

## REVIEW

# Using multimedia technology to enhance self-advocacy of people with intellectual disabilities: Introducing a theoretical framework for ‘Multimedia Advocacy’

Paul Watts<sup>1</sup> | Gosia Kwiatkowska<sup>2</sup> | Andy Minnion<sup>2</sup>

<sup>1</sup>School of Health Sport and Bioscience,  
University of East London, London, UK

<sup>2</sup>The RIX Centre, University of East London,  
London, UK

## Correspondence

Paul Watts, School of Health Sport and  
Bioscience, University of East London, London,  
UK.

Email: [p.n.watts@uel.ac.uk](mailto:p.n.watts@uel.ac.uk)

## Abstract

**Background:** Multimedia Advocacy is the use of digital technology for people with intellectual disabilities as means of developing identities, being heard, connecting to family and care networks and, advocating for change.

**Methods:** We explore principles and theories that underpin Multimedia Advocacy, mapping disciplinary approaches that have influenced the concept and praxis.

**Results:** We describe relevant theories from cultural and media studies, personal therapeutic practices, communication, universal design, and systemic adoption of technology. We discuss new ways of achieving person-centred working with digital technology. We aim to develop a stronger theory/practice dialogue between these disciplines.

**Conclusions:** The theories described highlight the importance of embedding access and use of digital technology within everyday settings. Long-term implementation plans and buy-in from all organisational levels are required for Multimedia Advocacy tools to be embraced by health and social care systems so the voice of an individual is included and genuine person-centred practice is achieved.

## KEYWORDS

digital technology, multimedia advocacy, person-centred practice, philosophy, theory

## 1 | INTRODUCTION

People with intellectual disabilities continue to be socially excluded and significantly marginalised despite governmental acknowledgment of this issue and some positive changes in policy and practices (Office for National Statistics, 2021). Prior to the Covid-19 pandemic, people with intellectual disabilities experienced some of the highest rates of loneliness and social exclusion (Macdonald et al., 2018) with likely impacts on physical and mental health outcomes (Leigh-Hunt et al., 2017). During the pandemic, the impact of lockdowns, social distancing, and shielding intensified these impacts as people with intellectual disabilities experienced interrupted routines (Seale, 2020), disrupted care and support services (Hughes & Anderson, 2022) and

the loss of opportunities to participate in a range of social and educational activities. Digital technology has been shown to have great potential to mitigate some of the negative impacts of social isolation experienced by people with an intellectual disability prior to the pandemic, and those that have been exacerbated by the pandemic (Seale, 2022). However, access to a wide range of services and technology remains poor for people with intellectual disabilities, including internet and digital services (Bates et al., 2017; Equality and Human Rights Commission, 2017; Office for National Statistics, 2020; Seale, 2022).

The use of digital devices including mobile phones and tablets by people with an intellectual disability is substantially lower than in the general population (Chelkowski et al., 2019) and latest estimates

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suggest that less than 50% of people with an intellectual disability have internet access, compared to more than 90% of people without an intellectual disability (Chadwick et al., 2017; Chiner et al., 2017). Barriers to use of digital technology include the risks perceived for people with an intellectual disability and those in their support networks and the accessibility of the technology itself (Chelkowski et al., 2019). However, there is an emerging evidence base demonstrating that the incorporation of digital technologies into the lives of people with an intellectual disability can enhance their social, educational, health and care experiences (Seale, 2022). This has led to a growing consensus and explicit recognition across health and social care policies and strategies that digital technology has a critical role to play in addressing the exclusion and inequality experienced by this population. Indeed, in response to reforms enshrined in Children's Services (Curran, 2010), Adult Social Care (Department for Health and Social Care, 2018) and the National Health Service (NHS) Long-Term Plan (NHS, 2019), public and voluntary organisations across the UK have pioneered the application of innovative 'digital advocacy' tools for the design and delivery of care and support for people with intellectual disabilities in partnership with their families and a range of professional and service-provider agencies (Bakkum et al., 2022; Martin et al., 2021; Trevisan, 2016). This typically entails the use of consumer mobile devices and specially adapted social media-style Apps alongside new models of communication and interaction between citizens and service providers.

Since, 2004, work at the Rix Centre, University of East London has focused on addressing issues of social exclusion for adults and children with intellectual disabilities and has been at the forefront of the development of 'Multimedia Advocacy' which utilises digital technology to enable people to have their views, wishes, choices and aspirations made known to those around them (Kwiatkowska et al., 2012). The Rix Centre promotes research and development in the use of digital and multimedia technologies with a mission to improve the lives of people with intellectual disabilities and to enable them to realise the benefits that digital inclusion and appropriately designed tools can bring to their lives. The approach of the Rix Centre is to work in 'co-production' partnerships with people with intellectual disabilities, their families and the professionals and organisations that work with them to explore new technologies and the ways that they can be used to help people to learn, speak up for themselves, gain independence and manage their care and support in ways that work best for them. A particular focus of RIX research is in developing improved self-advocacy and communication through the use of contemporary digital media tools that enable the creation and sharing of personal media content. The process of multimedia production, made easy and accessible, can help individuals to organise their thoughts, articulate their views and influence change in their lives. This article's authors have pioneered their own software tool in the Rix Wiki, which combines accessible multimedia authoring capability with a mind-map design to enable people to build their own websites. Designed for accessibility and ease-of-use, RIX Wikis are used by many young people with intellectual disabilities as a rich and engaging platform for information about themselves. Using

video, pictures, sound and words, Wikis can capture the voice and aspirations of the individual and enable them to share their stories, preferences and goals with the key people in their life (Rix Research and Media, 2023).

Multimedia Advocacy uses the design of digital technology to provide a person with an intellectual disability access to traditionally inaccessible sources of multimedia and digital communication as a means of: developing, shaping and presenting their identities; having their voice heard and listened to; supporting connections to their family, community and care support networks; sharing experiences and advocating for change in their home, care and life settings. This paper aims to explore the philosophies, principles and theories that underpin Multimedia Advocacy. We aim to identify and map the range of disciplinary approaches that have influenced and informed Multimedia Advocacy, both as a concept and as praxis. The rationale for this theoretical exploration is to begin a discussion about what is, or ought to be, Multimedia Advocacy and to ensure that such approaches continue to benefit users in a meaningful and empowering way. Theorising a concept such as Multimedia Advocacy requires making the underlying assumptions of the concept explicit (Walker, 2003). For Multimedia Advocacy to become part of wider practice, the evidence base, theory and underlying assumptions need to be explicit. Through the mapping of its attendant values, influences and drivers, we can consider its scope and engage with ideas and concepts in further depth to help shape, develop and consolidate this way of working towards a more inclusive society. Furthermore, Multimedia Advocacy needs to be understood so that concepts around how people with intellectual disabilities are perceived and discriminated against can be challenged and people empowered.

## 2 | MULTIMEDIA ADVOCACY AND SELF-ADVOCACY

Multimedia Advocacy is ideally, 'self-advocacy' with support from multimedia if and when support is needed and in the form that it is needed. Advocacy simply means speaking up. The most direct form of advocacy is self-advocacy, meaning speaking up for yourself, having your voice heard, being listened to, knowing what is important to you, knowing what are your rights and how to exercise them on a day to day basis (Roberts et al., 2016). Self-advocacy skills are particularly important for people with intellectual disabilities as they have a lot of education, social care and health care professionals involved in their lives. A person in regular receipt of support can experience little personal agency and lack confidence in making choices and decisions about their lives. They are often expected to attend meetings with many professionals and support workers where decisions about their lives are constantly being made. Unless the relevant person has good advocacy skills to support a person to surface and express themselves when needed, their wishes and wants might never be heard. Test et al. (2005) have developed a conceptual framework for self-advocacy, which consists of four areas: (1) 'Knowledge of self'; (2) 'Knowledge of rights'; (3) 'Communication', and (4) 'Leadership'. We use the

four areas of this conceptual framework as a basis for introducing and discussing theories underpinning Multimedia Advocacy and to demonstrate how the concept and practice of Multimedia Advocacy contributes to these four areas of self-advocacy.

### 3 | MULTIMEDIA ADVOCACY AND 'KNOWLEDGE OF SELF'

Knowledge of self can develop by exploring and identifying: What is a person good at?; What are their strengths?; What are their likes and dislikes?; What are their dreams and aspirations?; What do they want to achieve in life, in the short term and in the long term?; What help they might need, from whom and when? Multimedia Advocacy can support this area by providing a process in which selfhood is explored and articulated. For example, at the Rix Centre, interactive photo shoot sessions have been used to help the person reflect upon their appearance and personal style and capture what is important to them in a facilitated and accessible way. The concepts and principles that underpin using digital media in this way to reflect on self-image are influenced by a spectrum of pre-existing practices and disciplines including community photography, media production and publishing, therapies that engage art, drama and photography (Jones, 2020), citizen journalism and digital storytelling (Lambert, 2013). Each field of practice has its body of critical theory and debate aligned to it, with accompanying theoretical language and conceptual frameworks with which they engage to varying degrees (Abrams, 2016; Rebmann, 2012). These practices feature a common valorisation of the person's voice and views—the self-expression of individuals who are marginalised and whose views, opinions and stories are seen to have been unheard as part of their social exclusion. Where theorised, the act of self-representation is typically articulated as a political intervention that addresses the injustices, inequalities or exclusion of the participating population (Thumim, 2012).

#### 3.1 | Origins of multimedia advocacy in culture and media studies

Cultural studies have contributed much of the language, critiques and a framework for activism on which Multimedia Advocacy relies. In the 1960s and 1970s, literary theorist and philosopher Roland Barthes wrote extensively on how the construction of self is configured around a visual image from childhood onwards (Allen, 2004). From Barthes, identity politics has been highlighted within cultural studies and has described issues of representation and the use of photography as means of contributing an individual's sense of self and identity. Such work on representation and its impacts on selfhood critiqued the adverse impacts of dominant media and advertising that stereotyped people according to their gender, race, class and disability. A contemporary example of this is how 'selfies' are used as part of construction of a person's identity through the creation and sharing of an image that can be used to critique stereotypes around disability and provide an alternative representation of identity.

Cultural and Media studies' critique of 'dominant representations' informed emerging community arts and media practices from the 1970s and 1980s that deployed new, more accessible media technologies to produce 'alternative representations' of women, ethnic minorities, working class communities and disabled people that empowered the subjects and challenged prejudicial stereotypes (Spence, 2021). Cultural studies literature has highlighted the way photography has historically been used to document disabled people as part of medical and criminal records of those perceived to be different and degenerate (Spence & Dennett, 1979). Similarly, media studies theory critiques a legacy of the philanthropic representations of disabled people, especially when they are children, as tragic victims, worthy of charitable patronage and points to the lack of positive representations of people with intellectual disabilities in mainstream media. A cultural studies critique of stereotypes of disabled people has informed alternative media practices that actively produce and circulate positive imagery and narratives of people with intellectual disabilities to raise awareness through cultural forms and channels (Hevey, 1992).

In consideration of subjects as producers as well as consumers of media, the discipline has widened the scope of its interrogation of the implications of media practices on identity and selfhood (Bailey, 2005), and has subsequently explored the active agency of making self-produced media and the effect that has on the power relations in our rapidly changing society, as theories have run to catch up with the practices of social media (Hearn, 2017). Personal and social media have evolved as the primary mechanisms around which an individual will explore and affirm their identity in our culture.

Many traditional models of care challenge the sense of power and control that an individual with an intellectual disability has over their life. Daily care often incorporates supporters' assumptions about the person's preferences and aspirations, and their very capacity for self-determination that are imposed with outdated and paternalistic models of support that are the legacy of our care services' philanthropic origins. Multimedia Advocacy exploits increasingly easy-to-use media making tools to contest such cultural perceptions and to proactively represent the interests and choices of people with intellectual disabilities. These tools can provide an alternative framework that enables the person to develop, capture and communicate their own account of themselves and the life they want to lead. A standard introduction to a Multimedia Advocacy approach entails creation and sharing of self-made images and text on 'the things that I like' such as favourite colours, clothes or activities. This helps to establish a foundational sense of selfhood for individuals whose sense of their own agency is diminished through a lifetime of being subject to others speaking up for them. The process establishes a basis for stronger selfhood and capacity for self-advocacy. This can develop into a comprehensive and authentic 'About Me' account for the individual, which health and care professionals increasingly recognise as an essential foundation for design of an effective personalised care and support package (Professional Record Standards Body, 2023). Creating an 'About Me' account provides a means of engaging and supporting a person to understand and affirm the validity of their own preferences

and choices. The added value of housing my About Me information in digital multimedia format is that it can be continuously updated to reflect a changing and evolving impression of selfhood, shaped, maintained and owned by the individual with an intellectual disability in an easy and accessible way.

This dimension of Multimedia Advocates resonates with Cultural Studies' critique of the codes and politics of media representations and how they shape and influence a person's selfhood and perceived status through dynamic interaction with photographic, audio or video media that influence and shape how people are perceived and understood. People with intellectual disabilities and their supporters need to be conscious of how media representations work as purveyors of often subtle messages, meanings and value judgements as they create personal media for sharing (Caton & Chapman, 2016).

### 3.2 | Digital storytelling

Digital storytelling has subsequently emerged as a distinct practice that aligns with these critiques from cultural studies describing how media shape power and representation of social roles (Knobloch-Westerwick et al., 2014). Digital storytelling refers to the creation of audio and visual media, combining photography, video and narration to produce short stories. It has been applied in therapeutic settings (Thumim, 2017) and for community development (Lambert, 2013). Digital storytelling has evolved as an often formulaic method, involving a facilitator as a critical leading and steering digital storytelling practitioner and sometimes a dominant person who is in-turn steered and guided by digital storytelling methods enshrined in books (Thumim, 2017) and manuals (La Rose & Detlor, 2021) with extensive instructional detail on processes to follow through to the production of digital stories. In therapeutic and care settings, this can typically result in the process of using media to tell stories following a rigid method to facilitate the telling of the story back to a group. This is often a closed therapeutic loop that does not extend proactively to wider parts of the storyteller's life and therefore, the story and the storytelling stays within the discourse of its own process.

The text or media produced through digital storytelling has greater potential to be used to drive a person's self-advocacy and their pursuit of justice, equality or social inclusion. The stories produced through digital storytelling can be powerful agents of change (Dunford, 2017), but the value of the story as a potential intervention in the real world in terms of social positioning and power is often not actively pursued so not realised when digital storytelling is used as a closed therapeutic intervention. Digital storytelling provides a valuable reflective and prescriptive practice scaffold, backed by in-depth debate about part of the spectrum of Multimedia Advocacy processes and practice—specifically the media making process, the team dynamics and role play associated with creating personal media content. Multimedia Advocacy shares some process similarities with digital storytelling but also extends beyond digital storytelling in the way that stories are produced and implemented. Digital storytelling may form part of the Multimedia Advocacy spectrum by facilitating a focus on

selfhood, but as a closed-loop with a dependency on prescribed practitioner methods, digital storytelling can form only part of the Multimedia Advocacy processes.

Multimedia Advocacy can be less prescribed than digital storytelling and less ordered and structured by facilitators and the methods they apply. The Multimedia Advocacy process drives self-advocacy by focusing on the importance of changing processes and the way in which these actively shape the identity/selfhood of the individual, especially in terms of challenging stereotypes around dis/ability. Furthermore, the process of Multimedia Advocacy can be seen as incomplete until the digital story has been shared to help the person communicate their experience, their view, choice or aspiration and so impact the shape and direction of their lives by enabling the person's self-advocacy in supported situations. Therefore, the process must be embedded with and impact lived experiences, support, care, education and relationships. While digital storytelling has refined a component of the self-advocacy pathway—especially 'knowledge of self' and potential to apply that to a more assertive understanding of rights, this pathway to impact on people's power relations and lived experience is not then traced and pursued within this practice—it is a closed loop. Whereas, in Multimedia Advocacy the therapeutic intervention is actively designed to propel the person forwards as a self-advocate—which correlates to the requirement for 'knowledge of self and rights' that Test et al. (2005) has identified from self-advocacy literature.

## 4 | MULTIMEDIA ADVOCACY AND 'KNOWLEDGE OF RIGHTS'

Knowing our rights in the first place is essential for understanding our options. For example, knowing that one has the right to communication might help to acquire funding for an appropriate communication device that would enable one's voice to be heard. Multimedia Advocacy can support this area by helping a person to chart their place as a citizen and a social being entitled to pursue the life that they want to lead in dialogue and negotiation with others. All of us do this as part of our transition from parental dependency to independence across the life-course and people with intellectual disabilities will typically benefit from extra learning and support to make this change.

A person-centred plan or similar self-advocacy based approach helps the person to map out the domains of their lives, housing, work, wellbeing and relationships and learn about their options, rights and entitlements (Duchan & Black, 2001). Multimedia Advocacy can support this process and set goals that map to our personal wishes and preferences, envisaging a future we would like to inhabit with imagery that captures ideals as well as the familiar. For example, a session centred on reviewing photos and media clips of places where we would like to live or visit, things we would like to do, or possessions we would like to own can help to lay out an aspirational vision of a person's life for review and reflection. Audio visual media can evoke a more nuanced and multi-sensory picture of a person's vision of what they might aspire to than a verbal exchange or a written list of goals

can. A more accessible conversation provides a richer account of the individual's aspirations and helps to affirm their rights and entitlement to be supported effectively to pursue their goals. Multimedia Advocacy work at the RIX Centre and elsewhere has found fertile and receptive ground for adoption and implementation with practitioners and policymakers that recognise person-centred thinking as pivotal in the pursuit of a more inclusive society.

#### 4.1 | Person-centred thinking

Prior to the existence of multimedia and digital communication tools, psychologist Dr Carl Rogers developed the person-centred approach (Rogers, 1951). He based his approach on the idea that the client is an expert and knows best what is good for them; the therapist's role is to work with an individual in a non-directive and non-judgemental way to help the client bring the best out of them and reach their full potential. Person-centred thinking requires the relevant person to be at the centre of the interaction; professionals, families and friends need to work together, learn from each other and always keep the person 'in the driving seat'—actively involved. There have been many tools and guidelines issued by various bodies to help guide the adoption of person-centred practice in various contexts including social care (O'Brien et al., 1997).

The major critique of person-centred thinking is that it is difficult to achieve in practice due to lack of adequate resources, including money and time (Towell & Sanderson, 2004). Media production processes within Multimedia Advocacy provide an inclusive format for person-centred 'discussions' to occur between the supported person and the carer. The process of working with pictures, video and sound can disrupt established professional working habits with their legacy of a top-down paternalism. These methods are already in the public domain, are easy to do and are not obscured by professionalised jargon or practice standards. New methods for capturing and evidencing a person's wishes, choices and needs provide a fresh basis for the care communication process to play out, in which roles can be redefined.

Multimedia Advocacy embodies person-centred thinking while recognising that this will not work unless self-advocacy is enabled through the facilitation of communication with *active* listeners. Multimedia Advocacy tools enable people with intellectual disabilities to be the voice at the centre of conversations about their life domains, such as where they live, their activities and their wellbeing, and for family, community and care support networks to regularly and actively listen to this voice. Within each of these life domains Multimedia Advocacy tools can scaffold the process of engaging with and understanding the rights a person with an intellectual disability has to shape these areas of their life. For example, a selected RIX Wiki mind map template can provide structure for developing an understanding of preferences and wishes within each of these life domains, thus fostering understanding of the individual's right to self-determination on the attributes of where they live, the activities they participate in and how they like to be supported to reach for the life to which they aspire.

#### 4.2 | Actor-network theory

Multimedia Advocacy recognises that forming, developing and enacting relationships with family, community and care support networks is essential for a person with an intellectual disability to self-advocate and shape their own health and social care pathways and settings. Actor-network theory (Adam & Tatnall, 2017) is a framework that focuses on the enacted relationships and interactions between people and their environments. People with intellectual disabilities may experience hundreds of supporters in their lives who have a shallow knowledge of their identities, their back-stories or their passions. There is a risk of individuals being little known or understood and narrow, fixed and superficial accounts of people's lives being circulated as a result. A picture of the person assembled by professionals and support teams can foreground medical diagnoses, care-needs or safeguarding risks, in place of an account of a person with a history and personality. Multimedia Advocacy can help counter this risk for highly supported people, with a more active practical role than they might have in an exclusively verbal session, fortifying the individual's agency in representing their unique selves and their complex lives.

Actor-network theory encourages the understanding of experiences by identifying complex networks of 'actors' within a person's social or care network, or non-human 'actors' such as the parts of the environment or system that act as barriers or facilitators to learning or health and wellbeing (Callon & Blackwell, 2007). For example, Multimedia Advocacy tools may be an essential actor for someone with intellectual disabilities as they can enable a relationship to be formed, shaped and enacted. Actor-network theory suggests that a person's potential for achievement depends on how well they can engage and influence these key actors, by navigating the associated codes and structures controlling access to power and influence over the actors. This may include shaping how Multimedia Advocacy is used within their care setting as an actor and as a powerful tool to navigate relationships, networks and power structures (Adam & Tatnall, 2017). This links to third area of Test's framework for self-advocacy ('Communication').

The theories discussed above have focussed on the role of identity, rights, power, and relationships in shaping the concept and practice of Multimedia Advocacy. In addition to these theories, there are a wide range of theories and models across several disciplines that seek to explain—often recognising and addressing the roles of identity, rights, power and relationships—how and why there is persistent inequity of opportunities to access multimedia technology for communication and self-advocacy and, in some cases, to provide practical approaches to addressing this inequity. These theories and models are described below with a critical focus on their utility for addressing inequity of access to communication media and technology for people with intellectual disabilities.

### 5 | MULTIMEDIA ADVOCACY AND 'COMMUNICATION'

It is not enough to have a voice, we have to have means and opportunities to practice our communication skills and have our voice heard.

Multimedia Advocacy can support this area with a new set of tools and processes to use to enhance the person's communication about themselves and their rights. For example, production of a personal video can surface and capture the person's account of themselves and the direction they wish to take in their lives to realise their rights and aspirations. Multimedia Advocacy provides tools and processes to support self-advocacy through communication and does so by embracing principles including the removal of barriers to communication and by providing digital technology that enables communication of self-advocacy. These principles are informed by the social model of disability and subsequently the concept of universal design (UD).

## 5.1 | The social model of disability

The highly influential social model of disability (Oliver, 2013) has been used extensively to describe how people with intellectual disabilities are not disabled by individual learning impairments, but by societal barriers including limited access to digital technology used for communication. However, some critics of the social model of disability have suggested that beyond describing these societal barriers, it is of limited practical use when it comes to acting on these societal barriers (Samaha, 2007). Despite these critiques, the social model of disability is relevant to Multimedia Advocacy in that it represents a paradigm shift away from the dominant medical model in the way that disability is perceived and in approaches to providing support, therapy and care (Gabel & Peters, 2004). Multimedia Advocacy focuses on using digital technology in a way that suits and adapts to the needs of the person while also enabling traditional notions of disability to be challenged. For example, by providing platforms for people with intellectual disabilities to produce and communicate their own representation of their life, identity and dis/ability through their preferred form of textual, audio and/or visual media. The social model of disability has provided a foundation for theories and practice which have taken forward these principles of addressing societal barriers to modes of communication.

## 5.2 | Universal design

The social model of disability has informed principles of UD (Steinfeld & Maisel, 2012; Story, 1998) and universal design for learning (UDL) (King-Sears, 2009) which aim to remove physical and societal barriers for people with physical disabilities and intellectual disabilities. UD(L) encourages approaches that are 'not unique or personal, but universal and inclusive, accommodating diversity' (Rose, 2018). The principles of UD(L) include: equitable use; flexibility in use; simple and intuitive use; and tolerance for error (Smith & Preiser, 2011). These principles are useful for guiding approaches to designing digital technology for communication and advocacy that accommodates a range of physical and cognitive skills and abilities. However, there has been less focus on how UD(L) approaches may be applicable to forms of communication in everyday life. Multimedia

Advocacy builds on the principles of UD(L) by providing platforms for advocacy and communication that actively remove physical and societal barriers to digital technology, accommodating a range of uses and users across settings within the home, care settings, and as part of everyday life.

## 5.3 | Models of assistive technology

Models of assistive technology have sought to focus more on practical solutions to overcome barriers in access to communication technology for people with disabilities. The human activity assistive technology (HAAT) model (Cook & Polgar, 2013) describes an integrated system composed of the 'consumer' (the person with the disability), their activities, their context (social and physical environment) and the technology itself. The HAAT Model and its extension the comprehensive assistive technology (CAT) model (Hersh & Johnson, 2008) focuses on a holistic and simultaneous evaluation of these four inter-related components, emphasising that a focus only on the technology or the person with the disability is likely to be ineffective in enhancing communication experiences or improving health and wellbeing outcomes. These models recognise that the social and physical context must adapt for the experience and wellbeing of a person with a disability to be enhanced by the assistive technology.

Models of assistive technology have important practical applications, but focus more on facilitating the research and design of the technology, then subsequently matching the technology to people with disabilities, who are conceptualised passively as 'end users'. A criticism of these models, especially when applied to people with intellectual disabilities, is that the focus is on 'assistive' technology rather than 'enabling' technology (Jewell & Atkin, 2013). The distinction is that assistive technology aims to 'increase, maintain, or improve the functional capabilities of persons with disabilities' (Assistive Technology Industry Association, 2022), whereas the focus of enabling technology is to 'support a person with disabilities to live as independently as possible' (Jewell & Atkin, 2013). For Multimedia Advocacy, the focus is *enabling technology* that is available if required to support a person with intellectual disabilities to communicate and self-advocate independently.

Advances in digital technology, such as the proliferation of mobile devices and social media platforms have transformed the way that augmentative and alternative communication (AAC) aids can facilitate communication for people with an intellectual disability as tools proliferate and their costs diminish (Waller, 2019). AAC technology can facilitate a person-centred support approach by enabling and enhancing communication and information exchange between the person with an intellectual disability, their family and social and care networks (Gibson et al., 2020). For example, the RIX Wiki utilises mobile technology and elements of popular social media to create a secure, accessible and easy to build personal portfolio. One feature of the Wiki is an 'invite' feature, whereby the user can select precisely the content or information they wish to share, with whom they want to share it and when they want that to start and stop. This feature can assist and

augment a persons' communication in a one-to-one conversation or a meeting, effectively serving as personally tailored AAC device for communicating needs, preferences and aspirations and reinforcing social presence and agency people so often misunderstood or excluded.

## 6 | MULTIMEDIA ADVOCACY AND 'LEADERSHIP'

Leadership is the final part of the self-advocacy framework, where a person can use their voice to share their perspectives with others and advocate on behalf of not only themselves but also for others. Effective self-advocacy means '*Leading your life*'—taking charge of one's own life course oneself to the fullest extent possible, such self-determination builds confidence and assertion skills that correspond to leadership and translate readily to speaking up for others as well as oneself. This experience of leadership is empowering for the person in place of the routines of being *cared for* and supported in so many aspects of their lives. The self-advocate is an active citizen whose personal media can also have a strong social impact. Multimedia Advocacy can support this by providing media formats that can be selectively shared or go public more readily than entries in care plans stored in filing cabinets—however person-centred they may be.

Personal and social media networks provide new accessible channels through which to share our personal stories, thoughts and views. Support teams that use Multimedia Advocacy are playing an active role in a more fluid and impactful information exchange environment. These innovations in support practice demand new understandings, skills and good practice models and professional standards for education, health and care providers. Working with personal media needs new technical and creative skills as well as protocols for engagement with a wider spectrum of professional and ethical issues. For example, issues such as consent and privacy in social media and publication contexts present significant areas of risk for vulnerable people that demand refinement of the support team's knowledge and understanding.

'Leadership' can, in one sense, be interpreted as an overtly political effort to represent and advocate for people with an intellectual disability as a community (Ellem et al., 2022). In another sense, perhaps more relevant to Multimedia Advocacy, leadership is required for '*leading your own life*' in a way that is self-determined. This may simply entail achieving incremental progress in having one's social and care preferences listened to and acted upon. Leadership in this sense is more personal and can involve working towards the mobilisation of a team around a person with an intellectual disability to work in a person-centred way, progressively advancing to a point where that person can command control over how their wishes and preferences are fulfilled. Multimedia advocacy can support this process by providing a platform for understanding, communicating and reinforcing these wishes and preferences throughout a person's care pathway or the growth of personal and social relationships; processes that can be

more effectively led by the person with an intellectual disability with the right Multimedia Advocacy digital tools.

### 6.1 | Theories applied to the adoption of digital technology

For Multimedia Advocacy to achieve its aims—to provide universally available digital technology to enable self-advocacy—a further area of theory that it is important to understand are those applied to the adoption of digital technology in a range of settings. For a person with an intellectual disability to take charge of and lead their own life course to the fullest extent possible, they should have available mechanisms for influencing their own care pathways and care settings. There are often barriers to the extent to which a person can have this influence, including how digital technology is used or not used as part of care planning and communication. For example, carers or practitioners may resist digital technology for Multimedia Advocacy as they are reliant on existing models of care or concerned that new technology may interfere with their ability to provide care or therapy as usual (Safi et al., 2018).

Several behavioural theories have explained the social and psychological constructs that underpin the adoption of new technology across many settings. Perhaps the best known of these is the diffusion of innovations theory (Rogers & Williams, 1983) which describes adoption of technologies in terms of how population groups differentially adopt technology and how adoption is influenced by factors related to the technology and the context in which it is to be adopted. In our experience of disseminating and implementing Multimedia Advocacy tools we have encountered and grappled with these factors. Our observations from these experiences fall into two main categories: (i) We are introducing the use of digital media over a text-based record keeping system in which photo and video formats are not readily seen as authoritative evidence or planning formats compared to a paper-based evidence system; (ii) in existing systems, photos and media belong with leisure and learning activities rather than the care planning process. Multimedia Advocacy brings the voice into the record in ways that challenge the discourse and language of established health and care services. The change in tone and power relations that a Multimedia Advocacy approach entails is a significant cultural and behavioural shift that disrupts perceived boundaries. For example, Multimedia Advocacy challenges frequent distinctions made between 'formal care data' and 'anecdotal information', between 'providing care' and 'having a conversation', even the distinction between 'work' and 'play'.

The unified theory of acceptance and use of technology (Venkatesh et al., 2016) synthesises traditional models of behaviour change resulting in a multilevel model of behaviour change at organisational-, institutional-, and individual-levels to describe predictors of the adoption and maintained use of new technology. An example of a traditional behaviour change theory is the theory of planned behaviour which describes the role of intentions, attitudes, norms and perceptions in influencing the type of changes in behaviour that

would be necessary to facilitate the adoption of new technology (Ajzen, 2020). A limitation of the TBP in explaining barriers to the adoption of digital technology is the strong focus on acceptance at the individual-level, perhaps without sufficient attention to the impact of the setting in which the technology is being implemented and the role of organisational and institutional factors (Lai, 2017). An example of a model that takes a more holistic approach to understanding adoption is the non-adoption, abandonment, and challenges to the scale-up, spread, and sustainability (NASSS) model described by Greenhalgh et al. (2017) in relation to adoption of digital theories in health and social care settings.

The NASSS model describes persistent problems with the adoption of new technology: technologies are either *not adopted* or quickly *abandoned* by professionals or patients; technology succeeds in surviving as a *small-scale* demonstration project but is not scaled-up, *spread* to other settings or *sustained* over time. The lack of specificity of some of these models is a limitation when considering how people with intellectual disabilities may adopt digital technologies. However, the value of these theories may be in considering adoption of technology at the organisational- or institutional-level. The technology that underpins multimedia advocacy tools and approaches is advancing at pace. It is therefore important to use models of adoption that are flexible and responsive to the advances in technology, changing approaches to care pathways for people with an intellectual disability and changes to the settings, structures and policies that necessarily influence the adoption of new digital technology for Multimedia Advocacy. For example, Diffusion of Innovations Theory and NASSS may be useful in understanding organisational adoption of new technology and funding decisions about resources including digital technology for people with intellectual disabilities. When introducing digital technology to support Multimedia Advocacy in new settings, these

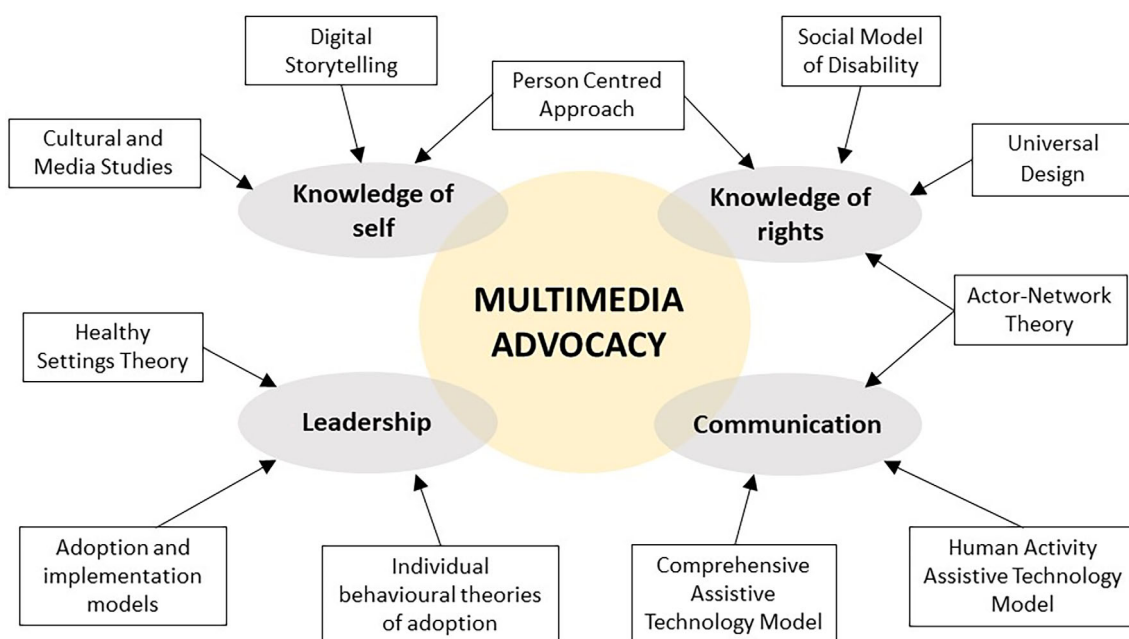
theories can help test assumptions about the likelihood of adoption and identify areas where interventions, training or engagement may be necessary to facilitate sustained adoption.

## 6.2 | Healthy settings approaches

Settings-based approaches focus on the need for social and physical environments that enable healthy choices and remove barriers to healthy choices. Vlot-van Anrooij et al. (2020) recently used a mixed methods approach to apply a settings-based approach to the health and well-being of people with intellectual disabilities. Drawing on the knowledge and experience of people with intellectual disabilities and healthy settings subject experts, the authors identified conceptual clusters that were perceived to be important components of the social and physical environment that impacts the health and wellbeing of people with intellectual disabilities. The clusters were: Healthy home environment; enabling environment; homely environment; tailored environment; encouraging support; supportive network; financial aspects; confidence building support; an open conversation; values about healthy lifestyle; healthcare and prevention; accessibility, and; opportunities to engage. Multimedia Advocacy may provide an important link between these components of the environment and a person with intellectual disabilities by facilitating communication and providing a mechanism through which these components of the environment can be influenced to provide a more supportive setting.

## 7 | CONCLUSIONS

Multimedia Advocacy uses the accessible re-design of digital technology to provide a person with an intellectual disability access to



**FIGURE 1** Inter-relationships between the theories that underpin Multimedia Advocacy.



traditionally inaccessible sources of multimedia and digital communication as a means of: developing, shaping and presenting their identities and selfhood; having their voice heard and listened to; supporting connections to, and information exchange with, their family, community and care support networks; sharing experiences, advocating for change in their physical, social and structural environments and settings, and; playing an active and recognised role in the shaping of health and social care systems and policies. Figure 1 shows the inter-relationships between the theories that underpin Multimedia Advocacy under the structure of test's self-advocacy framework (Test et al., 2005). Multimedia Advocacy, informed by these theories, facilitates communication and interaction between the person with an intellectual disability, their life settings and their social and care networks.

The fundamental problem that Multimedia Advocacy addresses is health inequalities faced by people with intellectual disabilities, who on average die 16 years earlier (Heslop & Hoghton, 2018). Reports highlight avoidable suffering and deaths, with poor care-coordination and collaboration between agencies a significant factor (Heslop et al., 2013). Multimedia Advocacy has the potential to address some of the root causes of health inequalities faced by people with intellectual disabilities, including high rates of social isolation and loneliness (Macdonald et al., 2018). These problems have been intensified by the Covid-19 pandemic, which is a particular concern as social isolation and loneliness are known to be associated with a range of adverse physical and mental health outcomes (Leigh-Hunt et al., 2017), contributing further to existing health inequalities experienced by people with intellectual disabilities. These experiences arise from systemic issues and are perpetuated by a history of segregation and marginalisation, and ableism. There is great potential for digital technology to mitigate some of these negative impacts, however, access to a wide range of digital services and technology remains poor for people with intellectual disabilities (Seale, 2022). Therefore, continued efforts are needed to improve access to digital technology and promote the use of innovative Multimedia Advocacy tools to enhance the social, educational, health, and care experiences of people with intellectual disabilities.

A further key issue identified is lack of understanding of the needs of individuals with intellectual disabilities, with families of people with intellectual disabilities, who hold this knowledge and understanding, commonly reporting that they feel professionals do not listen to them. Multimedia Advocacy tools such as the RIX Wikis capture the personal needs and wishes of individuals with insights of families and carers to inform better understanding. Multimedia information, collated by the person and their immediate support circle alongside their personal care records, can provide a consistent, trusted information source for a transformational model of care for people with an intellectual disability.

The NHS long term plan identifies a need for a 'fundamental shift in how we work alongside patients and individuals to deliver more person-centred care', describing a goal to 'train staff to have the conversations which help patients make the decisions that are right for them' (NHS, 2019). Multimedia Advocacy tools and practices can

equip this aspirational shift and help patients, carers, staff and professionals work together differently, engendering the '*shared responsibility for health*' envisaged in the long-term plan. The Professional Records Standards Body unequivocally highlights the critical value of 'About Me' information (Professional Record Standards Body, 2023) as a component of social and healthcare record-keeping and information-exchange provided by patients and carers. Multimedia Advocacy tools, including the RIX Wiki facilitate precisely this kind of process to meet the Long Term Plan's visions of workforce and patients using digital technology to understand and act on data they can each generate and access.

Multimedia Advocacy also provides a framework to work within contemporary settings as the use of digital technology in education, health and social care is becoming a standard practice and use of social media is embedded within the systems and settings that people with an intellectual disability live. However, the Covid-19 Pandemic has highlighted that many people with intellectual disabilities have had limited access to digital technologies and adequate support to use them effectively, resulting in decreased well-being and social isolation (Seale, 2022). The theories described in this paper highlighted the role of the support staff as actors who influence and determine successful adoption of digital technologies for Multimedia Advocacy. For any organisation to engage and successfully embed person-centred practices, digital technology and Multimedia Advocacy, a long term implementation plan is needed and buy-in from all organisational levels is required. Multimedia Advocacy tools need to be embraced by new health and social care digital systems so that the voice of an individual is included and a genuine person-centred service delivery is achieved.

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