INCLUSION OF STAKEHOLDERS WITH NEURODIVERSITY IN PROGRAM DEVELOPMENT AND EVALUATION

Kimberly M. Brdar
Marywood University

kmbrdar@m.marywood.edu

Inclusion of Stakeholders with Neurodiversity in Program Development and Evaluation

Kimberly M. Brdar

Abstract

A research paper describing the necessary involvement of program participant stakeholders in the development and evaluation of programs; particularly programs intended for individuals with neurodiversity. The neurodiversity movement highlights the importance of consideration to the social context of the population and paradigm. A literary analysis of inclusive practices in research provides insight into the benefits and challenges of inclusive program development and evaluation. An examination of the ethical inclusion of individuals with neurodiversity highlights the process of informed consent, adaptation of materials, and merit of input that can result in increased understanding and meaningful outcomes.

Keywords: program evaluation; stakeholders; neurodiversity; inclusivity; informed consent; collaborative inquiry

Background

Program evaluation is the determination of the merit or worth of a program within the political and organizational context in which it is conducted (Mertens & Wilson, 2018). In contrast to research, a process that seeks to produce new and generalizable knowledge, evaluations are used to make decisions and modify programs within a specific context (Dawoody, 2021a). Although there are many different approaches to program evaluation, prior to initiation, evaluators begin by obtaining a complete project description and meeting with stakeholders of the program (established or proposed) (Posavac, 2011).

Stakeholders include anyone with a vested interest in the program, policy, or product being evaluated (Posavac, 2011). Stakeholders include people who have decision-making authority over the program, people who have direct responsibility for the program, people who the program is intended for, families and communities of individuals the program is designed for, and people disadvantaged by the program (Mertens & Wilson, 2018). Stakeholders can include policymakers, funders, advisory boards, administrators, managers, direct-care staff, clients, families, and communities (Posavac, 2011; Mertens & Wilson, 2018). Stakeholder identification and engagement are essential elements in developing and evaluating a program (Posavac, 2011). If the development or evaluation puts greater emphasis on the interests of a particular stakeholder, the program may not be useful for all impacted stakeholders (Posavac, 2011).

Stakeholders provide program evaluators with an understanding of the program's philosophy, vision, and objectives being evaluated (Goodman & Thompson, 2017). Understanding the purpose and outcome of a program and how and when it should occur enables the evaluator to development and initiate a program theory (Dawoody, 2021f). The involvement of stakeholders ensures clarity of goals and evaluation criteria as the paradigms of various stakeholders impacts interpretation and determination of program merit and worth (Mertens & Wilson, 2018). The collaborative efforts of program evaluators and stakeholders provide a deeper understanding of the structure and nature of a program and the expectations and characteristics of stakeholders, influencing the approach selected to address the evaluation process (Rodríguez-Campos, 2012; Posavak, 2011). In addition, the evaluation is strengthened through the inclusion of the community and people served (Posavak, 2011).

There is an ethical component to the identification and participation of stakeholders as there are varying paradigms to consider within a program, and the evaluation can affect stakeholders differently (Posavac, 2011). A paradigm is an assumption addressing an individual's perspective; it is the philosophical assumptions an individual makes based on how they frame what is ethical, authentic, and valid knowledge and systemic inquiry (Mertens & Williams, 2018). An individual's paradigm is their world view, constructed through life experiences (Mertens & Williams, 2018). Differences in criteria and paradigm can lead to differences in program development and evaluation; "when people disagree… it is often because they are using different criteria to make their choices" (Posavac, 2011). Depending on the paradigm of the stakeholder, their interests in program efficiency, effectiveness, cost, or need may differ, and as such their interpretation of evaluation results may also vary (Posavac, 2011; Brandon & Fukunaga, 2014; Dawoody, 2021g).

Stakeholders can be involved in program evaluation in various ways in varying phases of the process, including evaluation design, data collection, and interpreting evaluation results (Brandon & Fukunaga, 2014; Rodríguez-Campos, 2012). The selection, control, and depth of participation are elements of stakeholder participation that evaluators must consider as part of the program evaluation (Rodríguez-Campos, 2011).

The neurodiversity movement highlights the importance of inclusive practices to validate and clarify the needs of individuals with neurodiversity (Russel, 2020). Inclusive practices have been highly influential in research; inclusive research seeks to empower populations to participate as members of the research team rather than the research happening to or for them (Fletcher-Watson, et al., 2021). Inclusive research has been completed with varying degrees of involvement from neuro-diverse participants. Involvement ranges from tokenism to emancipated research; most commonly, individuals serve as advisors or members of a self-advocacy group (Bigby, et al., 2013). Ethical considerations of inclusive research include informed consent, comprehension, effective communication, and confidentiality (Hamilton, et al.,2017; Ho, et al., 2018; Jarmillo-Velez, et al., 2020; Kadam, 2017; Turcotte-Tremblay, & Mc Sween-Cadieux, 2018; Hills, et al., 2019; Taua, et al., 2014).

Problem Statement

While the neurodiversity movement has promoted a well-documented increase in inclusive practices in research, the neurodiversity stakeholder paradigm continues to be marginalized in the development and evaluation of programs (Jacobson, et al., 2013). To adequately define and address the needs of individuals with neurodiversity, the development and evaluation process should "regard [the] social context" of this population (Posavac, 2011). Although it is not without ethical and pragmatic challenges, inclusive-research design may present valid considerations for addressing the inclusion of the neuro-diverse population in program development and evaluation.

Intention

The purpose of this study is to examine the applicability of inclusive-research design to the inclusion of neuro-diverse stakeholders in program development and evaluation. This article will address the various roles, challenges, and ethical aspects of inclusive program development and evaluation through a systematic review of the empirical literature. The central questions of this research composition are:

1. What impact does the inclusion of stakeholders with neurodiversity have on program development and evaluation?
2. How do we ensure ethical inclusivity?
3. How can inclusive research inform the potential of inclusive program development and evaluation?

Literature Review

Inclusion of Neuro-Diverse Stakeholders

Stakeholders identifying as clients, individuals for whom the program is intended, are considered "the best source of information on their own condition," (Dawoody, 2021i). Yet, they are the least likely to have a voice in the planning and implementing programs and evaluations (Posavac, 2011). The inclusion of client-stakeholders is essential in the representation of this population, particularly if the client-stakeholder paradigm is differentiated from other stakeholders such as people with neurodiversity and cognitive disability (Robinson, et al.,2014). While planning the evaluation, it is essential that stakeholders agree on the jointly selected criteria for the goals and evaluation of the program and its applicability and appropriateness for the participants in the program (Posavac, 2011).

The term "neurodiversity," coined by Judy Singer in 1998 as part of the autism rights movement, is an umbrella term for individuals with a variation from typical neurocognitive functioning (Kapp, 2020). Neurodiversity originally referred to individuals with autism spectrum disorder (ASD); however, it can be applied to the 300 diagnoses in the DSM-5, including individuals with attention deficit hyperactive disorder (ADHD), dyslexia, Tourette's, synesthesia, and other learning and developmental differences (Baron-Cohen, 2017). The way in which individuals with neurodiversity take in external information, combine, process, and respond is different from individuals considered to be "neuro-typical;" therefore, the inclusion of perspectives from neuro-diverse individuals may be necessary to increase understanding (Fletcher-Watson, et. al, 2021). Without inclusive practices, the development and evaluation of the program are limited to a "neuro-typical" understanding of the "neuro-diverse" experience, challenges, engagement, and motivation (Pena, et al.,2020). However, including stakeholders with neurodiversity is complicated by access limitations, recruitment, and the social and communication impairments typical of this population (Cascio & Racine, 2019).

According to the Diagnostic and Statistical Manual (DSM)–5, to be diagnosed as having ASD an individual must display "persistent deficits in social communication and social interaction across contexts" (DSM-5). Individuals with ASD present with a spectrum of challenges associated with communication, social skills, and language. Individuals with ASD considered verbal might have challenges such as limited and very concrete language, echolalia, and idiosyncratic language use (Preece & Jordan, 2010; Wood, 2020). The communicative expression of individuals with ASD may not always be recognized or offered ample opportunity (Wood, 2020).

Whose voice are we hearing?

During inclusive research, program development, and evaluation, organizational personnel is usually more involved than the sponsors or the clients (Posavac, 2011). People close to participants, such as family members, may also provide information, especially when the participants are very young or incapacitated (Posavac, 2011). It is often assumed that program personnel and family members understand the individual's wants and needs, a necessary component of developing a program provided for their welfare (Posavac, 2011), however research has shown that having a single informant may result in an inaccurate or incomplete picture of an individual's needs and strengths (Hume, et al., 2018). Additionally, differences in perception lead to a lack of alignment across informants, illustrating the importance of triangulation and using multiple sources to ensure accurate and complete responses (Hume, et al., 2018).

Opportunities for self-advocacy add value to the interpretation of data as it provides a unique paradigm of insight and access to an "insider cultural knowledge" (Walmsley, et al., 2018). In addition, self-advocacy opportunities equate to "giving a voice to people with disabilities" (Fullana, et al., 2016). The use of visual supports and talking mats can aid in communication but may restrict the range of communication to the photographs or symbols offered. In these situations, it is common for peers or familiar adults to serve as an individual's proxy informant (Preece & Jordan, 2010).

Neurodiversity paradigms

Conceptualizing neurodiversity as a paradigm forces an elimination of the concept of “otherness” as it reframes the definition of “normal” (Pearson, et al., 2014; Pena, et al., 2020). The concept of “otherness” assumes that individuals with disabilities are different and has led to negative stereotyping, prejudice, limited opportunities, and segregation (Pearson, et al., 2014). In contrast, the neurodiversity movement proposes neurodiversity as a paradigm, shifting perspective to differences in cognitive functioning as normal variations of the human condition (Pena, et al., 2020). Neuro-diverse thinking sees multiple, non-exclusive, and often non-linear possibilities; it is an all-inclusive acceptance of every neurological difference without exception" (Pena, et al., 2020; Russell, 2020). Identifying individuals as neuro-diverse acknowledges neurological diversity and the existence of “Neuro-tribes" (Silberman, 2015) as part of a spectrum of neurological diversities rather than in the comparison of a standard or "neuro-typical" individual (Baron-Cohen, 2017; Kapp, 2020). Through the neurodiversity movement the autistic community shifts away from “deficit-driven understandings” and recognizes the contributions and value neuro-diverse individuals make to society (Pena, et al., 2020). “While the goal of inclusion is equality of opportunity; equality does not mean sameness" (Pearson, et al., 2014).

In the development and evaluation of programs, evaluators' consideration of neuro-diverse paradigms is vital to understanding and addressing the needs of this community. The collaboration and engagement of the neuro-diverse community in program development and evaluation of outcomes improve cultural competence and ensure agreement of program goals and construct validity (Pena, et al., 2020). Cultural competence is specific knowledge of the people and place in which the evaluation is being conducted. "Cultural competence requires awareness of self, reflection on one's own cultural position, awareness of others' positions, and the ability to interact positively with others" (AEA, 2011).

One approach to addressing the neurodiversity paradigm is the use of a Community-Based Participatory Approach (CBPA). This approach addresses the power imbalance between individuals who develop/evaluate programs and the community being served by providing an opportunity for full engagement of community partners (Pena, et al., 2020). Built on core principles that foster equitable partnership, capacity building, co-learning, and action toward health and social justice, CBPA partners with community leaders, members, community-based organizations, and practitioners; the inclusion of diverse and expert perspectives results in a response that is grounded and responsive to the needs of the community (DeJonckheere, et al., 2019). A key influencer of the CBPA, in Paulo Friere's book *Pedagogy of the Oppressed* he states "to liberate the oppressed without their reflective participation in the act of liberation is to treat them as objects that must be saved from a burning building," Rather than treating marginalized members of communities as objects we must treat them as engaged subjects whose participation is needed throughout every stage of the process (Jull, et al., 2017). As one of the most important and accessible data sources, the personhood of program participant-stake holders should be recognized as part of the community despite potential challenges (Posavac, 2011; Cascio, et al., 2020a). While inclusivity is important in addressing the unique paradigm and needs of the stakeholders of neuro-diverse program participants, ethical issues must be considered (Morina, 2020).

Ethical Inclusivity & Informed Consent

As a program developer/evaluator, the first responsibility is to protect people from harm (Posavac, 2011). Consideration of informed consent, comprehension, communication, accessibility, and confidentiality is necessary to ensure ethical inclusion in program development and evaluation (Posavac, 2011; Mertens & Wilson, 2018). For neuro-diverse individuals, ethical inclusivity is particularly challenging as arguments can be made addressing their right to contribute, right to be protected from exploitation, and how to determine their decision-making capacity to agree to participate independently or with support (Iaconol & Carling-Jenkins, 2012), often resulting in exclusion from research and marginalization of this paradigm (Auerswald, et al., 2017). Significant history of mistreatment and exploitation of these vulnerable populations has helped shape current notions of ethical inclusion of individuals in program evaluation and research with the use of systems such as Institutional Review Boards. Informed consent must be thought of as a continuous dynamic process, not an isolated event (Kadam, 2017).

Informed consent

Informed consent requires participants to receive and comprehend information appropriately to make an autonomous decision (Dawoody, 2021g; Kadam, 2017). Consent to participate is considered informed when potential participants are provided with enough information to consider all options before deciding whether or not to participate (Posavac, 2011).

During the informed consent process evaluators should provide participants with all the necessary information regarding the process (duration, procedures); providing this information in multiple modalities (paper form and an oral explanation) helps to ensure information is understood (Jarmillo-Velez, et al., 2020). While evaluators must ensure that they provide enough information, they need to be cautious about revealing too much information and threatening the validity of the evaluation (Posavac, 2011). Once a participant has provided meaningful informed consent, the evaluators should reaffirm consent to participate throughout the process (Jarmillo-Velez, et al., 2020).

For informed consent to be considered meaningful, participants must demonstrate competence, comprehension, and voluntariness (Kadam, 2017). Evaluators have an ethical obligation to protect participants by ensuring understanding and agreement from program participants before the start of the evaluation and throughout the process until the end of the participant's involvement (Posavac, 2011; Jarmillo-Velez, et al., 2020).

If an individual is considered to be vulnerable due to social injustice, dependencies, impaired capabilities, or other issues, they are deemed to be incapable of protecting themselves and are not able to legally consent or refrain from providing informed consent (Jarmillo-Velez, et al., 2020; Kadam, 2017). For individuals with impaired capabilities, it may be necessary for a legally designated representative to provide surrogate consent with the participant's agreement (Kadam, 2017). To ensure the ethical participation of individuals who are not able to provide informed consent, evaluators can consider the use of assent forms in addition to the informed consent of a proxy or individual representative (Veritas, 2014; Weisleder, 2020). Assent forms provide individuals a way to assent (agree) or dissent (disagree) to participate in congruence with the informed consent of a parent/guardian/advocate (Weisleder, 2020). This honors the ethical right of participants to decline participation even if their legal representative has provided informed consent (Veirtas, 2014).

Competence

The consideration of competence is an ethical complexity for participants who are considered part of vulnerable groups, such as those with cognitive impairments and disorders (Jarmillo-Velez, et al., 2020). An individual's level of competence validates their ability to make an informed decision, understand information, consider the situation and consequences, apply reasoning, and communicate choices (Kadam, 2017; Hamilton, et al., 2016).

A commonly underrepresented paradigm, the capacity of individuals with neurodiversity who are also non-verbal is often inappropriately assessed (Hills, et al., 2019; Goddard & Goddard, 2012). The social perception is that individuals with 'cognitive impairment' and communication issues (including those with non-verbal ASD) are unable to understand or independently consent to participation (Hills, et al., 2019).

One example of this is the autobiographical tale *I am Intelligent* (Goddard & Goddard, 2012); this story illustrates the experiences of a young girl (Peyton) diagnosed with non-verbal ASD and her family as they endure 22 years without effective communication. After losing her language skills as a young girl, Peyton could not communicate her understanding of the world, situations, and conversations around her. She became defined by her diagnosis; underestimated, depressed and suicidal until she was liberated at age 22 through facilitated communication. Her sentence structures were often inverted and her words were sometimes invented, but her messages were clear.

Facilitated Communication (also known as assisted or supported typing) is “a technique that involves a person with a disability pointing to letters, pictures, or objects on a keyboard or on a communication board, typically with physical support… on the hand, wrist, elbow, or shoulder” (American Speech-Language Hearing Association, 2018). Despite the American Speech-Language Hearing Association’s position on facilitated communication as inconsistent with communication rights of autonomy and freedom of expression (American Speech-Language Hearing Association, 2018), this and similar stories highlight the need for careful consideration of competence (McKinley, 2011) and address the misconception that "not being able to speak means not having anything to say" (Grandin, 2011).

Comprehension

Assessing comprehension of the information and process is another essential element of informed consent (Kadam, 2017). In addition to cognitive impairment, factors such as mental disorders, age, education, income, and medical diagnosis such as dementia are potentially inherent vulnerabilities that may impact the eligibility of participants (Falvo, et al., 2021; Kadam, 2017). Comprehension may be further limited by factors associated with the evaluator; poor communication skills, limited availability, and technical terminology may increase anxiety and decrease awareness of potential participants (Kadam, 2017). Evaluators may also need to consider how the generational differences associated with a broader age gap may impact understanding for older participants (Flavo, et al., 2021).

To reduce complexity and increase comprehension, information must be presented in a way that is more accessible to participants. Evaluators must provide all information in appropriate and comprehensible formats for potential participants and ensure support necessary to facilitate autonomy (Jarmillo-Velez, et al., 2020). Consent forms often use complex language that is difficult for participants to process and understand (Antal, et al., 2017). Ideally, information should be reduced in complexity and length, available in multiple modalities, affordable, transportable, modifiable, and within the boundaries of ethical and legal implications (Lindsley, 2019). Participant-centered language and the use of clear, concise communication enhances comprehension (Lindsley, 2019). Assessing comprehension before signing consent can be competed using techniques such as the “Teach back Method,” wherein participants are asked to say in their own words what has been described,” (Kadam, 2017).

In a 2017 study on improving comprehension of the informed consent process, Antal, et al. replaced a paper consent document with a video and multimedia website, provided interaction over the phone rather than face-to-face, and accepted electronic consent rather than necessitating ink on paper. Interactive components of their consent procedure promoted comprehension through short multiple-choice quizzes and over-the-phone discussions. The Sensory-Modality learner-centered strategy promotes improved information processing by pairing two or more sensory systems (Antal, et al., 2017). Consistent with the cognitive theory of learning, sensory modality is an effective way to provide information through separate learning processes such as visual and auditory processing (Antal, et al., 2017).

The needs of each participant should be considered when adapting materials. An assessment of needs through individual interviews can assist in the determination of the strategies necessary to facilitate understanding for each participant (Fullana, et al., 2016).

Voluntariness

For program development/evaluation and research, the inclusion of program participant-stakeholders (those for whom the program is intended or research studies) is beneficial as they are considered "experts by experience," however, it is important to remember that everyone and anyone who fits this paradigm may not be able or willing to be involved, (Bigby, et al., 2013). The most widely accepted definition of voluntariness is Beauchamp and Childress' 2009 definition, whereby a person acts voluntarily "if he or she wills the action without being under the control of another's influence," (Mamotte & Wassenaar, 2015). An individual's voluntariness must be free of exploitation, vulnerability, unfortunate circumstances, and misunderstandings (Mamotte & Wassenaar, 2015). If an individual does not have an adequate understanding of the proposal, if a parent/advocate/proxy agreed to participate without consultation, influential social relationships or silent refusals can limit an individual's perceived options and lead to participation that is not voluntary (Kamuya, et al., 2011). Additionally, the hierarchal authority has been known to interfere with free and informed consent (Turcotte-Tremblay & Mc Sween-Cadieux, 2018).

On the other end of the spectrum, participants who possess voluntariness may not be given the opportunity to participate due to limited awareness, access, and self-advocacy (Bigby, et al., 2013). With a limited pool of potential participants, there is a danger that the perspective of one individual could be generalized as representative of a much larger and diverse group. (Bigby, et al., 2013).

Communication

The diverse understanding and comprehension needs of participants can create challenges in the process of obtaining informed consent (Kadam, 2017). This process is an opportunity to assess the needs and determination strategies necessary to facilitate accuracy in communication with each participant (Fullana, et al., 2016; Kadam, 2017). Providing a way for individuals to utilize their chosen method of communication ensures an authentic, respected, and validated representation (Hills, et al., 2019).

Individuals with neurodiversity may experience challenges with communication and social participation barriers. To be diagnosed with ASD an individual must display "persistent deficits in social communication and social interaction across contexts" (DSM-5). Limited understanding of social situations, maladaptive behaviors, and conflicting priorities can all play a role in the interpretation of questions and responses (Ghanouni, et al., 2019). Conventional communication can be challenging for individuals with neurodiversity, especially those who are limited or non-verbal or those with intellectual disabilities (Courchesne, et al., 2021). Individuals with neurodiversity who are also non-verbal represent a commonly underrepresented paradigm due to challenges ensuring comprehension, communication, and capacity to provide meaningful informed consent (Hills, et al., 2019). Additional communication issues may result from individual diversities related to comprehension of expressive language, processing speed, speech initiation challenges, or language that is limited and very concrete, echolalic, and idiosyncratic (Pena, et al., 2020; Wood, 2020).

By pairing communication strategies, evaluators can facilitate increased understanding. The use of adapted communication strategies such as sign-language, the Picture Exchange Communication System (PECS), talking mats, and communication devices (electronic devices that utilize a program that facilitates communication) are common communication strategies that can be used to facilitate autonomous communication, build rapport, and engage with participants (Ho, et al., 2017; Hills, et al., 2019). However, it should be noted that the use of visual supports and talking aids can also restrict the communication of individuals to the photographs or symbols being offered (Wood, 2020). When desired communication is not supported through the visuals provided, the individual may seek alternative ways to communicate (Wood, 2020).

Alternative communication acts such as a change in emotional valence or physical proximity, or maladaptive behaviors are common for individuals with ASD (Courchesne, et al., 2021). Research has shown a correlation between anxiety and restricted and repetitive behaviors (Joyce, et al., 2017). Consideration of individuals' cognitive, behavioral, and sensory needs are important factors to ensuring accessibility as it may impact an individual's ability to utilize communication devices independently (Hamilton, et al., 2016; Hills, et al., 2019). Failure to recognize and comprehend alternative communications increase the likelihood of maladaptive behaviors or 'acting out behavior' (Marshall, 2017).

A proxy may be necessary to facilitate, provide dexterity assistance or psychological support in using an alternative communication device (Hills, et al., 2019). A proxy who is familiar can help interpret communications; however, caution must be paid to the interpretation of responses as a proxy may interject their perspective, or their presence may cause an alteration in the perspective of the individual (Courchesne, et al., 2021). Individuals who are non-verbal or with profound disabilities are often victims of inferred or attributed opinions (Preece & Jordan, 2010). The relationship between the facilitator and the individual can impact willingness, motivation, and accuracy (Hills, et al., 2019). Caution must be paid to the interpretation of choices to discriminate between non-verbal communications and potentially behavioral responses (Pearlman & Michaels, 2019). To gauge the accuracy of an individual's response, evaluators should plan for multiple interactions; and triangulation through the use of numerous proxies as individuals may respond differently for many reasons such as stimuli or stress (Pearlman & Michaels, 2019). The method of triangulation is used to increase credibility and validity of research findings by combining theories, methods, or observers to prevent bias (Noble & Heale, 2019).

Accessibility

In addition to consideration of alternative communication, documents may need to be provided in alternative formats to facilitate accessibility, provide protection, and ultimately ensure ethical inclusion (Morina, 2020). Traditional methods of obtaining information and feedback are often not accessible for individuals with cognitive and communication limitations (Lilijenquist, et al., 2016). Many individuals with neurodiversity struggle with reading, comprehension, and fine motor skills necessary to provide informed consent or complete self-reporting instruments such as Likert scales (Lilijenquist, et al., 2016).

The creation of accessible data collection methods and instruments are necessary to provide individuals with neurodiversity opportunities to participate in program development and evaluation (Pena, et al., 2020). Mainstream data collection methods and instruments that are designed inclusively are inherently accessible and usable "by as many people as reasonably possible ... without the need for special adaptation or specialized design" (University of Cambridge, 2021). Data collection methods and instruments may also be designed to be diverse or vary to ensure accessibility and understanding. Alternative methods such as closed-ended questions, large print, simplified language, auditory and visual tools are proven methods to improve effective communication with individuals with neurodiversity (Favlo, et al., 2021). Asynchronous data collection, such as email interviews, discussion threads, or the ability to save responses and return later, are techniques that foster communication in less burdensome ways (Pena, et al., 2020; Adams, et al., 2016).

Considering the variation in needs and abilities in the neurodiversity paradigm, it would behoove evaluators to provide multiple accessibility options; presenting questions in various ways such as matching with a word bank, multiple-choice, icons, and true/false responses optimizes accessibility needs variations (Pena, et al., 2020). Holistic personhood, a cornerstone of ethics, considers the outlook of biological, psychological, and social dimensions concerning an individual (Cascio, et al., 2020a). One-size-fits-all approaches are not appropriate as they do not take individual and developmental needs into account (Marshall, 2017).

An example of accessibility is the creation of the Participatory Experience Survey (PES) and the Setting Affordances Survey (SAS); these were developed to assess experiences in recreational youth programs for individuals with intellectual and developmental disabilities (Liljenquist, et al., 2016). When used in combination, these surveys were determined to be effective ways to obtain information and include individuals with disabilities in program evaluations and design (Liljenquist, et al., 2016).

Confidentiality

The protection of personal data and maintenance of confidentiality is fundamental to the participation of any individual who is involved in research or evaluation (Jarmillo-Velez, et al., 2020). Ensuring confidentiality provides a level of trust that is paramount to sharing information and data that may be sensitive (Turcotte-Tremblay & Mc Sween-Cadieux, 2018). Protecting confidentiality is vital to ensuring that there is no undue harm resulting from participation, particularly for vulnerable populations who may not be able to protect their own interests

(Turcotte-Tremblay & Mc Sween-Cadieux, 2018). This is particularly important for individuals with neurodiversity as stigma, micro-aggressions, and discrimination could result if their identification/representation with this paradigm is made public (Pena, et al., 2020). Whenever possible, evaluators should provide an option for confidentiality, and if confidentiality is not possible, individuals with neurodiversity should have control over their disclosure narratives (Pena, et al., 2020)

Ethical Inclusivity & Participation

Beyond obtaining informed consent, the methods and levels of participatory and ethical inclusion of individuals with neurodiversity must be considered (Russel, 2020). Inclusivity research, envisioned as a way to provide individuals with neurodiversity opportunities for self-advocacy, is executed with varying levels of participation ranging from tokenism to emancipated research; most commonly, individuals serve as advisors or members of a self-advocacy group (Bigby, et al., 2013). While inclusive research practices are well-documented, the inclusion of individuals with neurodiversity in program evaluation and design is minimal (Jacobson, et al., 2013). To develop and evaluate programs that meet the needs of neuro-diverse individuals, consideration should be paid to the social context of this paradigm (Posavac, 2011). A study of inclusive research may provide a blueprint for ethical inclusion of individuals with neurodiversity program development and evaluation.

Research – v- evaluation

Although overlap exists between research and evaluation, they are recognized as separate disciplines (Dawoody, 2021b; Posavac, 2011; Mertens & Wilson, 2018). Understanding the key differences between research and evaluation is essential to conceptualizing potential differences in the applicability of inclusivity. Critical differences in evaluation and research are evident in understanding the purpose, participants, methods, and analysis of results.

Research and program evaluation both generate knowledge; research seeks to prove, and evaluation aims to improve (Dawoody, 2021e). Research uses scientific inquiry to create new knowledge that is generalizable based on the researcher's hypothesis; evaluation is a process used to judge the merit or worth of a program by establishing if the program meets stakeholder's desired outcome and if the desired outcome and merits the associated costs (Dawoody, 2021b; Mertens & Wilson, 2018).

Evaluation and research intersect in that research informs the needs, improvements, and effects of programs and policies (Mertens & Wilson, 2018). Research is a beneficial element in the development of a program theory as an examination of basic research can provide evaluators with descriptions of how to help people obtain social support (Posavac, 2011). Application of social research, like evaluation, contributes to our understanding of how to bring people together to address critical social issues (Mertens & Wilson, 2018). The universal goal of program evaluation is to provide the information necessary to make informed decisions based on stakeholder goals (Mertens & Wilson, 2018). Stakeholders must be actively involved in identifying outcome goals (Dawoody, 2021b).

Inclusive Research

Inclusive research seeks to include individuals with disabilities as partners and contributors (Strnadová & Walmsley, 2017). In contrast to traditional research models, inclusive research shifts away from research 'on' to research 'with' individuals with disabilities (Milner & Frawley, 2018; Fletcher-Watson, et al., 2021). Inclusive research requires the inclusion of individuals representing the paradigm or neuro-type being studied; individuals with ASD should be included in studies on ASD, individuals with dyslexia should be included in studies on dyslexia (Fletcher-Watson, et al., 2021). While critics of inclusive research express concern about the vulnerability of these populations, person-oriented research ethics argues that they are just as vulnerable to unjust exclusion (Cascio, et al., 2020a). Ultimately, inclusive research seeks to empower individuals with disabilities to have a voice in identifying and cultivating societal change (Strnadová & Walmsley, 2017).

There is a spectrum of approach to inclusive research (Chown, et al., 2017; Fullana, et al., 2016). Individuals can participate in a variety of ways, with each role leading to different outcomes, learning, and experiences (Puyalto, et al., 2014). Individuals with disabilities can serve in roles: advisory, leading, controlling, and collaborative group approach (Fullana, et al., 2016). Inclusivity can be categorized as participatory, collaborative, co-researching, cooperative partnership, and independently lead (emancipatory) (Fletcher-Watson, et al., 2021). Successful inclusive research requires that all participants understand their roles and responsibilities before initiation (Nind, 2014). Setting clear expectations, a commitment to honesty, and sharing mutual goals are essential elements of the partnership necessary for a successful collaboration on any research project. They are of the utmost importance in engaging individuals representing a multitude of paradigms (Fletcher-Watson, et al., 2021).

Participatory research seeks to incorporate the views of individuals with neurodiversity into research (Fletcher-Watson, et al., 2018). At this level of inclusivity, individuals are most likely to serve as consultants but may also be partners or non-participatory "token" participants (Fletcher-Watson, et al., 2018). Advisory participators, usually individuals who participate as part of advocacy groups, are considered "experts by experience," providing suggestions to questions or wording but do not typically serve a significant or empowered role in the research process (Bigby, et al., 2013).

Inclusive research seeks to give individuals greater opportunity to be involved in the decisions and process of research (Nind & Vinha, 2014). Inclusive research may be defined as collaborative, co-research, or cooperative partnership (Bigby, et al., 2013). The inclusion of individuals with disabilities enhances the validity of research as it provides insight, a window into this paradigm interpretation of the world (Milner & Frawley, 2018; Nind, 2014). Review of inclusive research projects in Australia and the Republic of Ireland sought to address the tension between inclusive research as an empowering process for individuals with disabilities and the strength of the research as a result. The studies demonstrated overall benefit from the inclusion of people with intellectual disabilities as they grew in confidence and helped the team to navigate and address sensitive topics (Johnson, et al., 2013).

The Community-Based Participatory Approach (CBPA) is an example of inclusive action research that integrates research, evaluation, and program improvement. CBPA considers disabled individuals, staff, and allies as part of a community of decision-makers, sharing power and engagement across all phases (Pena, et. al, 2020). Providing access to different perspectives ensures research priorities are relevant, helps measure outcomes, provides access to hard-to-reach groups, assists in disseminating findings, and empowers individuals with neurodiversity (Walmsley, et al., 2018). To be fully inclusive, individuals need to be part of every stage of the research process; the research question should be relevant to their lives and interests, research should be collaborative, individuals should have some control over the research process, and the outcomes should be accessible (Milner & Frawley, 2018).

Emancipatory research puts individuals with disabilities into the driver seat to initiate and complete research with academic researchers serving as expert consultants who carry out the wishes of the individuals with disabilities (Walmsley, et al., 2018). The goal of this research style is to give individuals with disabilities the control to initiate, lead, and execute research on issues important to them; however, without the support of non-disabled allies, it may not be possible for individuals with intellectual impairment to complete the research process (Bigby, et al., 2013).

Inclusive Program Development & Evaluation

Program evaluation requires evaluators to become familiar with the program, the people served, program structure and goals, and the purpose of the evaluation (Posavac, 2011). Thus, the first step in program evaluation is the involvement of stakeholders (Dawoody, 2021a). Accessibility of and to stakeholders is a factor in the inclusivity level possible during an evaluation as it can be influenced by many factors, such as how evaluators relate to organizations (Posavac, 2011). Internal evaluators are employed by the organization for whom they perform the evaluation; external evaluators are hired from outside the organization to evaluate a program (Dawoody, 2021c). Internal evaluators have the advantage of program knowledge and greater access to program staff and participants (Posavac, 2011).

There are four major groups of evaluation strategies: scientific-experimental, management-oriented, qualitative, and participant-oriented (Dawoody, 2021c). While each of these strategies provides a unique and broad perspective on evaluation, it is common for evaluators to utilize multiple strategies during an evaluation. Unlike "distanced" evaluation approaches, collaborative, participatory, and empowerment evaluations emphasize a greater degree of stakeholder involvement (Rodríguez-Campos, 2012; O’Sullivan, 2012). Participant-oriented evaluation approaches promote active and ongoing engagement between evaluators and staff-stakeholders, resulting in enhanced data collection and analysis, stronger program design, and increased likelihood of comprehension and utilization (O’Sullivan, 2012). Participant-oriented evaluation models, such as client-centered and stakeholder models, emphasize the importance of program participants or consumer-oriented stakeholders (Dawoody, 2021c).

Collaborative stakeholder-based evaluation is the most basic form of inclusive evaluation as it requires evaluators to consider the issues from multiple perspectives. The collaborative stakeholder-based evaluation considers a full range of stakeholders as consultants; however, the evaluator remains in control of the implementation of the evaluation (Cousins & Chuinard, 2012).

Participatory evaluation treats program community members as partners with evaluators (Posavac, 2011). Program community members include program developers, managers, staff, funders, program participants or clients, and other relevant stakeholders. Also known as collaborative evaluation, in participatory evaluation the evaluators and stakeholders are linked in what is referred to as an "intersubjective space," in which all are active in the evaluation process (Cousins, & Chouinard, 2012); all stakeholders participate in the planning and evaluation of the program. There are two principal types of participatory evaluation: practical participatory evaluation and transformative participatory evaluation (Cousins & Chouinard, 2012).

Practical participatory evaluation focuses on program problem solving and enhancing evaluation through shared decision making about planning, instrument development, data collection, and analysis (Cousins & Chuinard, 2012). Through active and ongoing engagement with stakeholders, collaborative evaluation results in stronger design, enhanced data collection and analysis, and greater comprehension and applicability of results (O'Sullivan, 2012). This can increase the quality and relevance of the program (Robinson & Fisher, 2012).

Transformative participatory evaluation, also known as empowerment or emancipatory evaluation, is focused on social change, with stakeholder inclusion focused on challenging who controls the evaluation and the paradigm by which knowledge is determined (Cousins & Chouinard, 2012). In this model of evaluation, the decision-making is balanced between the trained evaluator and the stakeholders (Cousins & Chouinard, 2012). In addition to the collection of data, analysis, and dissemination, transformative participatory evaluation seeks to transform power relationships and promote social action (Cousins & Chouinard, 2012).

Ethical Collaborative Inquiry

Collaborative inquiry (which includes research and evaluation) calls for researchers and evaluators to collaborate with individuals, groups, or communities that have a stake in the program or project being studied or evaluated (Cousins & Chouinard, 2012). Justification for collaborative inquiry stems from concerns with social justice, understanding paradigm and context impact on knowledge, and increasing applicability and usefulness of research or evaluation (Cousins & Chouinard, 2012). Competencies considered necessary for collaboration include building a relationship that is mutually trusting, communicating, and collaboration in which everyone contributes (Embregts, et al., 2018).

In addition to obtaining informed consent, program developers and evaluators have an ethical obligation to protect vulnerable populations, including those with neurodiversity, through accessible inclusion. When engagement of individuals with disabilities occurs prior to program development/assessment, it improves understanding of the needs of individuals within this paradigm, enhances the development of goals and outcomes, and ultimately increases construct validity (Pena, et al., 2020). Furthermore, the development of supportive, respectful, and trusting relationships is paramount to the success of an inclusive collaboration (Pena, et al., 2020). Varying scales of inclusivity can be measured in terms of factors such as the level of control in decision making, diversity among stakeholders participating, power relations between stakeholders, manageability of evaluation implementation, and depth of participation (Robinson & Fisher, 2012).

Consideration of data collection methods and instruments design can increase accessibility, bearing in mind that a one-size-fits-all approach will not meet the individual needs in the spectrum of this paradigm (Marshall, 2017). For example, many individuals with intellectual disabilities cannot read well (Strnadová & Walmsley, 2017); modifications such as print variations, simplified concrete language, and close-ended questions, audio and visual tools can address issue issues with experience expressive language, processing speed, or speech initiation that are typical in individuals diagnosed with ASD (Favlo, et al., 2021; Pena, et al., 2020; Strnadová & Walmsley, 2017). Cluley's research on the use of photovoice, a visual method that focuses on participant-led photography, illustrates adaptations that provide accessibility and generate valuable findings (Cluley, 2016). This "radically different approach to research" provided significant insight into the lives of people with disabilities (Cluley, 2016). Pilot-testing data collection instruments are helpful to identify and revise questions that may be confusing (Pena, et al., 2020). Working with individuals who are not trained in research or evaluation processes can be particularly challenging (Strnadová & Walmsley, 2017). The team should budget time and resources to provide training on planning and assessment skills relating to the project in which participants show interest in learning (Pena, et al., 2020). Recognition should be given for any contributions made (Strnadová & Walmsley, 2017).

Analysis

This study sought to address a gap in research by examining the applicability of inclusive-research design to the inclusion of stakeholders with neurodiversity in program development and evaluation. A systemic review of the literature was utilized to explore the roles, challenges, and ethical aspects of inclusivity. The central questions of this research composition are a) what impact does the inclusion stakeholders with neurodiversity have on program development and evaluation? b) how do we ensure ethical inclusivity? and c) how can inclusive research inform the potential of inclusive program development and evaluation?

Identifying and engaging the stakeholders is crucial to obtain various perspectives and define the program goals and objectives (Mertens & Wilson, 2018). Evaluators help stakeholders to clarify their values and assumptions in order to delineate criteria by which merit will be determined (Posavac, 2011). While planning the evaluation, stakeholders must agree on the jointly selected criteria for the goals and evaluation of the program and its applicability and appropriateness for the participants in the program (Posavac, 2011). Evaluators should consider if the goals of the service are designed to meet the needs of the people providing it, the organization funding it, or the individuals receiving it (Marshall, 2017). For example, programs that seek "to turn an autistic child into a non-autistic one" have been shown to induce post-traumatic stress disorder (Greenburg & Rosa, 2020). These programs may have been avoided altogether if individuals with autism had been included in program development. Furthermore, to ensure meaningful stakeholder engagement, evaluators need to understand and work with the individual's unique set of intellectual, visual, sensory, auditory, communication, and motor processing abilities (Greenburg & Rosa, 2020). Program developers need to differentiate between accommodations that provide support and accessibility and those that may perpetuate oppression (Marshall, 2017). Program participants-stakeholders are considered "the best source of information regarding their own condition," (Dawoody, 2021i). Yet, they are the least likely to have a voice in the planning and implementation of programs and evaluations (Posavac, 2011).

The inclusion of neuro-diverse stakeholders in the development and evaluation of programs intended for neuro-diverse individuals is paramount to ensuring representation and determination of program worth in relation to the neurodiversity paradigm (Robinson, et al., 2014). Program development and evaluation should not be completed in isolation from the community characteristics of the people it is intended to serve (Posavac, 2011). The paradigm of individuals with neurodiversity differs from that of neuro-typical individuals due to different experiences and challenges that shape engagement and motivation (Pena, et al., 2020). Research has shown that individuals with neurodiversity process and respond to external stimuli differently than neuro-typical individuals (Fletcher-Watson, et. al, 2021). However, the brain differences of neuro-diverse individuals are not well established or replicated; many neurodevelopmental conditions are diagnosed via observation, cognitive testing, or self-report, and not via neurological anatomy or physiology (Russell, 2020). However, research by Heasman and Gillespie supports previous research on the under-recognized ability of peers with ASD to be motivated by and able to manage interactions with one another (Heasman & Gillespie, 2019). The interactions of individuals with neurodiversity provide a deeper understanding of social and communication differences (Heasman & Gillespie, 2019).

The neurodiversity movement conceptualizes an all-inclusive acceptance of the variation of neurological differences as a spectrum of paradigm diversity (Pena, et al., 2020; Russell, 2020; Baron-Cohen, 2017; Kapp, 2020). Individuals with neurodiversity should not be defined as in terms that are "deficit-driven" or "otherness," but instead with respect and support as a natural variation of individuals with different minds and abilities (Greenburg & Rosa, 2020). Rosie Garland-Thomson states, “The meanings attributed to extraordinary bodies reside not in inherent physical flaws, but in social relationships in which one group is legitimated by possessing valued physical characteristics and maintains its ascendancy and its self-identity by systematically imposing the role of cultural or corporeal inferiority on others," (Straus, 2013).

As a society, we have studied, defined, and organized individuals with neurodiversity through a variety of lenses; medical, social, disability, etc. Individuals are classified or identified as neuro-diverse in comparison to the neuro-typical. However, there is no single way for a 'typical' brain to be wired, so how can one define which brains are 'typical' and' diverse?' (Baron-Cohen, 2017). Where is the developmental line? “Identity is formed not to show differences, emphasize diversity, or celebrate disability, but to define disability in one’s own terms and according to one’s own experience and terms of reference in the social environment,” (Glodkowska, et al., 2018). Regardless of how (and if) we choose to define (or not define) individuals with neurodiversity, ethical inclusion of neuro-diverse stakeholders in the development and evaluation of programs intended for neuro-diverse individuals is ideal as program participants-stakeholders are considered “the best source of information regarding their own condition,” (Dawoody, 2021i). When program participant-stakeholders are not able to adequately communicate their condition/perspective, care should be taken to not exclude those whose needs are most complex. The triangulation of proxy informants and alternative communication methods helps to ensure accurate and ethical inclusion. The inclusion of individuals, groups, and communities who have a stake in the program or project, also known as collaborative inquiry, is justified in the social justice, paradigm understanding, and context impact that results (Cousins & Chouinard, 2012). Collaboration depends upon trusting relationships in which everyone contributes (Embregts, et al., 2018).

Arguably the most important element of ethical inclusivity is the clarification of values and assumptions relating to the development or analysis of a program and the individuals served by the program (Posavac, 2011). Evaluators have a duty to consider the interests of different stakeholders and analyze the implicit values held by stakeholders and themselves (Posavac, 2011). Developing a program theory helps identify and address differences in values, assumptions, and program criteria (Posavac, 2011).

During the process of developing a program theory, evaluators must adhere to a code of ethics that includes respect for the security, dignity, and self-worth of the respondents, program participants, clients, and other evaluation stakeholders (Posavac, 2011). Evaluators who do not include neuro-diverse program-participant stakeholders fail to provide individuals within this paradigm the respect and dignity to clarify their needs and values assumptions. Evaluators have a responsibility to protect people from harm, yet programs are developed, evaluated, and established based on criteria of stakeholders whose interests may not address the needs and values of the people whom the program serves. Suppose program participant stakeholders do not have the opportunity to define their needs and values. How can evaluators accurately assess the merit and worth of a program in relation to the needs and values of the paradigm it intends to serve? Not all program participants will know what they need, "but that does not mean that their views can be ignored" (Posavac, 2011).

Ethical inclusion of participant stakeholders with neurodiversity is paramount in their protection (Cousins & Chouinard, 2012; posavac, 2011), but ethical inclusion is a complicated and multifaceted issue. Beyond the choice to value to the neurodiversity paradigm and to recognize and address preconceived notions, ethical inclusivity of individuals with neuro-diversity requires evaluators to balance individual’s right to contribute and right to be protected from exploitation, determine ability to give informed consent, and capacity to participate (Iaconol & Carling-Jenkins, 2012).

The process of informed consent requires potential participants to make an autonomous decision to participate based on their comprehension of information about the program, capacity to weigh risks and alternatives, and communicate agreement (Dawoody, 2021g; Posavac, 2011; Mertens & Wilson, 2018; Kadam, 2017). If a person was misled, was not given enough information, or does not understand the risks involved, then consent is not considered informed, even if the person agreed to participate (Dawoody, 2021g). Informed consent should be regarded as a layered, dynamic, and continuous process (Kadam, 2017). Evaluators need to assess comprehension, communication, accessibility, and ongoing voluntariness of participation through the entirety of the process (Posavac, 2011; Mertens & Wilson, 2018). Facilitating the informed consent and ethical inclusion of individuals with neurodiversity is complicated by the communication and social participation barriers inherent in the diagnostic criteria of these disorders.

Communication and social participation differences and limitations of individuals with neurodiversity may necessitate the adaptation of materials and participation facilitation to ensure comprehension and accessibility in program design and evaluation (Jarmillo-Velez, et al., 2020). Conventional communication and traditional methods utilized in the collection of information and feedback may be challenging for individuals with variations of cognitive and communication ability (Lilijenquist, et al., 2016; Courchesne, et al., 2021). Therefore, evaluators must be prepared to address a spectrum of diverse needs and abilities and to accept a spectrum of diverse communications and motivations.

Alternative communication acts such as a change in emotional valence or physical proximity and repetitive behaviors are common for individuals with neurodiversity such as ASD; failure to recognize and comprehend alternative communications is a failure to validate communication and increases the likelihood of maladaptive behaviors (Courchesne, et al., 2021; Marshall, 2017). A proxy or familiar advocate can help facilitate comprehensive communications with individuals who have alternative or limited verbal communication; however, evaluators must exercise caution in interpreting communications to avoid inferred or attributed opinions (Hills, et al., 2019; Preece & Jordan, 2010).

Collaborative inquiry (which includes research and evaluation) calls for researchers and evaluators to collaborate with individuals, groups, or communities that have a stake in the program or project being studied or evaluated (Cousins & Chouinard, 2012). Inclusivity in research has been vastly documented, but examples of inclusive program development and evaluation remain limited. Research seeks to provide new knowledge that is generalizable and accessible, however as evaluations are specific to the program and context in which they are performed, they are not published or easily reviewed. Therefore, models of inclusive program evaluation must be derived from examples of inclusive research. The existing overlap between research and evaluation validates the study of inclusive research as its application has the potential to inform inclusive program development and evaluation practices.

The goal of inclusivity in research is to validate and strengthen findings related to a particular paradigm through the inclusion of individuals who represent the population being studied (Fletcher-Watson, et al., 2021, Milner & Frawley, 2018). Inclusivity in research varies in degrees, and individuals can participate in a variety of ways (Chown, et al., 2017). The degree of inclusivity may be participatory, collaborative, cooperative, or independent (Fletcher-Watson, et al., 2021). The roles assigned have the potential to lead to different outcomes (Puyalto, et al., 2014). It is important that all participants understand and agree to their roles and responsibilities prior to the initiation of research (Nind, 2014). The establishment of roles is important to ensuring active participation as a lack of specificity may cause the illusion of participation or pseudo-participation in which individuals serve as “consultants” but are not active participants in the evaluation (Cousins & Chouinard, 2012).

Inclusive research has been shown to provide access to different perspectives, ensure research priorities are relevant, help measure outcomes, provide access to hard-to-reach groups, assist in disseminating findings, and empower individuals with neurodiversity (Walmsley, et al., 2018). In addition, successful examples of inclusive research demonstrate improved confidence and successful navigation of sensitive topics as a result of the inclusion (Johnson, et. a., 2013). While inclusive program development and evaluation differ in purpose and scope from inclusive research, the level, procedure, and ethics of inclusion are universal issues to collaborative inquiry.

Recommendations

This section examines how the guiding principles for evaluators necessitate the inclusion of stakeholders with neurodiversity in ethical, collaborative inquiry (research, program development, and program evaluation). Recommendations inspired by this research study are made as they address the core values of the American Evaluation Association's interconnected and interdependent guiding principles. The five principles of systematic inquiry, competence, integrity, respect for people, and common good and equity are explored as they relate to program development, program evaluation, and inclusion of stakeholders with neurodiversity (AEA, 2018).

***Recommendation 1* –** Consider the neurodiversity paradigm

The Neurodiversity movement conceptualizes the respect, support, and inclusion of individuals with different minds and abilities and highlights the importance of inclusive practices to validate and clarify the needs of individuals with neurodiversity (Greenburg & Rosa, 2020; Russel, 2020). Representation, interpretation, and understanding of the neurodiversity paradigm may be like learning a new language; it may mean processing information and developing or evaluating a program in a way that is not “typical.” Understanding the criteria by which the neurodiversity paradigm makes choices and defines value may be essential to ensuring the program’s worth; yet, the challenges associated with the inclusion of individuals in this paradigm continue to cause their marginalization in program development and evaluation.

“Evaluators strive to contribute to the common good and advancement of an equitable and just society" (AEA, 2018). Evaluators need to recognize and balance the interests of clients and stakeholders, address inequity, mitigate bias and power imbalances, and promote the just, equitable, and democratic common good of society (AEA, 2018). Evaluators should seek to empower populations to participate as members of the research, development, or evaluation team rather than it happening to or for them (Fletcher-Watson, et al.,2021). Evaluators should strive to develop their cultural competence of neurodiversity by reflecting on their own preconceived notions and developing the ability to genuinely interact with people with differing cultural perspectives. Evaluators should work to establish comprehensive documents and methodologies that are accessible in a multitude of ways.

***Recommendation 2* -** Evaluator Specialization or Training Related to Program/Population

Ethical program development and evaluation considers cultural context and population for whom the program is intended. Program development and evaluation intended for individuals with neurodiversity requires that evaluators and/or their team is familiar with the varying social, emotional, sensory, communication, and neurological intricacies of this population. Without specialized training or the supplementation of expertise, a neurologically typical evaluator likely lacks the competence necessary to understand how an individual with neurodiversity takes in, processes, and responds to external information. One of the guiding principles for evaluators is competence, "evaluators provide skilled professional services to stakeholders" (AEA, 2018). Evaluators need to ensure that the evaluation team has the abilities, skills, and experiences necessary to complete the evaluation within the cultural context and supplement any weak or missing competencies through education, training, supervised practice, and the assistance of others (AEA, 2018). Program evaluation requires evaluators to become familiar with the program, the people served program structure ad goals, and the purpose of the evaluation (Posavac, 2011). Evaluators should have access to programming or continued education opportunities to develop evaluation specializations. The policy should be to evaluate the paradigms of various stakeholders and ensure the competence of each paradigm within the evaluation team prior to accepting evaluation opportunities. Evaluation associations should provide and promote a searchable directory that searches evaluators based on identified specializations.

The organizational policy should be to utilize an internal evaluator who is familiar with the program and population whenever possible. In addition, organizations might consider instituting a program that recruits staff to become trained evaluators as this could provide an ideal combination of competencies.

Recommendation 3 – Ensure ethical access to all stakeholders

Respect for people is a guiding principle for evaluators; “evaluators honor the dignity, well-being, and self-worth of individuals and acknowledge the influence of culture within and across groups" (AEA, 2018). This principle highlights the value and understanding of the interests and perspectives individuals bring to the evaluation and the importance of ensuring willingness and informed consent while reducing the risk of harm for participants (AEA, 2018).

Before evaluators can address the complexities of obtaining informed consent, they must have ethical access to all stakeholders. While internal evaluators have the advantage of access to the program, staff, and participants, external evaluators may not have access to each paradigm of the program represented by stakeholders. For example, evaluators may have access to administrative staff but not direct care staff; to an advocacy group of “high-functioning” individuals with ASD but not the non-verbal individuals with ASD who also participate in the program being evaluated.

Evaluator programming and training should include how to identify stakeholders and establish ethical access to ensure fair representation of every stakeholder. Evaluators should not include individuals with neurodiversity to serve as a token representation or assume that there is a "disability perspective" that differs from the group (Strnadová, et al., 2014). Understanding and valuing the unique paradigms of individuals across groups is important to the development of the program theory and the validity of the outcome.

Recommendation 4 – Develop a Strategy to Ensure Comprehensive Communication

The Diagnostic and Statistical Manual (DSM) states that individuals with a diagnosis of ASD must display "persistent deficits in social communication and social interaction across contexts" (DSM-5). Individuals with neurodiversity, such as ASD, present with a spectrum of communication, social skills, and language challenges. Inclusivity of individuals with communication and social deficits in program design and evaluation may require adaptations based on the participant's individual needs (s).

A policy recommendation should be for evaluators to seek collaborative involvement of multi-disciplinary professionals, proxies, and individuals to identify and address the presentation of information and the adaptation of materials to increase comprehension and ease communication with all participants. Triangulation of proxies, parents, advocates, and professionals is important to ensure accuracy and avoid misinterpretation of information.

Recommendation 5 – Adaptation of Materials and Methods

In addition to the social and communication issues inherent in neurodiversity, cognitive impairment, mental health, age, and diagnosis can impede comprehension of information and process. Evaluation policy should require evaluators to meet with program-participant stakeholders prior to initiation to determine the adaptation strategies necessary to facilitate each participant's understanding. During the planning phase, evaluators should consider the adaptions of materials and methodology that will be necessary to make them more accessible to participants. Information should be available in reduced complexity and length. To increase accessibility, evaluators should use participant-centered language that is clear and concise, present information in multiple modalities, and consider using strategies such as the sensory-modality-learner-centered strategy that pairs two or more sensory systems for information processing (Antal, et al., 2017).

Recommendations for future research

A number of future research study recommendations can be derived as a result of and in relation to this study, which provided an overview of the importance and significance of the inclusion of individuals with neurodiversity in research, program development, and program evaluation. Additional research could provide a more in-depth understanding of the process of inclusion, the adaptation of information and materials, and the identification and selection of neuro-diverse stakeholders in order to ensure representation of the spectrum of neurodiversity within the population.

This paper also defined the various levels of inclusivity, including participatory, collaborative, and emancipation. Future research could develop a deeper understanding of the outcome variations that result from different levels of inclusivity.

Use of proxy informants was discussed as a way to address inclusion of individuals with limited verbal abilities however the use of proxy informants has been criticized as there remains an element of interpretation that may lead to the misrepresentation of individuals. However, without the use of proxy informants, individuals with the most complex needs are not able to participate and their paradigms are not adequately represented. Research into the use of multiple proxies and alternative communication practices cohesively may provide information on how to better represent the full range of communication and provide additional opportunities for self-advocacy.

Finally, this paper discussed the importance of the inclusion of the neurodiversity paradigm in order to address the need and values of this population as it may not be fully understood from a neuro-typical paradigm. Future research could further explore this issue and the processing and interpretation of programs developed for and by individuals with neurodiversity but staffed and run by individuals who are neuro-typical.

Summary

Stakeholder identification and engagement is an important element in program development and evaluation as it ensures clarity of program goals and outcomes in relation to the values and needs of the individuals being served and the program cost. Unfortunately, although program participants are considered "the best source of information regarding their own condition" (Dawoody, 2021i), they are the least likely to have a voice in the planning and implementation of programs and evaluations (Posavac, 2011).

Program development and evaluation is a methodology used to explore the need for a social service, if that service will be used if it meets the unmet needs identified, and if its outcome justifies the cost (Posavac, 2011). Program evaluation begins with developing a theory of program based upon the agreed-upon evaluation criteria identified by the stakeholders.

Stakeholders include anyone who has a vested interest in the program, policy, or product being evaluated (Posavac, 2011). Stakeholders include people who have decision-making authority over the program, people who have direct responsibility for the program, people who the program is intended for, families and communities of individuals the program is intended for, and people disadvantaged by the program (Mertens & Wilson, 2018). Stakeholder identification and engagement is an important element in developing and evaluating a program (Posavac, 2011).

Accessibility of and to stakeholders may vary depending upon the organization and evaluator. Internal evaluators are employed by the organization for whom they are performing the evaluation. External evaluators are hired from outside the organization to evaluate a program (Dawoody, 2021c). Internal evaluators have the advantage of program knowledge as well as greater access to program staff and participants (Posavac, 2011). The involvement of stakeholders ensures clarity of goals and evaluation criteria as the paradigms of various stakeholders impacts interpretation and determination of program merit and worth (Mertens & Wilson, 2018).

Merit is defined as the absolute intrinsic quality or in regard to a particular criterion; how effective is the program in meeting the needs of those it was intended to help? To determine the merit of a program, evaluators must collect data relevant to a particular criterion and ascribe value to it. The value of a program in a particular context is called its worth, this is an outcome of the evaluation (Mertens & Wilson, 2018). In order to determine the merit or worth of a program, evaluators must establish what defines merit or worth based on the values and assumptions of stakeholders and the context identified through the development of a theory of the program (Posavac, 2011). If the development or evaluation puts greater emphasis on the interests of a particular stakeholder, the program may not be useful for all impacted stakeholders (Posavac, 2011).

Historically, individuals with neurodiversity have had to rely on the 'expertise' of neuro-typical professionals, such as medical and behavioral specialists, to develop programs and interventions to serve their needs and values (Marshall, 2017). The inclusion of individuals with neurodiversity in program development and evaluation is minimal due to the ethical complexities. Program developers and evaluators have a responsibility to protect people from harm and must consider the ethical implications of inclusion such as informed consent, comprehension, communication, accessibility, and confidentiality (Posavac, 2011; Mertens & Wilson, 2018). The informed consent of participants requires the ability to understand information about the process and risks of involvement and make an autonomous decision based on that understanding. In order for informed consent to be considered meaningful, participants must demonstrate competence, comprehension, and voluntariness (Kadam, 2017).

These issues are paramount to the inclusion of any vulnerable population and are particularly challenging for neuro-diverse individuals whose social and language barriers may increase the challenge of ethical and informed consent. Individuals may have diversities related to comprehension of expressive language, processing speed, speech initiation challenges, or language that is limited and very concrete, echolalic, and/or idiosyncratic (Pena, et al., 2020; Wood, 2020). The manifestation of persistent deficits in social communication and social interaction in individuals with ASD can impact an individual's ability to effectively participate by utilizing traditional methods. Limited understanding of social situations, maladaptive behaviors, and conflicting priorities can all play a role in the interpretation of questions and responses (Ghanouni, et al., 2019).

Adaptations and accommodations may be necessary to ensure comprehension and accessibility (Jarmillo-Velez, et al., 2020). The traditional methods utilized in the collection of information and feedback may not be appropriate for individuals with variations of cognitive and communication ability (Lilijenquist, et al., 2016). A spectrum of diverse needs and abilities exists between individuals with neurodiversity, making a "one size fits all" approach to accessibility inappropriate as it does not consider different individual and developmental needs (Marshall, 2017). In addition to the adaptation of materials and procedures, a proxy may be necessary to facilitate, provide dexterity assistance or psychological support in using an alternative communication device (Hills, et al., 2019). A proxy can assist in the facilitation and interpretation of communications (Courchesne, et al., 2021). The relationship between the proxy and individual must also be considered as it can impact willingness, motivation, and accuracy (Hills, et al., 2019). In order to avoid the alteration or misinterpretation of communication efforts, triangulation of responses by multiple proxies and/or multiple opportunities may be necessary (Pearlman & Michaels, 2019).

Inclusive practices have been highly influential in research, with lessons that can be applied to program development and evaluation. Inclusive research seeks to empower populations to participate as partners and contributors of the research team rather than the research happening to or for them (Fletcher-Watson, et al.,2021; Strnadová & Walmsley, 2017). Inclusive research requires the inclusion of individuals who represent the paradigm or neuro-type being studied (Fletcher-Watson, et al., 2021). Inclusive research has been completed with varying degrees of involvement ranging from tokenism to emancipated research (Bigby, et al., 2013). Individuals can participate in a variety of ways, with each role leading to different outcomes, learning, and experiences (Puyalto, et al., 2014).

Successful inclusive research requires that all participants understand their roles and responsibilities prior to initiation (Nind, 2014). Setting clear expectations, a commitment to honesty, and the sharing of mutual goals are important elements of the partnership necessary for a successful collaboration on any research project, and are of the utmost importance in the engagement of individuals representing a multitude of paradigms (Fletcher-Watson, et al., 2021). The neurodiversity movement highlights the importance of inclusive practices to validate and clarify the needs of individuals with neurodiversity (Russel, 2020). The “nothing about us without us” ethos emphasizes the need for inclusive practices and representation of the neurodiversity paradigm (O’Brien, et al., 2014).

The neurodiversity movement conceptualizes neurodiversity as a paradigm, a different but normal variation of cognitive functioning within the human condition (Pena, et al., 2020). The neurodiversity movement seeks to recognize the contributions and value neuro-diverse individuals make to society (Pena, et al., 2020). As there is not a single way for a 'typical' brain to be wired, so how can one define which brains are 'typical' and which are 'diverse?' (Baron-Cohen, 2017). The inclusion of individuals, groups, and communities who have a stake in the program or project, also known as collaborative inquiry, is justified in the social justice, paradigm understanding, and context impact that results (Cousins & Chouinard, 2012).

While the neurodiversity movement has promoted a well-documented increase in inclusive practices in research, the neuro-divergent stakeholder paradigm continues to be marginalized in the development and evaluation of programs (Jacobson, et al., 2013). Research and program evaluation both generate knowledge; research seeks to prove, and evaluation aims to improve (Dawoody, 2021e). Research uses scientific inquiry to create new knowledge that is generalizable based on the researcher's hypothesis; evaluation is a process used to judge the merit or worth of a program by establishing if the program meets stakeholder's desired outcome and if the desired outcome and merits the associated costs (Dawoody, 2021b; Mertens & Wilson, 2018). Although they are recognized as separate disciplines, an overlap exists between research and evaluation (Dawoody, 2021b; Posavac, 2011; Mertens & Wilson, 2018). Evaluation and research intersect in that research informs the needs, improvements, and effects of programs and policies (Mertens & Wilson, 2018). Research is a beneficial element in the development of a program theory as an examination of basic research can provide evaluators with descriptions of how to help people obtain social support (Posavac, 2011). Application of social research, like evaluation, contributes to our understanding of how to bring people together to address critical social issues (Mertens & Wilson, 2018). The universal goal of program evaluation is to provide the information necessary to make informed decisions based on stakeholder goals (Mertens & Wilson, 2018).

In order for a program to adequately define and address the needs of individuals with neurodiversity, the development and evaluation process should "regard [the] social context" and paradigm of this population (Posavac, 2011). A paradigm is an assumption addressing an individual's perspective; it is the philosophical assumptions an individual makes based on how they frame what is ethical, real, and valid knowledge, and systemic inquiry (Mertens & Williams, 2018). An individual's paradigm is their world view, constructed through life experiences (Mertens & Williams, 2018). Differences in criteria and paradigm can lead to differences in the desired criteria in program development and evaluation (Posavac, 2011).

Program evaluation requires evaluators to become familiar with the program, the people served, program structure and goals, and the purpose of the evaluation (Posavac, 2011). The first step in program evaluation is the involvement of stakeholders (Dawoody, 2021a). The inclusion of neuro-diverse stakeholders in the development and evaluation of programs intended for neuro-diverse individuals is paramount to ensuring representation as well as determination of program worth in relation to the neurodiversity paradigm (Robinson, et al., 2014). Program development and evaluation should not be completed in isolation from the community characteristics of the people it is intended to serve (Posavac, 2011). By embracing the inclusion of individuals with neurodiversity programs can be more attuned to the needs of the people they serve and ultimately support more meaningful outcomes.

About the Author

Kimberly Brdar is a PhD student in Marywood University's Strategic Leadership and Administrative Studies Program. She holds a Master of Science in Education from Dominican College of Blauvelt and a Bachelors of Arts from Binghamton University in English. Ms. Brdar is the Coordinator of Educational Grants and Curriculum Integration at The Center for Discovery, a 501(c)(3) not-for-profit, nationally known provider of educational, health, clinical, and residential services for children and adults with severe complex disabilities and medical frailties, including a growing number of individuals with Autism Spectrum Disorders.

Sources

Adams, D., Handley, L., Heald, M., Simkiss, D., Jones, A., Walls, E., & Oliver, C., (2016). A Comparison of Two Methods for Recruiting Children with an Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities,* 30, 696–704. DOI: 10.1111/jar.12263

AEA (2011). Public Statement on Cultural Competence in Evaluation, *American Evaluation Association.* www.eval.org

AEA (2018). Guiding Principles, *American Evaluation Association*

American Speech-Language-Hearing Association. (2018). *Facilitated communication* [Position Statement]. Retrieved from www.asha.org/policy/

Antal, H., Bunnell, H. T., McCahan, S. M., Pennington, C. Wysocki, T., and Blake, K. V. (2017). A cognitive approach for design of a multimedia informed consent video and website in pediatric research, *Journal of Biomedical Informatics*, 66, 248-258

Baron-Cohen, S. (2017). Editorial Perspective: Neurodiversity – a revolutionary concept for autism and psychiatry, *The Journal of Child Psychology and Psychiatry.* https://doi.org/10.1111/jcpp.12703

Bigby, C., Frawley, P., & Ramcharan, P. (2013). Conceptualizing Inclusive Research with People with Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities*, 27, 3–12. DOI: 10.1111/jar.12083

Brandon, P. R. & Fukunaga, L. L. (2014). The State of Empirical Research Literature on Stakeholder Involvement in Program Evaluation, *American Journal of Evaluation, 35(1), 26-44.* DOI: 10.1177/1098214013503699

Cascio, M. A., Weiss, J. A., & Racine, E. (2020a). Person-Oriented Research Ethics to Address the Needs of Participants on the Autism Spectrum, *Ethics & Human Research*, 42(5), 2-16. https://doi.org/10.1002/eahr.500064

Cascio, M. A., Weiss, J. A., & Racine, E. (2020b). Making autism research inclusive by attending to intersectionality: a review of the research ethics literature. *Review Journal of Autism and Developmental Disorders, 7.*

Cascio, M. A., & Racine, E. (2019) *Research Involving Participants with Cognitive Disability and Difference: Ethics, Autonomy, Inclusion, and Innovation*, Oxford Scholarship Online. DOI:10.1093/oso/9780198824343.001.0001

Chown, N., Robinson., J., Beardon, L., Downing, J., Hughes, L., Leatherland, J., Fox, K., Hickman, L., & MacGregor, D. (2017). Improving research about us, with us: a draft framework for inclusive autism research. *Disability and Society*, 32 (5), 720-734.

Cluley, V. (2016). Using Photovoice to Include People with Profound and Multiple Learning Disabilities in Inclusive Research, *British Journal of Learning Disabilities.*

Courchesne, V., Tesfaye, R., Mirenda, P., Nicholas, D., Mitchell, W., Singh, I., Zwaigenbaum, L., & Elsabbagh, M. (2021). Autism Voices: A novel method to access first-person perspective of autistic youth. *Autism*. https://doi.org/10.1177/13623613211042128

Cousins, J. B., & Chouinard, J. A. (2012). *Participatory Evaluation Up Close: An integration of Research-Based Knowledge*. IAP.

Dawoody, A. (2021a). *Program Evaluation Lecture 1: An Introduction to Program Evaluation* [Class handout] Scranton, PA: Marywood University, 6004

Dawoody, A. (2021b). *Program Evaluation Lecture 2: Establish a Research Basis for a Program Design* [Class handout] Scranton, PA: Marywood University, 6004

Dawoody, A. (2021c). *Program Evaluation Lecture 3: Explaining Evaluation* [Class handout] Scranton, PA: Marywood University, 6004

Dawoody, A. (2021e). *Program Evaluation Lecture 5: Evaluate a Program* [Class handout] Scranton, PA: Marywood University, 6004

Dawoody, A. (2021f). *Program Evaluation Lecture 6: Developing and Using a Theory of the Program* [Class handout] Scranton, PA: Marywood University, 6004

Dawoody, A. (2021g). *Program Evaluation Lecture 7: Ethics in Program Evaluation* [Class handout] Scranton, PA: Marywood University, 6004

Dawoody, A. (2021i). *Program Evaluation Lecture 9: Developing Measures of Implementation and Outcomes* [Class handout] Scranton, PA: Marywood University, 6004

DeJonckheere, M., Lindquist-Grantz, R., Toraman, S., Haddad, K., & Vaughn, L. M. (2019). Intersection of mixed methods and community-based participatory research: A methodological review. *Journal of Mixed Methods Research*, *13*(4), 481-502.

Embregts, P.J.C.M., Taminiau, E.F., Heerkens, L., Schippers, A.P. and van Hove, G. (2018). Collaboration in Inclusive Research: Competencies Considered Important for People with and Without Intellectual Disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 15: 193-201. https://doi.org/10.1111/jppi.12248

Falvo, I., Fiordelli, M., Amati, R., Ibnidris, A., Albanese, E., & Fadda, M. (2021). Participants' Comprehension of the Informed Consent in an Epidemiological Study on Dementia Prevalence: A Qualitative Study, *Frontiers in Psychiatry*. DOI: 10.3389/fpsyt.2021.656822

Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., Leekam, S., Milton, D., Parr, J. R., & Pellicano, E. (2018). Making the future together: Shaping autism research through meaningful participation. *Autism*, *23*(4), 943–953. https://doi.org/10.1177/1362361318786721

Fletcher-Watson, S., Brook, K., Hallett, S. et al. (2021). Inclusive Practices for Neurodevelopmental Research. *Curr Dev Disord Rep* 8, 88–97. https://doi.org/10.1007/s40474-021-00227-z

Fullana, J., Pallisera, M., Català, E. & Puyalto, C. (2017). Evaluating a Research Training Programme for People with Intellectual Disabilities Participating in Inclusive Research: The Views of Participants. *Journal of Applied Research in Intellectual Disabilities* 30(4): 684–695.

Ghanouni, P., Jarus, T., Zwicker, J. G., Lucyshyn, J., Chauhan, S., & Moir, C. (2019). Perceived Barriers and Existing Challenges in Participation of Children with Autism Spectrum

Disorders: "He Did Not Understand and No One Else Seemed to Understand Him." *Journal of Autism and Developmental Disorders*, *49*(8), 3136–3145.

Glodkowska, J., Gosk, U., & Pagowska, M. (2018). The Authorship of Their Own Lives in People with

Disabilities: Research Strategy Framework, *International Journal of Psycho-Educational Sciences*, 7(3).

Goddard, P., & Goddard, D. (2012). I am intelligent. Guilford, CT: Skirt

Goodman, M. S., & Sanders Thompson, V. L., (2017) The Science of Stakeholder Engagement in Research: Classification, Implementation, and Evaluation, *Transl Behav Med*., 7(3):486-491. doi: 10.1007/s13142-017-0495-z.

Grandin, T. (2011). The way I see it. A personal look at Autism and Asperger's (2nd 63 ed.). Arlington, TX: Future Horizons.

Greenburg, C., & Rosa, S. D. R. (2020). Two Winding Parent Paths to Neurodiversity Advocacy, *Autistic Community and the Neurodiversity Movement*. https://doi.org/10.1007/978-981-13-8437-0_12

Hamilton, J., Ingham, B., McKinnon, I., Parr, J. R., Tam, L. Y., & Le Couteur, A. (2017). Mental Capacity to Consent to Research? Experiences of Consenting Adults with Intellectual Disabilities and/or Autism to Research, *British Journal of Learning Disabilities*. DOI:10.1111/bld.12198

Heasman, B., & Gillepsie, A. (2019). Neurodivergent intersubjectivity: Distinctive features of how autistic people create shared understanding, *Autism*, 23(4), 910-921. https://doi.org/10.1177/1362361318785172

Hills, K., Clapton, J., & Dorsett, P. (2019). Ethical considerations when conducting research with people with nonverbal autism: A commentary on current processes and practices. *Journal of Social Inclusion*, 10(2).

Ho, P., Downs, J., Bulsara, C., Patman, S., & Hill, A.-M. (2018). Addressing Challenges in Gaining Informed Consent for a Research Study Investigating Falls in People with Intellectual Disability. *British Journal of Learning Disabilities*, *46*(2), 92–100.

Hume, K., Steinbrenner, J. D., Sideris, J., Smith, L., Kucharczyk, S., & Szidon, K. (2018). Multi-Informant Assessment of Transition-Related Skills and Skill Importance in Adolescents with Autism Spectrum Disorder, *Autism*, 22(1), 40-50. DOI: 10.1177/1362361317722029

Iaconol, T., Carling-Jenkins, R. (2012). The Human Rights Context for Ethical Requirements for Involving People with Intellectual Disability in Medical Research. *Journal of Intellectual Disability Research, 56(11), 1122-1132.*DOI: 10.1111/j.1365-2788.2012.01617.

Jacobson, M. R., Azzam, T., & Baez, J. G. (2013). The nature and frequency of inclusion of people with disabilities in program evaluation. *American Journal of Evaluation*, *34*(1), 23-44.

Jaramillo-Velez, A. G., Aguas Compaireda, M., Granados Plaza, M., Marino, E. L, & Modamioa, P. (2020). Assessment of the Quality of Patient Information Sheets and Informed Consent Forms for Clinical Trials at a Hospital Neurology Service, *European Journal of Neurology*, 27, 1825–1831. DOI:10.1111/ene.14420

Johnson, K., Minogue, G. and Hopklins, R. (2014). Inclusive Research: Making a Difference to Policy and Legislation. *J Appl Res Intellect Disabil*, 27: 76-84. https://doi.org/10.1111/jar.12085

Joyce, C., Honey, E., Leekam, S. R., Barrett, S. L., & Rodgers, J. (2017). Anxiety, Intolerance of Uncertainty and Restricted and Repetitive Behaviour: Insights Directly from Young People with ASD. *Journal of Autism and Developmental Disorders*, *47*(12), 3789–3802.

Jull, J., Giles, A., & Graham, I. D. (2017). Community-based participatory research and integrated knowledge translation: advancing the co-creation of knowledge. *Implementation Science*, 12(1), 1-9.

Kadam, R. A. (2017). Informed Consent Process: A Step Further Towards Making it Meaningful! *Perspectives in Clinical Research*, 8(3). DOI: 10.4103/picr.PICR_147_16

Kamuya, D., Marsh, V., & Molyneux, S. (2011). What We Learned About Voluntariness and Consent: Incorporating "Background Situations" and Understanding into Analyses,

Kapp, S. (2020) Introduction, *Autistic Community and the Neurodiversity Movement,* The American Journal of Bioethics, 11:8, 31-33, DOI: 10.1080/15265161.2011.583328

Lilijenquist, K., Coster, W., Kramer, J., Rossetti, Z., & Rossetti, Z. (2016). Feasibility of the Participatory Experience Survey and the Setting Affordances Survey for use in

Evaluation of Programmes Serving Youth with Intellectual and Developmental Disabilities, *Child: Care, Health and Development.* DOI:10.1111/cch.12402

Lilijenquist, K., Kramer, J., Rossetti, Z., & Coster, W. (2019). Content development, accessibility and feasibility of a self-report tool for use in programmes serving youth with cognitive disabilities: The Participatory Experience Survey, *Australian Occupational Therapy Journal*, 66, 490-499. DOI:10.111/1440-1630.12571

Lindsley, K. A. (2019). Improving Quality of the Informed Consent Process: Developing an Easy-To-Read, Multimodal, Patient-Centered Format in a Real-World Setting, *Patient Educ Couns.* 102(5): 944–951. doi: 10.1016/j.pec.2018.12.022

Marshall, N. (2017). Child and Youth Care and Disability Rights: Listening to Young People, Challenging our Practice, *Relational Child and Youth Care Practice*, 30(2), 55-69. ISSN 2410-2954

McKinley, S. (2011). God saved me from silence! Thoughts and prayers of a non-verbal boy with autism who is gifted differently. Maitland, FL: Xulon Press.

Mamotte, N. & Wassenaar, D. (2015). Measuring Voluntariness of Consent to Research: An Instrument Review, *Journal of Empirical Research on Human Research Ethics*, 10(2), 121-131. DOI:10.1177/1556264615571552

Mertens, D. M., & Wilson, A. T. (2018). Program evaluation theory and practice. Guilford Publications.Milner, P., & Frawley, P. (2019). From 'on' to 'with' to 'by:' people with a learning disability creating a space for the third wave of Inclusive Research. *Qualitative Research*, 19(4), 382–398. https://doi.org/10.1177/1468794118781385

Milner, P., & Frawley, P. (2019). From 'on' to 'with' to 'by:' people with a learning disability creating a space for the third wave of Inclusive Research. *Qualitative Research*, 19(4), 382–398. https://doi.org/10.1177/1468794118781385

Morina, A. (2020). When People Matter: The Ethics of Qualitative Research in the Health and Social Sciences. *Health Soc Care Community*, 29, 1559–1565. DOI: 10.1111/hsc.13221

Nind, M. (2014). *What Is Inclusive Research?* Bloomsbury Academic, London.

ISBN 978-1-84966-811-8

Nind, M. and Vinha, H. (2014). Doing research inclusively: bridges to multiple possibilities in inclusive research. *Br J Learn Disabil*, 42: 102-109. https://doi.org/10.1111/bld.12013

Nind, M. (2017). The practical wisdom of inclusive research. *Qualitative Research*, 17(3), 278–288. https://doi.org/10.1177/1468794117708123

Noble, H., & Heale, R. (2019). Triangulation in Research, with Examples, *Evidence Based Nursing.* doi: 10.1136/ebnurs-2019-103145

O'Brien, P., McConkey, R., & Garcıa-Iriarte, E. (2014). Co-Researching with People Who Have

Intellectual Disabilities: Insights from A National Survey, *Journal of Applied Research in Intellectual Disabilities*. 27:65–75.

O'Sullivan, R. G. (2012). Collaborative Evaluation within a framework of stakeholder-oriented evaluation approaches, *Evaluation and Program Planning*, 35(4), 518-522. ISSN 0149-7189, https://doi.org/10.1016/j.evalprogplan.2011.12.005.

Peairson, S., Haynes, C., Johnson, C., Bergquist, C., & Krinhop, K. (2014). Education of Children with Disabilities: Voices from Around the World, *Journal of Applied Research on Children: Informing Policy for Children at Risk*, 5(2).

Pearlman, S., & Michaels, D. (2019). Hearing the Voice of Children and Young People with a Learning Disability during the Educational Health Care Plan (EHCP). *Support for Learning*, 34(2), 148–161.

Pena, E. V., Gassner, D., & Brown, K. R. (2020). Autistic-Centered Program Development and Assessment Practices (Practice Brief), *Journal of Postsecondary Education and Disability*, 33(3), 233-240.

Posavac, E. J. (2011). *Program Evaluation Methods and Case Studies*, (8th edition).

Preece, D., & Jordan, R. (2010). Obtaining the Views of Children and Young People with Autism Spectrum Disorders about Their Experience of Daily Life and Social Care Support. *British Journal of Learning Disabilities*, *38*(1), 10–20.

Puyalto, C., Pallisera, M., Fullana, J. & Vilà, M., (2016). Doing Research Together: A Study on the Views of Advisors with Intellectual Disabilities and Non-Disabled Researchers Collaborating in Research. *Journal of Applied Research in Intellectual Disabilities*. 29: 146–159.

Robinson, S., Fisher, K. R., & Strike, R. (2014). Participatory and Inclusive Approaches to Disability Program Evaluation, *Australian Social Work*, 67:4, 495-508, DOI: 10.1080/0312407X.2014.902979

Rodríguez-Campos, L. (2012). Stakeholder Involvement in Evaluation: Three Decades of the American Journal of Evaluation, *Journal of MultiDisciplinary Evaluation*, 8(17). ISSN 1556-8180

Russell, G. (2020). Critiques of the Neurodiversity movement, *Autistic Community and the Neurodiversity Movement*

Silberman, S. (2015). *Neurotribes: The Legacy of Autism and the Future of Neurodiversity*. New York, Avery

Straus, J. N. (2013). Autism as Culture, *The Disability Studies Reader* (4th ed.). Routledge.

Strnadová, I, Walmsley, J. (2017). Peer-reviewed articles on inclusive research: Do Co-Researchers with Intellectual Disabilities Have a Voice? *J Appl Res Intellect Disabil*. 31, 132– 141. https://doi.org/10.1111/jar.12378

Strnadová, I., Walmsley, J., Johnson, K. & Cumming, T. M. (2016). Diverse Faces of Inclusive Research: Reflecting On Three Research Studies, *Scandinavian Journal of Disability Research*, 18(1), 52-64, DOI: 10.1080/15017419.2014.964766

Taua, C., Neville, C., & Hepworth, J. (2014). Research participation by people with intellectual disability and mental health issues: An examination of the processes of consent. *International Journal of Mental Health Nursing*, 23, 513–524. DOI: 10.1111/inm.12079

Turcotte-Tremblay, A. M., & Mc Sween-Cadieux, E. (2018). A Reflection on the Challenge of Protecting Confidentiality of Participants While Disseminating Research Results Locally, BMC Medical Ethics, 19(1):45. https://doi.org/10.1186/s12910-018-0279-0

University of Cambridge (2021). Inclusive Design Toolkit. http://www.inclusivedesigntoolkit.com/whatis/whatis.html

Veritas, (2014). *What is ‘consent’ and ‘assent’ for research?* The Veritas Irb Inc. Editorial Board

Walmsley, J, Strnadová, I, Johnson, K. (2018). The added value of inclusive research. *J Appl Res Intellect Disabil*. 31: 751– 759. https://doi.org/10.1111/jar.12431

Weisleder, P (2020). Helping Them Decide: A Scoping Review of Interventions Used to Help Minors Understand the Concept and Process of Assent, *Front. Pediatr.* 8:25. doi: 10.3389/fped.2020.00025

Wood, R., (2020). The wrong kind of noise: understanding and valuing the communication of autistic children in schools, *Educational Review*, 72(1), 111-130. https://doi.org/10.1080/00131911.2018.1483895