Intellectual and Developmental Disabilities

A Social-Ecological Approach to Inclusive Research with People with Intellectual Disability

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Abstract

Inclusive research reflects a societal shift in how disability is understood from deficit-based to a social-ecological model. The purpose of this article is to delineate the barriers to and supports for inclusive research and the outcomes that are achieved through inclusive research using a social-ecological approach. In the social-ecological framing of inclusive research, a strength-based understanding of disability and the barriers to inclusive research were emphasized. The supports model was employed to describe the role of individual and environmental supports for the inclusion of researchers with intellectual disability. Personal, research, and social outcomes of inclusive research, mediated by supports, were explained. These outcomes interactively make changes in the context where inclusive research is conducted, further enhancing outcomes.

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A Social-Ecological Approach to Inclusive Research with People with Intellectual Disability

Inclusive research involves the active participation of people with intellectual disability as initiators, doers, writers, and disseminators of research versus mere subjects (Walmsley & Johnson, 2003). It is a shift away from research 'on' to research 'with' people with intellectual disability (Johnson, 2009; Walmsley & Johnson, 2003). The key principles of inclusive research include a commitment to social change, empowering participants, and understanding individuals in the context of the lives of people with disabilities (Walmsley & Johnson, 2003). Walmsley et al. (2018) described inclusive research as:

> (a) research that aims to contribute to social change, that helps to create a society, in which excluded groups belong, and which aims to improve the quality of their lives,
>
> (b) research based on issues important to a group, and which draws on their experience to inform the research process and outcomes,
>
> (c) research which aims to recognize, foster and communicate the contributions people with intellectual disability can make,
>
> (d) research which provides information that can be used by people with intellectual disability to campaign for change on behalf of others, and
>
> (e) research in which those involved in it are "standing with" those whose issues are being explored or investigated. (p. 758)

Inclusive research is based on values and ideas that place significant emphasis on research arising from the recognized interests and issues experienced by people with disabilities (Johnson, 2009). Thus, research questions should address problems identified by people with disabilities and advance their interests. Additionally, inclusive research should be a collaborative process, enabling people with intellectual disability to exercise control over the procedures and

the outcomes, and affirming the accessibility of the research questions, processes, and reports (Walmsley & Johnson, 2003).

This paradigm shift in how people with disabilities engaged with research occurred between 1948 and 2003, evolving from the recognition of the right to participate in the scientific process in the Universal Declaration of Human Rights (UDHR; United Nations, 1948) to Walmsley and Johnson's seminal definition of inclusive research (Walmsley & Johnson, 2003). This shift marked a move toward recognizing the ownership of people with disabilities over research, moving beyond the role of being mere subjects of study.

Right to Science

Inclusive research is the recognition of the right to science for people with intellectual disability to the process and outcomes of science, ensuring everyone benefits from and participates in the outcomes of the scientific process. A *right to science* can be understood as "sharing in scientific advancement and its benefits." This right was acknowledged in the UDHR, Article 27 (United Nations, 1948), laying the groundwork for inclusive research. The United Nations has specified the implementation of this right as "opportunities for all to contribute to science and scientific research" and "participation of individuals and communities in decision-making" to secure everyone to benefit from science (United Nations, 2023). Specific to the disability community, the United Nations Convention on the Rights of Persons with Disability (UNCRPD; United Nations, 2006) highlights that people with disabilities have the right to participate in all aspects of the lives of people with disabilities, including research (Shogren, 2023).

United Nations Convention on the Rights of Persons with Disability (UNCRPD)

UNCRPD (United Nations, 2006) names and advances the human rights of people with disabilities consistent with disability advocacy movements. The UNCRPD has been viewed as establishing a framework for conducting inclusive research (Johnson, 2009; O'Brien et al., 2014; Salmon et al., 2018; Vega-Córdova et al., 2020). Specifically, the UNCRPD has underscored the obligation to promote research and develop best practices of universally designed goods, services, equipment, and facilities (Article 4). It also states that in developing and implementing legislation and policies, people with disabilities should be consulted and involved. Additionally, discrimination is prohibited while equality is promoted (Article 5). It puts importance on promoting awareness of the rights and dignity of people with disabilities and their capabilities and contributions throughout society (Article 8). Also, there is a need for measures to ensure access to the physical environment, transportation, information and communications, and other facilities and services provided to the public such as universities (Article 9). Furthermore, disseminating collected data and statistics should be accessible to people with disabilities (Article 31). Lastly, the responsibility of state parties in promoting collaboration in research and ensuring access to scientific and technical knowledge is highlighted (Article 32). The Convention provides specific guidelines on how States can ensure such participation, including empowering people with disabilities to have a voice in decisions about individual lives and issues considered important by people with disabilities (Kearney et al., 2018). Inclusive research contributes to the advancement of meaningful scientific discoveries in the field of intellectual disability (Shogren, 2023).

Purpose

The purpose of this conceptual article is to shed light on a social-ecological approach to inclusive research for advancing personal and environmental support and the outcomes across

the micro, meso, and macro levels (Bronfenbrenner, 1994) that can be achieved through inclusive research.

A Social-Ecological Framing of Inclusive Research

Inclusive research reflects a societal shift in how disability is understood from deficit-based models to a social-ecological model. Inclusive research challenges traditional research models where the inherent talents of people with intellectual disability are often underestimated based on deficit-based perspectives (Stevenson, 2010, 2014). From a social-ecological perspective of disability, inclusive research can be understood as strength-based, using their strengths to lead to changes that influence and interact with individuals with intellectual disability. A social-ecological approach will promote inclusive research by eliminating barriers to and creating opportunities for individuals with disability to be involved in the researcher role (Shogren, 2023; Shogren & Dean, 2024).

Shift from Deficit-Based to Strengths-Based Understanding of Disability

The conceptualization of disability in our society affects how we perceive, diagnose, classify, and support people with disabilities (Buntinx & Schalock, 2010). Historically, disability has been associated with words like “differentness,” “atypical,” and “aberration,” resulting in discrimination and segregation of people with disabilities (Wehmeyer, 2013). This pathology-based approach contextualizes disability as a problem within the person; therefore, people with disabilities are regarded as objects to be fixed, cured, and rehabilitated (Wehmeyer, 2013). Only considering medical and other factors to be remediated fails to consider other, external factors that impact functioning (Wehmeyer, 2013). Failing to consider how society can change to recognize and celebrate disability as a natural part of the human experience leads to ongoing discrimination. It has been criticized by activists and academics allied with the

disability justice movement who call for a greater understanding of problems in the environment that limit human functioning (Marks, 1997).

Recognizing disability as an interaction of a person's unique profile of strengths and needs and the demands of the environment reflects a social-ecological approach (Schalock et al., 2021). This strengths-based approach focuses on cultivating strengths and challenging environmental biases and barriers to advance valued personal outcomes. The impetus for a social-ecological approach to disability was advances in modern understandings of disability shaped by the advocacy of people with disabilities during the social and political movements in the late 20th century (Wehmeyer, 2013). The self-advocacy movements in the late 1990s influenced people with intellectual disability to become visible advocates for themselves and others, which led to the enactment of legislation that brought significant changes in the lives of people with disabilities. As part of these movements, advocates and allies challenged barriers caused by oppression and discrimination from society (Bronfenbrenner, 1979; Shogren et al., 2009). This perspective has created conditions for people with intellectual disabilities to challenge exclusion from research (Tregaskis, 2002) and recognize how the involvement of people with disabilities in research helps uncover social barriers faced by those directly involved.

Barriers to Inclusion in Inclusive Research

When understanding inclusive research with a social-ecological approach, identifying environmental barriers that impede researchers with lived experience conducting research is important. Conventional systems and the culture of academia are representative barriers. According to Layton et al. (2024), cultural norms, attitudes, and beliefs in academia regarding workloads, pressure to work quickly, and inflexible elements in the funding process impede

inclusion. Also, they pointed out that indicators of research success, such as impact factors and hierarchical authorship status, often conflict with authentic and meaningful research inclusion. In addition, limited accessibility to research for people outside academia, such as restrictions related to funding systems, required academic affiliations, and library access, constrains their ability and feeling of belonging to engage in research. Finally, ethical mandates normally reviewed by Institutional Review Borad restrict choices and opportunities for participation in research, leading to further exclusion (Layton et al., 2024; Teixeira et al., 2021).

In addition to the norms and cultures of academia, a lack of access to learning opportunities about research also serves as a barrier (Linnenkamp, 2024; McDonald et al., 2013). People with intellectual disability may not have been provided opportunities to acquire fundamental research-related skills, including an understanding of the scientific process, data analysis, and dissemination. The positive impact of research training on individuals' confidence and identity has been affirmed; however, it is also recognized that training is costly and feasible only with substantial grant funding (Nind et al., 2016).

A Social-Ecological Approach to Inclusive Research

A social-ecological model can advance understandings of the role of supports in inclusive research and the influence of context and the constant interaction across micro, meso, and macro levels in shaping outcomes (Bronfenbrenner, 1979, 1994). A social-ecological conceptualization of disability suggests human functioning is based on an interaction of personal and environmental characteristics (Buntinx & Schalock, 2010). The current American Association on Intellectual and Developmental Disabilities (AAIDD) framework of human functioning recognizes disability as a state of functioning stemming from the interaction between a person and their environments. The supports model explains that when a mismatch between

personal capacities and environmental demands occurs, a need for supports results (Thompson et al., 2009). Supports can involve dismantling systematic barriers and establishing personal supports to access opportunities to participate in and conduct the research, addressing supports needs (Shogren & Dean, 2024).

This article conceptualizes the social-ecological approach to understanding inclusive research and its outcomes (see Figure 1). At its core, the model adopts a strengths-based understanding of intellectual disability with the goal of advancing the right of people with intellectual disability to participate in research and the scientific process. We argue there are multiple possible outcomes of inclusive research that can be understood through the ecological model proposed by Bronfenbrenner (1994), which is enhanced by personal and environmental supports (Shogren et al., 2021).

Employing the Supports Model

The supports model is used in our social-ecological approach to describe the mediating role of supports in advancing access to and engagement and leadership in inclusive research. A system of supports can address the mismatch between personal competencies and demands in conducting research. This requires changing and challenging academic spaces to integrate supports for inclusive research. Individual and environmental supports, cultivating personal strengths and challenging environmental barriers, can be planned and provided to lead to valued outcomes of inclusive research.

Individual Supports. Individual support should ensure that the researcher with intellectual disability fully participates in the research. Individual support is expected to enable researchers to contribute to the research process and outcomes by leveraging researchers' strengths and lived experiences. Regarding this, it is necessary to identify strengths, interests,

and abilities of researchers to match them with the tasks to be performed (Linnenkamp, 2024; Schwartz et al., 2020). Bigby et al. (2014b) described three approaches to the inclusion of people with intellectual disability in research: advising, leading and controlling, and participating as part of a collaborative group. Each approach varies in terms of level of control, role, and purpose, leading to different aspects of inclusion and participation in research. In addition to approaches, the strengths, interests, and abilities of researchers can be demonstrated differently depending on the tasks. Therefore, the preferences of each researcher can be reflected in the inclusion approach and research tasks on which individual support may be based. This is accomplished by asking researchers how they want to be supported and involved to determine what works best for them (Linnenkamp, 2024).

When necessary or upon request, learning opportunities about research should be made accessible to more accurately represent their strengths and interests, along with opportunities to take a lead in the research. For this, training for skills needed for research can be provided to build personal competencies. Nind et al. (2016) identified five models for capacity building in inclusive research from the literature: an apprenticeship model, a lifelong learner model, a challenging inequality model, an addressing deficits model, and a formal model. They added two models that they contended as better suited for inclusive research; an inclusive immersion model which is learning through fully engaging with the research environment and its particular challenges within the unique context of increased accountability and political sensitivity of inclusive research, and a dialogic model which is learning through engaging with and examining all people's (with and without disabilities) knowledge contributions (Nind et al., 2016).

All people should have opportunities to acquire conceptual, procedural, and attitudinal competencies to carry out research (Burke et al., 2003). Components of learning research may

include the formation of research questions and procedures and generating and analyzing data (Frankena et al., 2019; Kramer et al., 2011; Stevenson, 2014). In Vega-Córdova et al. (2020), researchers acquired skills to address the initial stages of a research process, such as (1) selecting and defining a research problem; (2) formulating hypotheses, objectives, and research questions; and (3) selecting the research design and related procedures, activities, and tools. This facilitated collaboration and enhanced their contributions (O'Brien et al., 2014; Vega-Córdova et al., 2020). In that these research components might be related to traditional methods, caution is needed when discussing competencies for research in an inclusive research context. Holding a strength-based perspective, training for necessary research knowledge and skills should be conducted without losing the unique perspectives of researchers with intellectual disability, which Nind et al. (2016) referred to as a conundrum. Pfeiffer et al. (2024) asserted that capacity-building discourse assumes there is a 'right' capacity for research that researchers with disabilities lack, thereby subordinating their knowledge by situating it within the 'sameness' of academe. These concerns about training indicate that the inclusive research paradigm should center on acknowledging their own knowledge and reflections on the data (Bigby et al., 2014a; Nind et al., 2016). Regarding this, O'Brien et al. (2022) emphasized that the insider perspectives on what defines training should be prioritized. Research training should not become another barrier that determines the qualification of researchers with lived experiences to participate in research. Additionally, it should aim to develop their strengths and interests while meeting their learning needs in conducting research.

Another individual support can include strategies that can reduce cognitive burden. People with intellectual disability might benefit from these strategies that make the research process more accessible, and these strategies might also benefit all members of a research team.

For example, information can be presented in an easy-to-read format, utilizing plain-language text, large font size, pictures, translations, videos, audios, and alternative formats such as audiovisual materials (Frankena et al., 2019; Vega-Córdova et al., 2020). Other strategies include minimizing the amount of text required for reading, adjusting the pace of meetings, and breaking complex tasks into multiple steps (Bigby & Frawley, 2010; O'Brien et al., 2014; Schwartz et al., 2020). Additional resources can include tools to engage in the research process, such as handbooks, videos, and customized training (Frankena et al., 2019; Vega-Córdova et al., 2020). Human resources can include additional meetings to prepare teams and provide feedback, assistive technology, and the designation of a support person. A support person can be staff from advocacy or service agencies, specialists, or researchers with and/or without disabilities acting as an interpreter and facilitator for the researcher with disabilities (Linnenkamp, 2024; O'Brien et al., 2014; Vega-Córdova et al., 2020). Having both technical and interpersonal skills for support personnel to support researchers with intellectual disability properly has been highlighted (Schwartz et al., 2020). It should be noted that support resources used in inclusive research can come from the person's natural environment (e.g., family, friends, and colleagues without disabilities).

Environmental Supports. Environmental supports for inclusive research aim to dismantle social, cultural, and political barriers that hinder the inclusion of researchers with intellectual disability (Shogren & Dean, 2024). As a research paradigm, the inclusive approach to research requires challenging conventional systems of academia that often fail to elevate the expertise of people with intellectual disability and are not designed to be accessible and inclusive. Creating novel approaches to knowledge production and conducting research can be another environmental support.

Firstly, the funding system requires different criteria and measures when applied to inclusive research. For instance, the cost of research is increased due to the additional time and resources resulting from accommodations and disability (Layton et al., 2024). Therefore, equity allocations tailored for researchers with disability need to be calculated to ensure equal outcomes (Ong et al., 2009) as an integral part of funding applications (Layton et al., 2024). This is crucial for accommodating flexible timelines in that inclusive research typically requires more time for completion.

Secondly, academic systems should ensure the benefit of the community of participants and/or researchers with intellectual disability by making the research production accessible to their community. Additionally, the publication system should permit the full disclosure of authors' identities regarding authorship, even if they are not affiliated with an academic institution. This is a way of respecting the ownership of knowledge and decision-making on how the research is used.

Thirdly, designing novel approaches to accessible and inclusive design can provide crucial environmental support considering that the conventional research approach that researchers without disabilities have owned might prevent full and active participation (Milner & Frawley, 2019). Researchers with and without disabilities can collaboratively develop new methods that fit the research (Nind et al., 2016). It is also necessary to acknowledge the differences in learning and knowing of researchers with intellectual disability and their unique perspectives to maximize the value of inclusive research. For example, Kerr et al. (2024) used alternative methodologies in research that were informed, guided, and validated by an Indigenous Advisory Group who were the members being studied. The importance of developing methodologies that integrate the knowledge of the group being studied, facilitated by involving a

group member, has been affirmed (Charbonneau-Dahlen, 2020), ensuring research is conducted respectfully and culturally appropriately. The key to redesigning and adopting research is to enable researchers with intellectual disability to have genuine control and ownership over the research process and outcome (O'Brien, 2022). This fundamentally respects wider ways of knowing, doing research, and being human (Grace et al., 2024).

Building on this, it is imperative to re-examine what constitutes 'research' to create greater opportunities for engagement and the contribution of experiential knowledge. Traditional academic research often demands extensive cognitive effort and years of training, which can inadvertently limit accessibility for people with intellectual disability. In this regard, research should be redefined to include activities such as service evaluations (Copeland et al., 2014), co-design initiatives (Bayor et al., 2021), and community-based inquiries (Hughes et al., 2020), which are recognized as scholarly contributions, to establish more inclusive pathways for participation. These forms of inquiry uphold scientific rigor while providing accessible entry points for researchers with lived experience to contribute meaningfully. Furthermore, such practice-based research serves as a training ground to develop foundational skills and transition into academic collaborations. To make inclusive research a reality and establish it as a standard, sustainable approach within disability research, it is essential to embrace these diverse forms of inquiry and integrate them into widely accepted research practices.

Valued Outcomes of Inclusive Research

Leveraged by supports, inclusive research can impact various outcomes across the personal, research system, and social levels. These outcomes can cascade across ecological systems (Bronfenbrenner, 1979, 1994), interactively making changes in the context where inclusive research is conducted and further enhancing outcomes.

Personal Outcomes

In the context of the social-ecological model, quality of life (QOL)-related human functioning domains can be utilized to measure the effect of supports on personal outcomes (Schalock & Verdugo, 2012). Participating in inclusive research could potentially enhance human functioning. A specific explanation of how personal outcome domains (i.e., personal development, self-determination, interpersonal relations, participation, emotional well-being, physical well-being, material well-being) can be impacted by inclusive research is provided in Table 1.

First, personal development can be improved through engagement in a research role. Inclusive research itself provides people with disabilities opportunities for learning and new experiences that strengthen communication, collaboration, and problem-solving (Frankena et al., 2019; Schwartz et al., 2020), while also building competencies for conducting research (Cumming et al., 2014; Povee et al., 2014; Williams et al., 2005).

Second, outcomes related to self-determination can be enhanced including learning to self-advocate (Callus, 2019; Williams et al., 2005) as well as setting and planning for goals in inclusive research (Hogansen et al., 2008), all of which can support being a causal agent over one's life (Schwartz et al., 2020). Causal Agency Theory describes the importance of contextual factors and experience in developing "causality beliefs." This theory suggests that when individuals see the impact of their actions on the environment, they are more likely to perceive themselves as an agent of change (Shogren et al., 2015). Causal Agency Theory can be applied to inclusive research, and benefits may include repeated opportunities for people with intellectual disability to see how their input influences research, leading to increased autonomy in research, raising awareness of their situation, and motivating them to bring about change (Kramer et al.,

2011; Walmsley et al., 2018). Self-determination within inclusive research can also enable people with disabilities to create significant personal and social changes, which can considerably impact their lives.

Third, interpersonal relations may be improved through inclusive research opportunities as researchers with intellectual disability can develop relationships and meet various people who would not otherwise encounter (Frankena et al., 2019), build trusting relationships (Bigby et al., 2014b; O'Brien et al., 2014), and become a member of a team (Schwartz et al., 2020).

Fourth, participation is promoted as researchers with intellectual disability engage in research activities with community members and/or other researchers with and without disabilities (Nierse & Abma, 2011). If barriers to participation are revealed and eliminated in the process of inclusive research, people with disabilities benefit by having more opportunities to participate and get actively involved in advocacy in their community.

Fifth, the rights of people with disabilities can be promoted and protected by inclusive research as inclusive research supports the right to science and a recognition of the right of people with intellectual disability to identify and shape research questions (Shogren, 2023). Inclusive research involves removing barriers that prevent everyone from accessing data and information, including research results. Furthermore, people with intellectual disability can influence and participate in developing and implementing legislation and policy emerging from inclusive research. Inclusive research is founded on respect for the lives and voices of people with disabilities, aiming to ameliorate social inequalities (Weaver & Cousins, 2004).

Sixth, emotional well-being can be impacted if people with disabilities find the research process enjoyable (Frankena et al., 2019), have feelings of being valued and confident, and experience success (Bell & Mortimer, 2013; Nind & Vinha, 2014; Schwartz et al., 2020).

Seventh, physical well-being can be promoted through addressing health-related research needs and outcomes, including research and advocacy to address health inequities. This can support a better understanding of the health conditions of people with intellectual disability, leading to improved healthcare experiences (Frankena et al., 2019; Michell, 2012).

Lastly, material well-being can be advanced if researchers with intellectual disability are financially compensated for work and gain access to new employment opportunities (Bigby & Frawley, 2010; Frankena et al., 2019; Schwartz et al., 2020).

Research Outcomes

In addition to direct benefits to people with intellectual disability, inclusive research can also advance change and meaningful outcomes within the academic research system. Inclusive research can enhance the quality and external validity of research. The involvement of people with disabilities brings out more relevant research questions, more appropriate data collection methods, more in-depth analysis of data, and better distribution of research results (Bigby & Frawley, 2010; Bigby et al., 2014a; Tuffrey-Wijne et al., 2009; Walmsley et al., 2018). Inclusive research promotes authenticity, as researchers with disabilities are committed to the research topic that comes directly from the needs and problems they identify as a priority, which provides culturally valid, first-hand experiences (Walmsley et al., 2018). As inclusive research practices are adopted and scaled across research teams, research universities, and research funders, there is a large potential for change in the systems that support research. In sum, inclusive approaches can enhance the research process and improve research quality by incorporating the perspectives of people with intellectual disability, which is an added value of inclusive research (Walmsley et al., 2018).

Research findings from inclusive research show that active involvement of researchers with intellectual disability influences research results and may make it more relevant for people with disabilities, helping to develop feasible and effective interventions and services based on a comprehensive understanding of needs (Dykstra Steinbrenner et al., 2015; Kester et al., 2022). Incorporating research findings can enhance the capacity of those in charge of legislation and service planning to meet the needs of people with disabilities. Inclusive research can be used to identify the factors that influence the quality of life of people with intellectual disability with its accessible methodologies (O'Brien et al., 2022). Further, such approaches can have impacts beyond intellectual disability research and influence research with other populations and in multiple domains (e.g., health, education, clinical, and community services).

In addition to the positive impact of research itself, inclusive research provides an opportunity for allies to fulfill their duty to advocate for the people on whom their research focuses (Walmsley et al., 2018). Additionally, for researchers with lived experience, having a role as a researcher enhances the personal competency and social image of people with intellectual disability through the development of 'valued skills', which are two main ways to achieve role valorization (Walmsley, 2001). According to social role valorization theory, holding a valued social role is expected to lead to access and provision of desirable aspects of life for people devalued by their own society (Wolfensberger, 1983). Thus, this can positively impact people with disabilities as well as the research system by challenging deficit-based approaches and advancing social-ecological approaches.

Social Outcomes

As demonstrated in the new definition of inclusive research from Walmsley et al. (2018), social outcomes are a key focus of conducting inclusive research, promoting social

change by creating a society where marginalized groups belong (Walmsley et al., 2018). Through the dissemination of research, inclusive research seeks to raise public awareness about strengths-based approaches to understanding intellectual disability (Povee et al., 2014) and impact legislation and policies. For instance, inclusive research findings on intimate relationships between people with intellectual disability (Bane et al., 2022) led to the Law Reform Commission in Ireland changing the Criminal Law (Sexual Offences) Act 1993 which banned sexual relationships between people with intellectual disability. Another example is the Oxfordshire Self-Advocacy Organization in England which utilized inclusive research results to raise the quantity of Annual Health Checks available to people with intellectual disability (Michell, 2012; Walmsley, 2011).

An additional social effect of inclusive research is the amelioration of inequalities inherent in our society (Weaver & Cousins, 2007), as it disperses power between people with and without disabilities (Bigby et al., 2014a), increases awareness of issues faced by people with disabilities, presses for creating more equitable policies, and challenges stigmas and assumptions about abilities (Frankena et al., 2019).

From the social-ecological perspective, personal, research, and social outcomes are interdependent and interconnected. Improved social outcomes influenced by inclusive research findings will again positively affect personal outcomes; for instance, people with intellectual disability are more likely to enjoy enhanced physical well-being when they have more annual health checks due to financial support from the government. Overall, there can be multiple and cascading impacts of inclusive research, when strengths-based systems of support are put in place.

Implications for Future Policy, Practice, and Research

A social-ecological approach to inclusive research underscores the importance of a strength-based understanding of intellectual disability and the removal of barriers that prevent people with intellectual disability from contributing to science and generating knowledge through inclusive research. This article highlights the mediating role of individual and environmental supports for inclusive research and the cascading and interactive impacts of inclusive research on personal, research, and social outcomes that affect human functioning. Therefore, future policy can focus on providing many opportunities and addressing systemic barriers for people with intellectual disability to conduct and participate in research. In particular, funding is needed for enhanced support to expand learning opportunities and provide financial compensation to researchers. The interactive nature of outcomes from inclusive research highlights the need to establish close connections between inclusive research, practice, and policy to effectively reflect research findings in policy. As a field, more strategies and systems of supports to encourage co-construction of knowledge through partnership between researchers with and without disabilities are needed. Additionally, academia should shift its culture and norms to value and recognize the importance of indigenous knowledge in the field of disability. Reforming the traditional funding system and publication process to be more accessible and inclusive for researchers with lived experience will advance this change.

Future research should investigate how individual supports can leverage personal strengths and interests in the inclusive research process. Furthermore, further research needs to explore the development and application of innovative research methodologies distinct from traditional approaches that acknowledge ways of conducting research that promote equality in partnerships with researchers without disabilities. In addition, the field could benefit from further exploration of quality indicators of inclusive research practices, as well as examination of the

impact of culture and intersectionality on research access, participation, and outcomes. Finally, future research should aim to establish and systematically document diverse participatory and practice-based approaches, ensuring that the expertise of individuals with lived experience is effectively recognized and utilized in research.

A key limitation of this work is the lack of participation of people with intellectual disability in the initial development of this understanding of inclusive research through a socio-ecological lens. Although this paper was written to promote inclusive research, it has not yet been evaluated with input from individuals with intellectual disability. Acknowledging the importance of incorporating perspectives from lived experience in publications, future research should involve researchers with intellectual disability in the evaluation and refinement of this concept to ensure its accessibility, relevance, and usefulness.

Conclusion

This article conceptualized a social-ecological approach to inclusive research. Inclusive research imbues values and objectives that should be highly sought after in disability research. Inclusive research respects and centers on lived experiences, cultures, and voices of people with intellectual disability and the community. Removing barriers and providing support to conduct research counters deficit-based thinking, ableism, and power differentials, which have historically led to the exclusion of people with intellectual disability from this type of intellectual work due to assumptions about capabilities and systemic barriers that are present in university and academic systems and spaces. In this respect, our field must continue to strive to advance inclusive research, benefiting the disability community and promoting social change.

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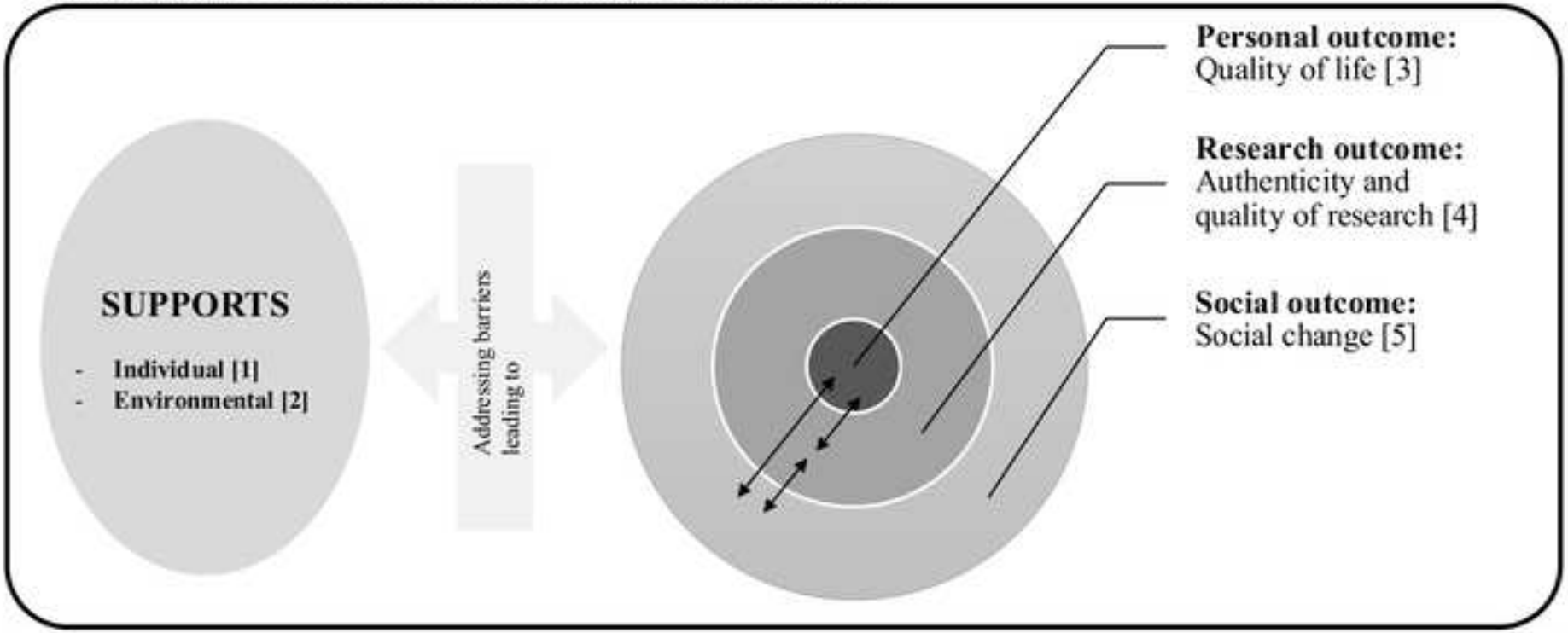
Figure 1

Outcomes of Inclusive Research on Human Functioning Mediated by Supports



Areas	Detailed Points and References
[1]	• Matching strengths and roles (Linnenkamp, 2024; Schwartz et al., 2020) • Providing opportunities to learn research (Burke et al., 2003) • Reducing cognitive burden (Frankena et al., 2019; Vega-Córdova et al., 2020)
[2]	• Challenging barriers in academia (Layton et al., 2024) • Innovative research approach (Kerr et al., 2024)
[3]	• Developing personal competency (Cumming et al., 2014; Frankena et al., 2019; Povee et al., 2014; Schwartz et al., 2020; Williams et al., 2005) • Increased self-determination (Callus, 2019; Hogansen et al., 2008; Schwartz et al., 2020; Williams et al., 2005) • Improved interpersonal relations (Bigby et al., 2014b; Frankena et al., 2019; O'Brien et al., 2014; Schwartz et al., 2020) • Promoted participation (Nierse & Abma, 2011) • Exercising the right to science (Shogren, 2023; Weaver & Cousins, 2004) • Achieving emotional, physical, material well-being (Bell & Mortimer, 2013; Bigby & Frawley, 2010; Frankena et al., 2019; Nind & Vinha, 2014; Michell, 2012; Schwartz et al., 2020)
[4]	• More valid findings with relevant research process (Bigby & Frawley, 2010; Dykstra Steinbrenner et al., 2015; Koster et al., 2022; Tuffrey-Wijne et al., 2009) • Representation of culturally valid, first-hand experiences (Walmsley et al., 2018) • Ethical and inclusive research process (Bigby & Frawley, 2010; Bigby et al., 2014a; Tuffrey-Wijne et al., 2009; Walmsley et al., 2018)
[5]	• Policy impact (Bane et al., 2022; Michell, 2012; Walmsley, 2011) • Increased societal awareness about disability (Povee et al., 2014) • Amelioration of inequalities in society (Bigby et al., 2014a; Frankena et al., 2019; Weaver & Cousins, 2007)

Table 1

Personal Outcomes Related to QOL and Human Functioning Domains

Domains	Examples of Personal Outcomes of Inclusive Research
Personal development	Improved skills related to research (Frankena et al., 2019; Schwartz et al., 2020), having opportunities to learn and experience (Cumming et al., 2014; Povee et al., 2014; Williams et al., 2005).
Self-determination	Improved self-advocacy (Callus, 2019; Williams et al., 2005), learning related skills (e.g., goal setting and attainment, problem-solving; Hogansen et al., 2008), being a causal agent (Schwartz et al., 2020).
Interpersonal relations	Meeting various people (Frankena et al., 2019), building trusting relationships (Bigby et al., 2014b; O'Brien et al., 2014), being a member of the team (Schwartz et al., 2020).
Participation	Engaging in research activities (Nierse & Abma, 2011), eliminating barriers to participating in the community
Rights	Protection of universal human rights (Shogren, 2023), amelioration of social inequalities (Weaver & Cousins, 2004).
Emotional well-being	Feeling enjoyment (Frankena et al., 2019), being valued, and growing in confidence (Bell & Mortimer, 2013; Nind & Vinha, 2014; Schwartz et al., 2020)
Physical well-being	Self-advocacy on healthcare needs (Frankena et al., 2019; Michell, 2012)
Material well-being	Financial compensation, building career opportunities (Bigby & Frawley, 2010; Frankena et al., 2019; Schwartz et al., 2020)