those involving unfamiliar geometric shapes. Internal consistency was examined by the split-half reliability test for all TAG-Games. A significant correlation was found in each test, implying internal consistency in the test design.



The proposed computational measures of  $C^{play}$  were strongly correlated to task performance measured by completion time and correctness, implying their potential roles for dynamically adjusting test difficulty to address individual or group differences. In order for cognitive assessment to produce sensitive assays, it is important for the test to involve sensitive items appropriate for each group or individual. For the target population presented in this paper, we manually adjusted test items from the original version used for young adults (age: 19–30). If fully validated,  $C^{play}$  can serve as a useful tool to automatically generate easier or harder items based on age and cognitive status. The relationship between TAG-Games and WPPSI/WISC subtests were also analyzed by examining correlations among the test scores. While some weak to moderate correlations were found between the TAG-Games and WPPSI/WISC subtests, further evaluations are needed to produce valid comparisons between the two sets of tests.

## 4.2. Limitation and Potential

The small sample size for each age group does not allow for a definite statement regarding the reliability and validity of this measure. The current prototype system, which is all handmade and lab fabricated, still requires an administrator to check if the blocks function properly time to time. The battery power must be extended. The current blocks need to be recharged after 2 h of continuous use. We encountered occasional technical malfunctions, mostly related to infrared (IR) sensors installed on the block surfaces which were connected to the main circuit with a removable socket for easy replacement. Once fully established and professionally manufactured, technical errors will be nearly zero with enhanced battery performance with optimized circuit design for reduced power consumption.

The defined  $C^{play}$  formulas for the task complexity associated with each type of TAG-Games showed significant positive correlations with completion time (i.e., the higher  $C^{play}$  the longer it takes to complete) and significant negative correlations with accuracy. The evaluation for  $C_A^{play}$  was only performed on the TAG-Game<sup>A</sup> with geometric shapes results, because its items have varying  $C_A^{play}$  values while TAG-Game<sup>A</sup> with the human or animal face images have the same  $C_A^{play}$  (= 22.92) value across all items. This value is the maximum available value for  $C_A^{play}$  for a 4-block item. This is because the task requires the player to identify one of the six images on each block and place it in an exact position and orientation without allowing permutation. However, children's performance in the items with the same complexity values resulted in significant differences in task performance depending on the types of block images used, i.e., geometric shapes, colors, emoticons, human faces, and animal faces. This is because the proposed complexity measure was defined based on discrete entropy changes by assembling the blocks, without taking account of the possible "familiarity" and "distinctive" factors. To address this limitation in the current definitions of  $C^{play}$ , different image processing approaches could be used to quantify color and shape variation as well as familiarity factors.

With these limitations in mind, the TAG-Games system is uniquely positioned as an automated assessment tool for cognitive skills through tangible manipulation of the blocks. The games do not require the use of language, potentially reducing cultural bias. TAG-Games have the potential for addressing limitations in the traditional assessment methods by (1) reducing cost by automating the process and therefore reducing or eliminating clinician/administrator time, (2) improving the quantity and quality of the measurable data, (3) enabling objective assessment, and (4) enabling wireless, remote administration for hard-to-reach areas. Once the proposed computational measures are fully validated, TAG-Games can be fully customized and tailored for each individual or group, potentially increasing sensitivity in assays. While the presented results suggest the potential of TAG-Games for cognitive assessment in children, the data here must be interpreted with caution.

## 4.3. Future Work

Our future work will focus on further validation of this new technology-based cognitive assessment for children by (1) continuing human subject evaluation to achieve a significant statistical power in the data, (2) improving the technology to be more user friendly (e.g., longer battery life, easy-to-use charging station, and enhanced graphics in the user interface), and (3) randomizing the order of the games and employed tests. Our team is highly interested in investigating the potential utility of this technology for in-home cognitive assessment for children who require continuous monitoring of their cognitive skills, such as those with attention deficits and hyperactivity disorder (ADHD), learning disabilities, autism spectrum disorder (ASD), and other cognitive or behavioral problems. To do so, our second phase of human subject study will involve two groups of children, healthy and cognitively delayed, and examine group differences and how TAG-Games can provide detailed information on each individuals cognitive performance and behavior changes over time. Further technical improvements would be necessary for this study to be conducted at each participant's home.

## AUTHOR CONTRIBUTIONS

KL: As the principal investigator of this project, she developed the technology, including SIG-Blocks and associated software algorithms. She also developed computational play complexity measures. DJ: As the graduate research assistant, he built the technology under supervision of KL. RS, LH, SG: As graduate research assistants of Psychological Sciences, they administered the Wechsler's tests on young children under supervision of ES. ES: As the co-investigator of this project, she collaborated on game design, designed the study protocols, and led the human subject study.

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# Discourse on Intellectual Disability and Improved Access to Assistive Technologies in Malawi

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Assistive technologies are one of the five elements under the Health Component of the World Health Organization CBR Guidelines that Malawi is using to implement the Community Based Inclusive Development (CBID) Programme. The technologies enhance independent living by removing barriers that come due to disability or old age and should, therefore, be prioritized. However, Malawi does not have a straightforward way of providing Assistive Technology. Individuals are considered upon the assessment of their needs whose intervention with respect to assistive products may not be available. This is mostly the case with persons with intellectual disabilities, in which there is very little expertise to work with, in Malawi, although they require assistive products to improve their quality of life just like other persons with disabilities. There are many sectoral policies and laws in Malawi, nonetheless, they do not have a positive input on persons with intellectual disability to access assistive technologies in terms of availability (provision), affordability (cost), and appropriateness (suitability and quality). Therefore, this paper intends to demonstrate the barriers that are faced by persons with intellectual disabilities, examine the policies, and pieces of legislation that would have influenced better access and maps the way on how barriers can be removed to ensure that Assistive Technologies are readily and easily accessed.

**Keywords:** intellectual disability (ID), discrimination, sensory impairment, Malawi, disability act, equality, health services

## INTRODUCTION

Persons with intellectual disability in Malawi are more disadvantaged and pushed to the margins of society. These may consist of mental illness, Down syndrome, autism asparagus syndrome, epilepsy, some types of cerebral palsy, and severe cases of hydrocephalus. Persons with intellectual disabilities, therefore require support because of the characteristics like slow learning, uncontrollable body movements, slurred speech, problems in decision making, and memory problems<sup>1</sup>. It is, therefore, very important that the government should initiate and improve services toward their inclusion. It includes access to appropriate technologies that are very essential for them to have equal opportunities like anyone else<sup>2</sup>.

<sup>1</sup>Disability in Uganda: Focus on Tororo District intellectual disability in Malawi may also consist of mental illness. [http://www.jlidd.jp/bestpractice/BP2008\(Uganda\).pdf](http://www.jlidd.jp/bestpractice/BP2008(Uganda).pdf) (As of 25 October 2018).

<sup>2</sup>National Policy on Equalization of Opportunities for Persons with Disabilities (Malawi Government Print, 2006) [www.nyasatimes.com/malawi-on-national-inclusive-education-strategy/](http://www.nyasatimes.com/malawi-on-national-inclusive-education-strategy/) (As of 7 November 2018).

The Community Based Inclusive Development (CBID)<sup>3</sup> program that was introduced in 1988 as a pilot project in Blantyre district (1) and is now extended to half of the country has not made a noticeable response to the diversity of disability and needs. In general, most of the support is delivered to persons with mobility and other physical challenges, visual and to a limited extent persons with hearing impairments. As a result, insufficient consideration has been given to persons with intellectual difficulties and those with developmental impairments (2). Limitations include lack of responsiveness to diversity; priority to access medical, education, and livelihood interventions; most CBID models that were fragmented were not aligned to the Government development structures at the community, district and national level<sup>4</sup>. On top of these there were also other challenges like sustainability being depended on the goodwill of volunteers; limited coverage and dependence on donor funding.

However, Malawi has developed a new National Harmonized CBID Model (2) whose main features are diversification and inclusiveness; partnership and collaboration; capacity building; participation of persons with disabilities; ownership and sustainability by district councils; and compliance with national and international standards. The new model that has adopted the World Health Organization CBR Matrix<sup>5</sup> also has a monitoring and evaluation framework targeting the district councils; has mechanisms for data collection and management, and is responsive to the local context (see **Figure 1**).

Since CBID is a rights-based approach to disability issues, it will ensure that persons with intellectual disabilities are included in all the intervention done under it comprising access to assistive technologies by persons with an intellectual impairment. This will be through identification of persons with intellectual disabilities, assessment and referrals to appropriate service providers depending on their needs using the CBID mechanism that uses the local Government structure<sup>6</sup> and has volunteers who move door to door at the village level (see **Figure 2**).

The Malawi Disability Act, 2012, defines disability as a “long-term physical, mental, intellectual or sensory impairment, which in interaction with various barriers may hinder the full and effective participation of a person on an equal basis with other persons”<sup>7</sup>. Thus, the advancement of inclusive development by mainstreaming disability would be demonstrating an understanding that persons with intellectual disabilities have to enjoy human rights like other persons other than taking

them as objects of charity. Since Malawi signed and ratified the United Nations Convention on the rights of Persons with Disabilities (CRPD) in 2007 and 2009, respectively<sup>8</sup> there is need of policy, legal and systemic reforms to ensure that persons with intellectual disabilities access appropriate technologies in Malawi.

Therefore, section Situation Analysis of this paper highlights the challenges faced by persons with intellectual disabilities in Malawi. It includes negative perceptions of them and the lack of technical know-how available to this type of disability. Section Overview of the Legal and Policy Framework analyses the current disability legal instruments and policy frameworks in comparison to the international standards in the provision of assistive technologies and its implications on persons with intellectual disabilities. Section Recent Developments justifies why CBID is the best way forward to improve the situation, followed by section Actionable Recommendations and the paper concludes.

## SITUATION ANALYSIS

Persons with disabilities in Malawi, just like in numerous other countries, have many challenges. These result in getting them marginalized from the mainstream society that makes it problematic for them to realize their essential social, political, and economic rights<sup>9</sup>. “The majority of them have a difficult life since they are poor, abandoned, uneducated, malnourished, discriminated, neglected, and vulnerable. The factors contributing to this pathetic situation are many and varied but include poverty, unemployment, and social isolation, environmental, institutional, attitudinal, and economic barriers” (as above).

## Misconceptions

Since persons with disabilities experience discrimination since birth or the moment they acquire a disability, life becomes a struggle from there onwards. It is also true with intellectual disability that is associated with some myth and misconceptions. An example that is given by Joseph Kisanji that talks about attitudes toward disability in Tanzania (3) would not be different to Malawi as a neighboring country. Joseph gives instances of proverbs used in Tanzania that show that intellectual disability is dreaded and not acceptable in the society (3). Persons with intellectual disabilities are believed to be a curse upon the family. Opinions like this make it difficult for individuals with intellectual disability to be taken as an equal citizenry. Because of such myths and misunderstandings, persons with intellectual disabilities are consequently severed and hidden from the public<sup>10</sup>.

<sup>3</sup>Previously known as Community Based Rehabilitation (CBR).

<sup>4</sup>The Malawi Growth and Development Strategy (MGDS III). <https://cepa.rmportal.net/Library/government-publications/the-malawi-growth-and-developmentstrategy-mgds-iii> (As of 25 October 2018).

<sup>5</sup>WHO CBR Matrix [www.who.int/disabilities/cbr/matrix/en/](http://www.who.int/disabilities/cbr/matrix/en/) (As of 7 November 2018).

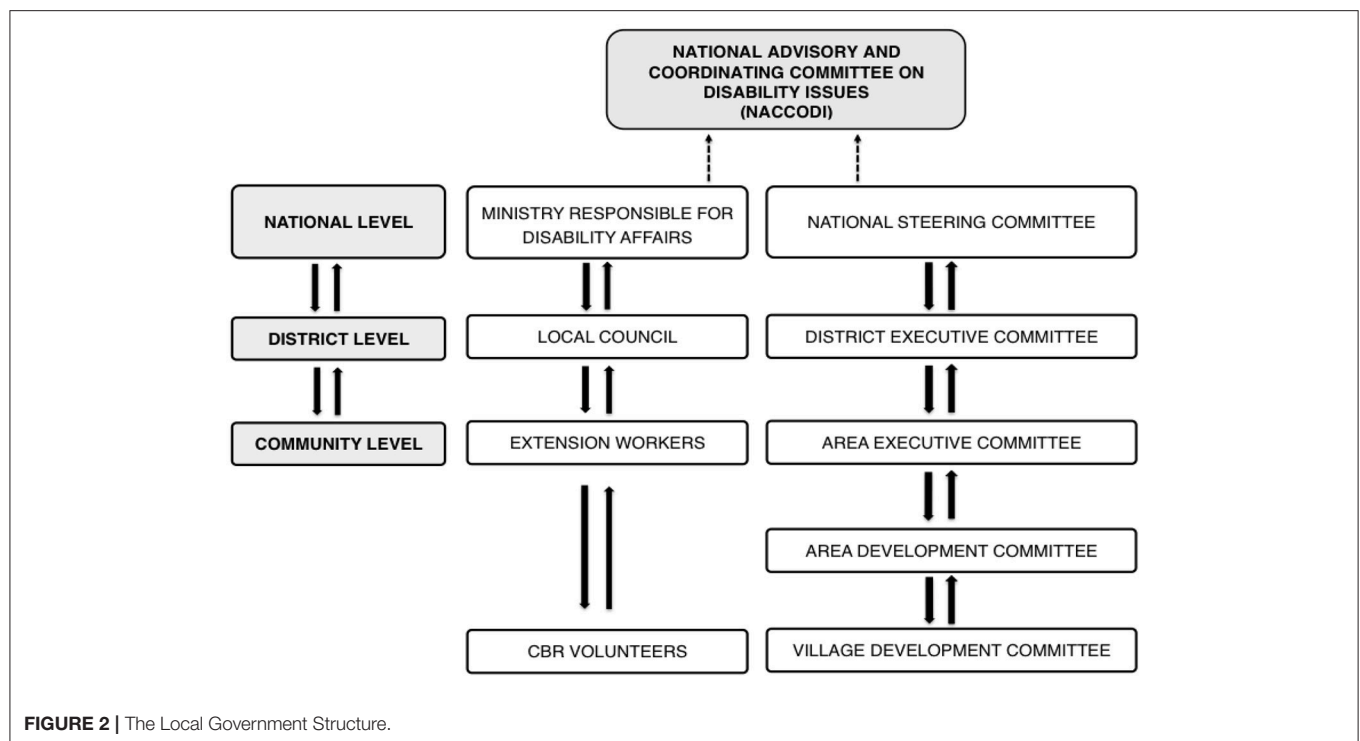
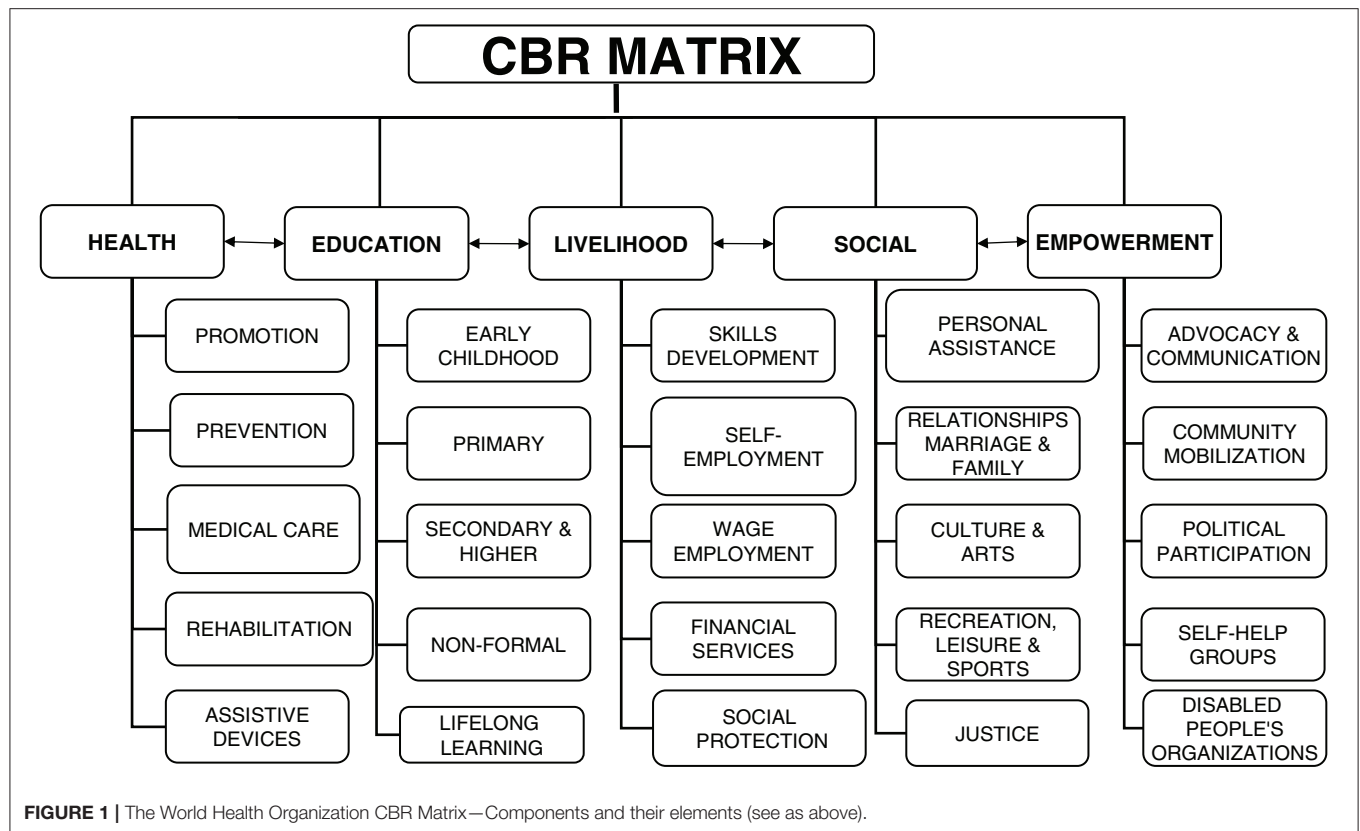
<sup>6</sup>The National Mainstreaming Strategy <http://www.maravipost.com/malawigovernment-commitson-disabilities-rights-launches-mainstreaming-strategyand-implementation-plan/> (As at 7 November 2018).

<sup>7</sup>Disability Act (Malawi Government Print, 2012) [www.scotlandmalawipartnership.org/download\\_file/267/207](http://www.scotlandmalawipartnership.org/download_file/267/207) (As of 7 November 2018).

<sup>8</sup>UN Enable, “Conventional and Optional Protocol Signatures and Ratifications” <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf> (As of 6 March 2018).

<sup>9</sup>See National Disability Policy (n 2 above).

<sup>10</sup>See National Disability policy (n 2 above).



## Lack of Enabling Environment, Mechanisms, and Resources

SINTEF<sup>11</sup> conducted a study that found out that a significant part of the sample that was used in the study indicated that they had problems to access health services. For example, of the 84% of the sample that required health services merely 61% received it and only 5% accessed assistive devices out of the 69% who were in need of them<sup>12</sup>.

Usually, health services are to a certain extent not accessible to persons with intellectual disabilities due to the key challenges that include a lack of appropriate technologies, inappropriate laws and policies, and their subsequent reinforcement. In addition, severe gaps in human and financial capabilities in the production of assistive products are there because the Government has not decentralized this to the private sector. Decentralization to the private sector would have enhanced competition, thereby, improving production; affordability due to competitive prices; quality; and appropriateness.

An interview with the Acting Principal of Montfort Special Needs Education Centre revealed that the Centre for Learning Difficulties does not use any appropriate technology<sup>13</sup>. She claims that learners with an intellectual disability simply need more time to learn since that is their problem. However, in another interview with the Programs Manager of the Parents of Disabled Children Association in Malawi (PODCAM), it is learnt that appropriate technologies can be used to assist persons with intellectual disabilities with their learning<sup>14</sup>. The PODCAM official points out that children with intellectual disability require assistive technologies, for example, computer games to stimulate their minds. It may be attributed to lack or low demand for the devices due to exposure or donor support being restricted to some geographical area<sup>15</sup> and includes lack of the CBID programme.

It is evidenced from neighboring countries like South Africa where they use Assistive Listening Devices (ALDs) that assist in amplification of sounds so that somebody is able to hear better; Augmentative and Alternative Communication (AAC) devices to assist individuals with communication impairments to express themselves; and Alerting Devices that assist those with hearing loss<sup>16</sup>. Hearing aids and sign language is also used for communication purposes<sup>17</sup>.

Technology assists persons with intellectual disabilities in many ways like communication cited above. But appropriate technology can also be used for mobility like using wheelchairs

that are controlled by computers; environmental control where electrical appliances, video and audio equipment can be operated by devices. Appropriate technology is also used in activities of Daily Living (ADL) like feeding, assisting individuals with memory difficulties to accomplish an activity or instructional materials that are in video form. In Uganda toys and playing materials can also be modified to ease play by children with intellectual disabilities<sup>18</sup>. Nonetheless, most of these are not available in Malawi.

## Lack of Data

The absence of disability-specific data on persons with an intellectual disability makes it quite difficult to locate them and establish the need for assistive devices. It is the reason the majority is not reached. It, therefore, necessitates the issue of data collection and management which is one of the features of CBID.

## OVERVIEW OF THE LEGAL AND POLICY FRAMEWORK

### International Law on Disability

#### The United Nations Convention on the Rights of Persons With Disabilities (CRPD) 2006

There are several international instruments but the most recent and specific to persons with disabilities is the United Nations Convention on the Rights of Persons with Disabilities<sup>19</sup>. It obligates States as in the following clauses:-

- **General Obligations:** promotion of research and development and provision of accessible information to persons with disabilities on appropriate technology and support services<sup>20</sup>.
- **General Mobility:** Facilitate access and encourage production of assistive technologies<sup>21</sup>.
- **Habilitation and Rehabilitation:** Promote the availability, knowledge, and use of assistive devices and technologies<sup>22</sup>.
- **Participation in Political and Public life:** Use of assistive technologies in the protection of the rights of persons with disabilities, for example, voting, health, education, employment, and community participation without barriers<sup>23</sup>.
- **International Cooperation:** Access, sharing, and transfer of assistive technologies<sup>24</sup>.

However, adequate domestication and enforcement are required to ensure compliance with the laid down international standards. Malawi has attempted to domesticate these obligations as highlighted below.

<sup>11</sup>SINTEF is an independent research institute <https://www.sintef.no/en/this-is-sintef/> (As of 25 October 2018). It has not been given in full.

<sup>12</sup>Loeb and Eide, "Living Conditions among People with Disabilities in Malawi," [http://www.washingtongroup-disability.com/wpcontent/uploads/2016/03/SINTEF\\_malawi\\_report.pdf](http://www.washingtongroup-disability.com/wpcontent/uploads/2016/03/SINTEF_malawi_report.pdf). (As of 23 March 2018).

<sup>13</sup>Interview with Lucy Magagula – Acting Principal, Montfort Special Needs Education College (Lilongwe, Malawi, 8 February 2018).

<sup>14</sup>Interview with Enoch Mithi – Programme Manager, Parents of Disabled Children Association of Malawi (Liwonde, Malawi, 23 February 2018).

<sup>15</sup>See (n 1 above).

<sup>16</sup>Assistive Devices and Equipment, Disability Info SA [uhambofoundation.org.za/new-wpcontent/upload/2016/...](http://uhambofoundation.org.za/new-wpcontent/upload/2016/...) (As of 25 October 2018).

<sup>17</sup>As above.

<sup>18</sup>See Disability in Uganda (n 1 above).

<sup>19</sup>Convention on the Rights of Persons with Disabilities (United Nations, 2006) <https://www.un.org/development/desa/disabilities/convention-on-the-...> (As of 7 November 2018).

<sup>20</sup>(As above) art. 4g and 4h.

<sup>21</sup>(As above) art. 20 b and 20 d.

<sup>22</sup>(As above) art. 26(3).

<sup>23</sup>(As above) art. 29a (ii).

<sup>24</sup>(As above) art 32d.



## The Local Legal Framework on Disability

### The Malawi Republican Constitution, 1995

Section 20(1) of the Bill of Rights in Chapter IV of the Malawi Republican Constitution<sup>25</sup> guarantees equal and effective protection for all persons and prohibits discrimination on any basis including on the basis of disability among others. Additionally, Section 13<sup>26</sup> calls upon the State to progressively develop policies and legislation toward achieving the goals of children and persons with disabilities, gender equality, health, and education among others. For persons with disability, the principle in section 13(g)<sup>27</sup> offers recognition of processes to the advantage of persons with intellectual disabilities to access and be actively involved in the community. Although not explicit, it would include the issue of assistive technologies that improve the quality of their lives.

### The Disability Act 2012

Section 26(e) of the Disability Act says “promote the design, development, production, and distribution of accessible information and communication technologies and systems, and ensure that the same are available for persons with disabilities at an affordable cost”<sup>28</sup>. The provision, although laying emphasis on information and communication, when coupled with section 4.6.1.2 of the National Policy on Equalization of Opportunities for Persons with Disabilities<sup>29</sup> guarantees issues of social, economic and participation of persons with intellectual disability through the provision of assistive technologies they require.

### Education Act of 2013

The 2013 Act that is attached to the values of accessibility, quality, relevance, efficiency, equality, equity, liberalization, partnership, decentralization, transparency, and accountability as also proclaimed in the Republican Constitution promotes equal access to education for all people in Malawi. Since the values are accorded irrespective of race, ethnicity, gender, religion, disability, or any other discriminatory characteristics it would assist in removing the discriminatory tendencies to persons with intellectual disabilities to access the assistive terminologies they need<sup>30</sup>.

### Handicapped Persons Act, Cap 33:02 of 1971

The Handicapped Persons Act of 1971<sup>31</sup> is currently being reviewed as it was based on the charity model of disability. However, it gives powers to the Malawi Council for the Handicapped (MACOHA) to design, implement, and monitor rehabilitation programs and services for the socio-economic empowerment of persons with disabilities. MACOHA also

regulates operations of organizations of and for persons with disabilities. It creates awareness on disability and facilitates active involvement of the community in disability issues.

MACOHA is thus well-placed, to make sure that persons with intellectual disabilities have access to assistive technologies through the planning of disability programmes and services in the country.

### Employment and Labor Act

Section 5 of the Employment and labor Act of 2000<sup>32</sup> which is the legal framework for regulating the basic employment conditions outlaws discrimination on the basis of disability whether at recruitment or during the course of employment or termination. It additionally encourages positive actions for the underprivileged groups, including persons with intellectual disabilities.

The Act thus gives another opportunity for non-discrimination of persons with intellectual disabilities to access assistive products or technologies in employment processes stipulated above.

### The Policy Framework

There are several sectoral policies that would assist in issues of access to appropriate technology although they do not explicitly mention intellectual disabilities. The policies have provisions that can be used to assist the development of assistive technologies and improve access by persons with intellectual disabilities. Some of the policies that are relevant enough are as follows.

### National Policy on Equalization of Opportunities for Persons With Disabilities (NPEOPWD), 2006

The National Policy on Equalization of Opportunities for Persons with Disabilities<sup>33</sup> has the purpose of promoting the rights of persons with disabilities so that they are able to play a full and active role in society. The goal is to guarantee solid steps that are taken for equality in the enjoyment of fundamental rights and responsibilities on an equal basis just like other Malawian citizens. To this effect, the policy concedes disability as a social construct and aims at giving guidelines for the inclusion of disability issues in the Government's development agenda as a human rights issue. It calls for combined efforts and harmonized management systems for planning, implementation, and monitoring at all levels.

One of the priority areas, as pointed out in section 4.12, is assistive technologies. Section 4.6.1.2<sup>34</sup> of the National Policy on Equalization of Opportunities for Persons with Disabilities states the need to “design and develop appropriate technologies, assistive devices, and learning materials.” Thus, a Policy Framework at the national level for appropriate technology in Malawi is available. “The objective of this priority area is to promote and support disability research and the development and application of appropriate technologies for disability programmes”<sup>35</sup>. However, there seems to be little on the ground.

<sup>25</sup>The Constitution of the Republic of Malawi Act 20 of 1994 <https://www.wipo.int/edocs/lexdocs/laws/en/mw/mw030en.pdf> (As of 6 March 2018).

<sup>26</sup>(As above) sect. 13.

<sup>27</sup>(As above) sect. 13g.

<sup>28</sup>See the Disability Act [http://www.fedomamalawi.org/public/themes/Fedoma/downloads/Disability\\_Act\\_2012.pdf](http://www.fedomamalawi.org/public/themes/Fedoma/downloads/Disability_Act_2012.pdf) (n 9 above).

<sup>29</sup>See the National Disability Policy (n 2 above) sect 4.6.1.2.

<sup>30</sup>The Malawi Education Act [https://www.malawilii.org/.../legislation/...act/.../num\\_act\\_2012\\_35](https://www.malawilii.org/.../legislation/...act/.../num_act_2012_35). (As of March 2018).

<sup>31</sup>The Malawi Handicapped Persons Act 1971 <https://dredf.org/legal-advocacy/international-disability-rights/international-laws/malawi-handicapped-personsact/>. (As of 23 March 2018).

<sup>32</sup>The Malawi Employment and Labour Act 2000 [http://www.intosa.com/uploads/download/file/289/Employment\\_Act\\_2000\\_.pd](http://www.intosa.com/uploads/download/file/289/Employment_Act_2000_.pd). (As of 23 March 2018).

<sup>33</sup>See National Disability Policy (n 2 above).

<sup>34</sup>(As above) sect. 4.6.1.2.

<sup>35</sup>(As above) sect 4.12.

The section includes strategies that would be used to achieve the above that includes the availability of financial and technical assistance to key stakeholders; boosting innovations in appropriate technologies; facilitate coordination in disaggregated data collection and research in all relevant studies including census. It also includes dissemination of data to all planners and stakeholders in the disability programming. Establishment of a national user-friendly Disability Management Information System (DMIS) interfaced with other management information systems in various sectors, for example, health, education, among others are part of the strategy currently being done.

### **Education Policy and Investment Framework (PIF)<sup>38</sup> and the National Education Sector Policy, 2016<sup>39</sup>**

Inclusive primary education is the goal of the Education Sector Investment Framework as well as the national education policy. The policies are aimed at developing and managing an education system that would increase enrolment, retention, and graduation of children with disabilities from school. It then offers improved access to the school environment that includes assistive technologies. Following these policy agenda, the Government has launched an Inclusive Education Strategy<sup>40</sup> that also targets learners with intellectual disabilities and could assist them to access assistive products in order to equalize their education opportunities.

### **TEVETA Policy and TEVET Act (2nd Edition of 2013)**

The Technical Entrepreneurial, Vocational Education and Training Authority (TEVETA) through its TEVET Act of 1999<sup>41</sup>, Policy<sup>42</sup>, and Strategic Plan<sup>43</sup> prioritize persons with disabilities and other vulnerable persons as a fundamental constituent of the authority. Under the pillar “Access and Equity” the strategic plan<sup>44</sup> supports access to vocational skills training by persons with disabilities.

### **Malawi National Health Policy, 2012<sup>45</sup>**

The healthy policy emphasizes the inclusion of the vulnerable groups that include persons with disabilities, women and the elderly in all health interventions. It is key to access of persons with intellectual disabilities to assistive technologies since the element of assistive technologies, in question, falls under the WHO CBR Guidelines Health Component.<sup>46</sup>

<sup>38</sup>Malawi Education Policy and Investment Framework (PIF) <http://www.sdn.org.mw/Education2010/Edu-policy.html>. (As of March 23, 2018).

<sup>39</sup>(As above).

<sup>40</sup>Malawi Inclusive Education Strategy <https://www.nyasatimes.com/malawi-on-national-inclusiveeducation...> (As of March 23, 2018).

<sup>41</sup>TEVET Act 1999, <https://www.google.com/search?q=TEVET+Act+malawi&oeq=TEVET+Act+malawi&q=chrome..69i57.14053j0j4&sourceid=chrome&ie=UTF-8.php/downloads/Tevet-act-pdf/detail> (As of March 23, 2018).

<sup>42</sup>TEVET Revised Policy 2013, [https://www.google.com/search?ei=KEYOXNuN8XgUazJmLAL&q=TEVET+policy+malawi&oeq=TEVET+policy+malawi&gs\\_l=psy-ab.12...164389.165964..168275...0.0..0.1945.1945.8-1.....0....1..gws-wiz.7DSvzXOfs\\_M Revised policy final.pdf/download](https://www.google.com/search?ei=KEYOXNuN8XgUazJmLAL&q=TEVET+policy+malawi&oeq=TEVET+policy+malawi&gs_l=psy-ab.12...164389.165964..168275...0.0..0.1945.1945.8-1.....0....1..gws-wiz.7DSvzXOfs_M Revised policy final.pdf/download) (As of March 23, 2018).

<sup>43</sup>TEVETA Strategic Plan 2013-2018, [http://www.teveta.mw/index.php/downloads/TEVETA Strategic Plan 2013 to 2018](http://www.teveta.mw/index.php/downloads/TEVETA%20Strategic%20Plan%202013%20to%202018) (As of March 23, 2018).

<sup>44</sup>TEVETA Strategic Plan (n 44 above) 16.

<sup>45</sup>Malawi National Health Policy <https://www.google.com/search?q=national+health+policy+malawi&oeq=national+health+policy+malawi&q=chrome..69i57.14667j0j4&sourceid=chrome&ie=UTF-8> (As of March 23, 2018).

<sup>46</sup>WHO CBR Guidelines Health - Component <https://www.ncbi.nlm.nih.gov/books/NBK310926/> (As of March 23, 2018).

## **RECENT DEVELOPMENTS**

The most recent development in Assistive Technology that Malawi has experienced was attending the summit on Assistive Technology in Geneva Switzerland from the 3rd to 4th August 2017. The summit was initiating a “Global Priority Research Agenda for Improving Access to High-Quality Affordable Assistive Technologies and Devices.” In short, it is called the GREAT Summit. Following the summit, a report was submitted to the Principal Secretary for the Ministry of Gender, Children, Disability and Social Welfare so that action is taken in Malawi so that it can move together with the rest of the world.

This prompted during the drafting of the Disability Bill 2019 for Appropriate Technologies to be included<sup>47</sup>. The Bill includes broader strategies for appropriate technology in Malawi to developing sectoral policies and legislation on health in line with the National Policy on Equalization of Opportunities for Persons with Disabilities (2006) article 4.12<sup>48</sup> and the Disability Act 2012 section 26<sup>49</sup>.

The other broader strategy is strengthening networking among public and private service providers in the areas of promotive, preventive, medical, and rehabilitative services to ensure a more coordinated case management. A good example under CBID is the Community Training on making and repairing of simple assistive devices (e.g., Appropriate Paper Technology -APT)<sup>50</sup>.

## **ACTIONABLE RECOMMENDATIONS**

Despite the numerous policies and legislation that would enable persons with intellectual disabilities to access assistive technology, there is though little happening on the ground<sup>51</sup>. There are numerous challenges like level of access and quality of the services for persons with disabilities for the past years; lack of data and statistics in the Malawi Growth and Development Strategy and previous absence of a Healthy Policy and legislation; limited access to mobility and other devices due to no decentralization of rehabilitation services within the Ministry of Health delivery structure; and inadequate number of specialists such as orthopedic surgeons, ophthalmologists, physiotherapists, and occupational therapists, rehabilitation technicians, medical social workers, and community nurses<sup>52</sup>.

Nonetheless, the Community Based Inclusive Development (CBID) promises to be a solution to the problem. CBID is a rights-based approach that is focused on development with an aim to mainstream disability in development work and in the Governments development agenda. Dissemination of appropriate technology information is already taking place through CBID. Therefore, there are features that would make CBID a recommended tool to remove the challenges of intellectual disabilities and access to appropriate technology.

<sup>47</sup>The Malawi Disability Bill 2018, Sect, 16.

<sup>48</sup>See the National Disability Policy (n 2 above).

<sup>49</sup>See the Disability Act (n 9 above).

<sup>50</sup>See (n 21 above).

<sup>51</sup>See National Disability Policy (n 2 above).

<sup>52</sup>See National Mainstreaming Strategy <https://www.nyasatimes.com/ministerkalirani-condemns-exploitation-of-people-with-disabilities-malawi-launchesmainstreaming-strategy/> (n 9 above).

The features of CBID that would assist this cause are diversification and inclusiveness that give answers to a wide and specific social-economic requirements of persons with varied types of disabilities, age groups and different cultural contexts; partnership and collaboration that permit sharing of best practices and accountabilities as well as gives a wide-ranging service delivery. Features also include the capacity building that consists of the transfer of skills for mainstreaming disability in development work from the grass-roots up to the national level; participation of persons with disabilities in CBID that calls for their active involvement and participation as rights holders in the spirit of “Nothing about Us without Us.”

Data collection and management, which gives effective planning, implementation, monitoring and evaluation of the programme is an important aspect hence Malawi has come up with a National Disability Monitoring and Evaluation framework, Inclusive Education Strategy and the National Mainstreaming Strategy. The National Coordination and Consultative Committee on Disability Issues

(NACCODI) has also been re-instituted by the Honorable Minister of Gender, Children, Disability and Social Welfare. This is a committee of Principal Secretaries to ensure that there is coordination among all Government sectors so that mainstreaming of disability is done.

Enhancing international cooperation as per the United Nations Convention on the Rights of Persons with Disabilities would be very important. For example, after the GREAT Summit in Geneva, the African Commission considered the possibility of concerted efforts to address issues of appropriate Technology in Africa<sup>53</sup>. Similarly, a provisional position paper was drafted at the University of Southern Queensland in the United Kingdom toward an international framework to ensure the availability and accessibility of affordable high-quality assistive technologies globally.

The provisional paper highlighted the need for states to develop national policies on appropriate technology provision that includes a policy on appropriate technology manufacturing; use of appropriate technology mainstreaming technologies to intensely stimulate appropriate technology and services; ensure evidence-based information on appropriate

technology and allied services available. On top of that develop training programmes in appropriate technology like has been done in Malawi in the development of training packages for CBID that has included appropriate technology.

Malawi has picked the cue since the issue of appropriate technology was also discussed with the Principal Secretary for the Ministry of Gender, Children, Disability and Social Welfare in a meeting on the 25th of October, 2018 at Mount Soche Hotel in Blantyre, Malawi, where the Principal Secretary implored organizations like the Ministry itself, the Malawi Council for the Handicapped and the Federation of Disability Organizations in Malawi to greatly include appropriate technology in their programmes and services.

## CONCLUSION

The introduction of the new harmonized CBID model in Malawi that matches the principle of the Sustainable Development Goals to “**Leave No One Behind**” is a great milestone. There is now hope that the aspect of intellectual disability and access to assistive technologies will improve further using the Mainstreaming Strategy, the CBID and other informal community structures. NACCODI will also play an important role to ensure that nobody is segregated from realizing his or her rights.

There is, nonetheless, need for reinforcement of legal policy instruments that are already in place and systemic reforms to ensure inclusive programming and development to achieve inclusivity of persons with intellectual disability.

Progressively, the challenges may be declining but it needs concerted efforts from all key partners and the much-needed coordination from the CBID programme.

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The author confirms being the sole contributor of this work and has approved it for publication.

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online at: <http://www.english.aifo.it/disability/documents/innovations/cover-contents.pdf> (Accessed March 23, 2018).

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<sup>53</sup> A letter was written by Lefhoko of the African Commission to come up with a continental effort to address the challenge of Assistive Technologies in Africa by coming up with guidelines, standards, policy and a strategy.

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