Broadening the Conceptualization of Literacy in the Lives of Adults with Intellectual Disability

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Current pedagogical approaches recognize literacy as a social practice and yet school-based conceptualizations continue to dominate understandings of literacy learning of individuals with intellectual disability. Such understandings lead to local or everyday literacy practices being devalued and overlooked. Thus, for adults with intellectual disability who might not possess a high level of proficiency in school-based literacy, it is important to develop understandings about their everyday literacy uses for such practices to be recognized as being socially and culturally significant. Approaches to research are needed, which enable collection of rich, detailed information about literacy use by adults with intellectual disability that go beyond standardized scores and rankings and outside of the classroom. This paper presents a view of methodologies that can be used to conduct future research in this area that will broaden the conceptualization of literacy for adults with intellectual disability.

DESCRIPTORS: literacy, disability, adult, phenomenological

Introduction

Being literate is highly valued in western society (Katims, 2000; Lonsdale & McCurry, 2004; Papen, 2005a), where school-based conceptualizations of literacy often dominate and proficiency is usually determined by standardized testing and mastery of basic skills such as word identification, spelling, and phonological decoding. Such conceptualizations of literacy may result in the marginalization of individuals whose literacy practices do not conform to these standards, such as many with intellectual disability, and provide a very limited basis for the exploration of the lived experience of literacy of these individuals. Despite the difficulties some individuals with intellectual disability have in mastering the basic skills of literacy, they live in societies that assume a certain level of accomplishment in these skills. While the importance of the development of basic literacy skills cannot be denied, this paper makes an argument for broadening the conceptualization of literacy to also incorporate an understanding of the everyday literacy of adults with intellectual disability. Broadening the conceptualization of literacy for this group may lead to: a better understanding of what constitutes literacy for adults with intellectual disability; a greater recognition of their value as literate members of society; a broader use of descriptive, qualitative methods of literacy assessment; and an informed pedagogy comprising literacy instruction that is meaningful and relevant in the lives of learners with intellectual disability. There is also the potential to influence how literacy is used in every day environments so that features that assist those with limited conventional literacy skills are included and/or emphasized. However, as it may be difficult to arrive at such an understanding without some changes to research practices, this paper also explores the contribution that participatory approaches to research may make to understanding lived experiences.

Conceptualizing Literacy

The definition of literacy is contentious and its "meaning has changed over time from an elementary 'decoding' of information to a range of more complex and diverse skills and understandings" (Lonsdale & McCurry, 2004, p. 5). Current conceptualizations of literacy in the academic field are generally distinguished by a pluralistic view that recognizes and accepts different historic and cultural traditions regarding literacy and acknowledge that these traditions often demonstrate close relationships among literacy, power, and authority (Carrington, 2005; Ferdman, 2004; Quigley, Folinsbee, & Kraglund-Gauthier, 2006; Street, 2006). Although ethnographic studies have made clear that literacy comprises multiple forms and is context specific (see, e.g., Chitraker, 2000; Chopra, 2001; Maddox, 2005; Papen, 2005b; Robinson-Pant, 2000; Rogers, 2002), much of the thinking about the importance of context, with respect to what comprises literacy, is overlooked in investigations of the literacy of individuals with an intellectual disability.

Literacy research and educational practice with these individuals does not generally appear to reflect this broader understanding of literacy but to have remained firmly entrenched in the traditional view of literacy, defined as "basic" or "skills-based" (Katims, 2000).

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Through this perspective, literacy is constructed as a set of decontextualized skills and is usually taught using direct instructional strategies, where the teacher is the authoritative expert and the learner is a passive novice. This traditional view of literacy has, at its core, the belief that, to function effectively in society, there is a set of basic literacy skills that need to be learned by individuals. Within this approach, literacy is predominantly understood to be print-based, universal, and valued for equipping individuals with a fixed set of skills (Papen, 2005a; Rasool, 1999).

Although it is evident that teaching based on this traditional view of literacy can increase the basic literacy skills of some learners with intellectual disability (see, e.g., Allor, Mathes, Roberts, Cheatham, & Champlin, 2010; Gallaher, van Kraayenoord, Jobling, & Moni, 2002), it rarely engages learners with meaningful, relevant, connected text or higher processes of using literacy for communication or reading for pleasure (Katims, 2000). Traditional approaches to literacy teaching and learning for this group, infrequently incorporate multiliteracies (such as visual and audio texts and multimedia) and fail to address literacy as a social practice. Therefore, conceptualizations of literacy of individuals with intellectual disability need to be broadened to reflect current understandings of literacy and, thus, to include multiliteracies and social practices of literacy. This understanding should then help to ensure that literacy teaching and learning is relevant and meaningful in the lives of adults with intellectual disability.

A Social Practice Approach to Literacy

A social practice approach to literacy "emphasizes the social relationships and institutions within which literacy is embedded" (Hamilton, 2000, p. 16). Furthermore, the social theory of literacy is concerned with everyday literacy events and practices, how people experience and engage with them, and the significance that they have in their lives (Papen, 2005a). For example, the importance of literacy as a social practice, for individuals both with and without intellectual disability, is highlighted by Forts and Luckasson (2011), who discuss the benefits that literacy has had in their everyday lives as acting as the springboard for their long-term friendship. Thus, a social practice approach enables literacy to be addressed beyond school-based conceptualizations and in the everyday lives of adults with intellectual disability. Central to the development of the social theory of literacy is the move away from the traditional, autonomous, model to the culture and context specific ideological model of literacy (Street, 1984, 2003, 2006).

Ideological Model of Literacy

An ideology is a system of ideas that are characteristic of various social groups. Street's (1984) ideological model of literacy posits that the concept of literacy is always contested because of its socially embedded nature and the dependency that learning particular literacies has upon the specific contexts in which they are learned (Street, 2003). Although not denying the technical or cognitive components of literacy, the ideological model recognizes these skills as social practices that are learned in specific cultural contexts (Baker & Street, 1994). Through this model, solutions to difficulties in the acquisition and practice of literacy are considered a social rather than an individual responsibility (Lonsdale & McCurry, 2004), whereby barriers such as limited access to information can be addressed and rectified by the community to ensure that literacy in the real world is accessible for all (Bray, 2003; Owens, 2006; Rodgers & Namaganda, 2005).

The ideological model also recognizes the concept of multiple literacies that require a range of skills within and across different cultures and contexts. Thus, for research, qualitative investigations of literacy in which participants have the opportunity to tell their own stories, in their own ways, within familiar contexts, are undertaken in preference to quantitative studies in which data collection focuses on psychometric measures (standardized tests, scores, and rankings; see Forts & Luckasson, 2011). However, people with intellectual disability may experience difficulties in giving form to and orally retelling stories of their experiences (Lonsdale & McCurry, 2004). These difficulties do not imply that their stories should not be told or should be devalued. Rather, the ideological model indicates different ways of objectifying and relating experiences that should be explored, adopted, and valued.

When Harry[1] joined a program for literacy teaching for adults with intellectual disability, his literacy skills were assessed using standardized tests for reading and receptive oral language acquisition. Harry did not reach baseline levels on these tests. Thus, these tests revealed very little about Harry's literacy abilities or interests. However, Harry had been asked to bring in something from his everyday life. Harry chose a poster of his favourite football team, The Broncos. Using this poster, together with his name and the printed name of The Broncos, as a springboard for ascertaining Harry's literacy strengths, it was ascertained that Harry recognised and could name several letters of the alphabet. He recognised some simple vocabulary such as his and The Broncos' names, as well as the words the, I, am, yes, no, on, off. He could name some colours from the poster and match these to colours around the room. He understood some spatial concepts such as

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[1] All names are pseudonyms. All vignettes have been drawn from real-life experiences.

big and little, and was able to provide a short oral description of the football team using the poster to aid his very limited speech and communication. This information, which was gathered by using approaches that recognized social aspects of literacy and communication, revealed interests and literacy strengths from which a meaningful and relevant individualized literacy program was developed for Harry.

Thus, the socially based ideological model offers an alternative approach to understanding the literacies of adults with intellectual disability and allows the development of a more complete picture of what constitutes literacy events and practices for this group in everyday social contexts. In addition, this approach also provides opportunities to explore any impact of school-based literacy instruction and learning on everyday literacy use to understand how adults with intellectual disability access and make sense of literacy in their lived worlds. The contemporary turn to social approaches to literacy and the subsequent recognition of literacy as social practice that differs among contexts led to the development of the new literacy studies (NLS).

NLS

In the 1990s, Gee (1991) and Street (1997) used the term "new literacy studies (NLS)" to characterize their research into understanding what constitutes literacy and for whom, from a social and analytic discourse perspective. NLS enabled researchers to move away from more traditional, psychometric studies of literacy acquisition to adopt a more *emic* view of the social practices of literacy. As opposed to an *etic* view, in which an outside observer describes human behaviour, an *emic* view draws on direct accounts from the participant about his/her meaningful personal experiences. Central to NLS is the view that literacy practices are context specific; that different contexts can create different meanings and values; and that in the absence of an understanding of context, any literacy artifact, event, or practice is without meaning and value (Gee, 2000).

Although much of the research associated with NLS has focused on the practices of literacy in various cultures and contexts, no information of its use with adults with intellectual disability was able to be found. However, a major focus of NLS is the move away from undertaking research into dominant literacy practices, pedagogy, and institutions, which has been the focus of research about individuals with intellectual disability (e.g. Pershey & Gilbert, 2002) to investigating local literacies across a range of contexts. Thus, NLS offers an appropriate approach to developing a rich, situated understanding of the local literacies used by adults with intellectual disability in their everyday lives.

Local Literacies

Local literacies are viewed as being self-generating or locally invented literacies, which develop informally in everyday contexts. Reading bus timetables, using automated transaction machines, writing and sending birthday cards, and using public information boards are examples of local literacies within Australian and other Western cultures. However, because of their informal nature and specificity to context they may not always be valued as legitimate. Yet, if they are understood as a specialized set of literacies, which are powerful in specific, local contexts, they become validated (Lonsdale & McCurry, 2004). Thus, a local, situated approach to understanding the literacy practices of people with intellectual disability may lead to such practices being recognized and valued as legitimate. Consideration of context is important to effectively document literacy as a social, situated practice to understand the different constructions of literate meaning and how literacy is used by different people in different contexts in everyday life. This perspective is of particular relevance for investigating the everyday literacy of adults with intellectual disability to demonstrate how literacy is constructed by them, in their worlds, to develop recognition and awareness in society that in the contexts of their everyday lives, adults with intellectual disability have the potential to become literate and functional members of the community.

Ben could identify three words from a standardized test of word recognition. Yet when presented with a list of words that he encountered in his everyday life, Ben revealed that he had a sight vocabulary of at least 25 words. These comprised words from: his favourite take-away foods; names of music artists found on CD covers, in music stores, and on the internet; and names of movie stars which were found in magazines, on DVDs and the internet. He was also able to use context clues and visual text (pictures/photos/icons) to identify functional vocabulary that he was unable to do when presented with these same words in isolation. Furthermore, in his everyday life, Ben lives independently and searches the internet, makes purchases, orders food, monitors his daily schedule, makes phone calls, and operates a range of technologies, all evidence of literacy use. A social practices approach that recognises the value of local literacies, revealed a range of literacies and ways in which Ben was using and making sense of literacy from within his lived world.

Furthermore, this approach provides opportunities to understand how adults with intellectual disability view and feel about their literacy in different contexts within their everyday lives.

Literate Identity

A person's literate identity is shaped by a repertoire of literacy resources constituted through prior knowledge, past experiences, and literacy practices (Bartlett & Holland, 2002; Barton & Hamilton, 2005). To construct meaning, similar experiences are grouped, forming domains from which a person may draw when engaging in literacy practices. These domains are collectively referred to as "discourse worlds," which are further separated into "life worlds" (experiences undertaken and knowledge formed outside of school) and "school-based worlds" (experiences and knowledge undertaken and formed within the bounds of school-based institutions; Cope & Kalantzis, 2000). Experiences and knowledge of literacy from school-based worlds, which may be a source of difficulty for individuals with intellectual disability, are often accorded greater value than that from life worlds, and therefore, school-based literacy experiences may have greater influence in shaping literate identity (Katims, 2000; Lonsdale & McCurry, 2004; Papen, 2005a).

Identities are constructed through both social and personal phenomena, and in practice, individuals are socially positioned by the collective view of their culturally shaped value. For adults with intellectual disability, the value placed on school-based literacy dominates pedagogical practices, perpetuating conceptualizations of a marginalized group of impaired individuals whose literacy skills are limited (Powell, 2003). In addition, experience in teaching adults with intellectual disability has shown that, for many who identify themselves as adults, school-based literacy instruction and resources are seen as being irrelevant and inappropriate in their adult lives.

In a post-school literacy program, Olivia would consistently refuse to participate in traditional school-based literacy activities or engage with school-based reading materials stating that they were babyish and so not for her. Thus, in order for her to develop her phonics and rhyming abilities, the lyrics of her favourite music hits were printed with the target elements highlighted and these were read while the soundtrack played (see also Morgan & Moni, 2008; Morgan, Moni, & Jobling, 2006 for practical suggestions of overcoming this issue).

Literacy and Adults With Intellectual Disability

Adults with intellectual disability are often constructed as being subordinate and lacking in valued cultural and social capital in a literate world (Katims, 2000). The view of those with intellectual disability as illiterate—a consequence of failing to recognize their literacy skills—contributes to this devaluation. Failure to recognize the literate abilities of adults with intellectual disability may arise from the fact that little is known about their everyday use and understanding of literacy. Thus, as there is limited knowledge and understanding of what everyday literacy looks like for adults with intellectual disability, dominant school-based conceptualizations of literacy that are constructed for typically developing learners are applied (Gerston, Fuchs, Williams, & Baker, 2001; van Kraayenoord, Elkins, Palmer, & Rickards, 2001; Vaughn, Moody, & Schumm, 1998).

Research has shown that in adolescence and young adulthood, learning and literacy can and do continue to develop in individuals with intellectual disability (e.g. Bochner, Outhred, & Pieterse, 2001; Lloyd, 2006; Moni & Jobling, 2001; Morgan, 2005; Pershey & Gilbert, 2002; Young, Moni, Jobling, & van Kraayenoord, 2004). However, there are limited opportunities for continuing post-school literacy education for adults with intellectual disability, and when literacy instruction is offered, it is often limited to school-based approaches in which the content may not be applicable for adults (see Morgan & Moni, 2008) and which emphasize instruction in word recognition and increasing learners' sight vocabulary (for examples of programs, see Movement for Canadian Literacy, 2004; TAFE (Queensland) Certificate II in General and Vocational Education, 2011).

More recently, post-school literacy and technology programs for adults with intellectual disability such as LATCH-ON (literacy and technology-hands on; see Moni & Jobling, 2000, 2001) have embraced sociocultural understandings of literacy by incorporating into the teaching and learning program the understanding of literacy as a socially constructed practice. Through this approach, adults with intellectual disability are seen as experts in their own lives whose literate abilities are recognized and valued. This approach offers an opportunity for literacy development together with recognition of multiple possibilities for continued literacy growth.

Despite the adoption of this approach to literacy teaching and learning with adults with intellectual disability by some providers of literacy focussed services, little is known about the ways these adults use and make sense of literacy in their lived worlds. In addition, even when sociocultural understandings of literacy are adopted, psychometric measures and normative approaches to assessment are often used to indicate levels of literate proficiency and to provide information about literacy strengths and areas of need (e.g. Bochner et al., 2001; Lloyd, 2006; Moni & Jobling, 2001; Morgan, 2005; Pershey & Gilbert, 2002; Young et al., 2004). While useful information may be gained from such assessment practices, using such measures does not consider or address the multiple and varied local literacies that are used in every day contexts in the lived world of adults with intellectual disability.

Using traditional benchmarks for determining the literacy abilities of adults with intellectual disability

provides limited information about the literacy use of adults with intellectual disability and how they make sense of their literate encounters in their everyday lives. In addition, it perpetuates preconceived notions of deficiency, which further contribute to their devaluing and marginalization in literate society.

> While Jack failed to achieve baseline levels on any standardized tests for literacy and numeracy, applying a social practices approach to Jack's literacy and numeracy not only broadened the conceptualization of what constitutes literacy and numeracy for Jack, but also revealed abilities, knowledge and skills that traditional psychometric testing failed to identify. In particular, he was able to interact with a high degree of social competence within the community. For example, Jack was able to independently use an ATM to withdraw cash for the purpose of making purchases. This required him to be able to understand and follow on-screen written instructions although he was observed to randomly select numerical amounts. In a classroom setting he was unable to name, or provide a value, for the various monetary notes. (Note: In Australia, notes come in different sizes, colours and pictures with the numerical value clearly marked). However, he knew that with "1 orange money" (a 20-dollar note) he was able to purchase a music CD, a T-Shirt, or to buy lunch and a drink and receive change.

Information of the kind and quality revealed here is unlikely to be produced by traditional research approaches alone. These approaches, in which study participants are viewed as subjects of investigation, are insufficient to capture the meaning of literacy and the uses to which literacy is experienced by adults with intellectual disability. Thus, approaches to data collection around everyday literacies are needed which enable the collection of rich, detailed, and descriptive information to provide as full an understanding as possible about literacy and its use by adults with intellectual disability.

It is posited that participatory research approaches provide affordances to collect rich, detailed information about the everyday literacies of adults with intellectual disability.

Participatory Research

Research studies can be broadly categorized as being either quantitative or qualitative. Quantitative studies generally employ data collection methods and analyses that promote and comprise numerical quantities, frequencies, and use of statistics. Data are typically reported in graphs and tables. In contrast, qualitative research may be described as naturalistic, interpretive research in which consideration of context is paramount. It is a multidimensional approach that seeks to explore and understand the essential nature of a phenomenon through rich, detailed description in naturalistic settings (Brantlinger, Jimenez, Kligner, Pugach, & Richardson, 2005). Qualitative methodology enables researchers to answer questions not only about *what* is happening, but also *why* or *how* it is happening (Brantlinger et al., 2005). Qualitative methodology encompasses collaborative approaches to research including participatory research.

Participatory research is a collaborative approach to conducting qualitative, inclusive research where people with disability—particularly, intellectual disability—are included in the research process. It is about doing research *with* and not *on* people with disability (Walmsley, 2004). This approach draws on the direct experiences, views, thoughts, standpoints, and, in this case, literate processes of the participants. Thus, it is essential that the participants are actively involved in the research process to enable their voices to be heard. Furthermore, as it is their experiences, practices and views that are of interest with issues concerning their lives, they have a right to be involved not only in the process but also in validation of accurate representation and dissemination of findings (McClimens, 2004, 2010; Rodgers, 1999; Stalker, 1998).

Participatory research is underpinned by three underlying, philosophical beliefs: first, that relationships where the researcher is the expert and the participants are subjects of study are inequitable; second, that when research is about them and involves them, people have the right to be consulted and included in the research process; and third, the quality of research and the data collected is improved when people with disability are involved (Stalker, 1998).

Participatory research provides an opportunity for people with intellectual disability to adopt the role of research partners, with the support of someone, usually the researcher, who does not have intellectual disability, and thus influence the research process (Gilbert, 2004). Their experiences and knowledge are authentically conveyed through a research process that gives them a legitimate voice and an opportunity to be heard (McClimens, 2004; Walmsley, 2001, 2004).

Traditional power delineations of *expert* and *novice*, in relation to knowledge and skills, are not embraced within participatory research. Rather, it is acknowledged that, through collaboration, a range of skills, expertise, and experiences are brought to the research by all participants (Brown & Boardman, 2011; Johnson, 2009; Michaels & Ferrara, 2005; Williams, Simons, & Swindon People First Research Team, 2005). For people with intellectual disability, noninclusive research paradigms may obscure their experiences and sense of their lived worlds. However, participatory paradigms adopt qualitative and phenomenological methodologies designed to explore the lived realities, experiences, and practices of the participants, thus positioning them as experts in their own lives. Participatory research is, therefore, particularly appropriate to the investigation of the everyday literacy use of adults with intellectual disability.

In participatory research, the researcher works in partnership with the participants, but division of labor may not always be equitable. While the researcher drives the research, expertise is shared with the participants who are collaborated with and involved in the various phases of the research process. The topics under investigation within participatory research will be those that are relevant in the lives of people with disability (Walmsley, 2001).

Participatory research can be undertaken in a variety of ways, depending on the topic under investigation, the researcher, and the participants (McClimens, 2010; Walmsley, 2004). Thus, there is no concrete, "one-size-fits-all" step-by-step procedure to guide researchers in undertaking participatory research. However, through participatory research, the participants may be "instigators of ideas, research designers, interviewers, data analysts, authors, disseminators and users" (Walmsley & Johnson, 2003, p. 10). Furthermore, through their inclusion and collaboration, the research is legitimized and validated (see also Timmons, Hall, Bose, Wolfe, & Winsor, 2011, for an example of participatory research).

Lewis (2009) suggested a range of methods through which to ensure the validity, credibility, and reliability of qualitative and thus participatory research. These include but are not limited to triangulation, through which multiple sources are used to explain an event or phenomenon; revealing researcher bias and using reflexivity (taking account of researcher presence and actions on the investigation); member checking (checking with the participants to ensure accurate representation and interpretation of data); collaboration; using thick, rich description; replicating the project through the use of multiple cycles; and obtaining feedback from peers.

As participatory research involves people with disability, it must also be framed by appropriate theories of disability. The phenomenological sociology of impairment, together with a Deleuzoguattarian rhizomatic approach to *becoming*, are two theoretical frames which consider the lived body in the real world while adopting a view of unlimited possibility that negates the view of limitation and dysfunction.

The Phenomenological Sociology of Impairment

The lived world is central to phenomenological philosophy, which seeks to describe the world through direct experience. Phenomenology posits the body as both subject and object (Paterson & Hughes, 1999). It considers the body as a social being and integrates impairment with disability (Paterson & Hughes, 1999; Snyder & Mitchell, 2001; Titchkosky, 2005). This view of the lived body within the lived world is the basis for the development of a phenomenological sociology of impairment (Paterson & Hughes, 1999).

The symbiosis or interaction of biological embodiment with social and cultural beliefs and values transforms the embodiment of impairment into narratives about the impact of impairment in their everyday lives (Hughes & Paterson, 1997). Thus, for people with an intellectual disability, a phenomenological sociology of impairment allows for recognition of disability arising from sources both biological and social while enabling them to describe their experiences in the lived world.

However, to appreciate the significant contributions that people with intellectual disability can make as collaborative partners in research, it is important to provide opportunities for *becoming* with a view of unlimited possibility. The Deleuzoguattarian Rhizomatic theory of *becoming* provides such a framework.

A Deleuzoguattarian Rhizomatic Theory of *Becoming*

A Deleuzoguattarian rhizomatic theory of *becoming* was developed by Deleuze and Guattari (1987) and uses the rhizome as a visually figurative term to describe neither the single nor the many but rather multiplicities that are a network of possibilities and constant growth. In rhizomatics, there is no beginning or end. A rhizome is always in the middle in an ever-changing process of *becoming*. Rhizomes comprise a multiplicity of lines of flight which break off, regrow, and extend in all directions (Goodley, 2007).

Applying a Deleuzoguattarian rhizomatic view to the phenomenological sociology of impairment allows for the replacement of the certainty of being or limited expectations, with an ever-changing, never-ending view of unlimited possibility through the process of *becoming* (Titchkosky, 2005). Through this view, spaces of resistance to traditional ways of seeing are opened up (Goodley, 2007). A rhizomatic approach enables people with intellectual disability and those who may work with them, to experience and experiment (Goodley). A Deleuzoguattarian rhizomatic view of intellectual disability negates the view of limitation and dysfunction by enabling the contested space, that is intellectual disability, to be populated by possibilities, and people *becoming* through lived experiences within their lived worlds (Shildrick & Price, 2005/2006).

With respect to the investigation of the everyday literacy practices and skills of adults with intellectual disability, a rhizomatic approach provides an alternative frame through which new methodologies may be developed for involving adults with intellectual disability in the research process and thereby providing a deep understanding of this area. Furthermore, it allows for research to be undertaken in naturalistic settings using a range of data collection instruments which can provide rich and detailed descriptions of the everyday literacy use of adults with intellectual disability. It also enables creative ways of involving the participants in data analysis

and dissemination of research findings, thus expanding literacy opportunities and providing new understandings about literacy beyond school-based conceptualizations.

Conclusion

It is important to explore the everyday literacy of individual adults with intellectual disability to document and understand what constitutes literacy for them in their worlds while also identifying their literacy strengths and identities. Research that fails to consider the uses to which adults put their literacy skills in their daily lives and that ignores, perhaps, idiosyncratic methods used to extract meaning from environmental sources of information, may perpetuate the view that this group of individuals is not literate. This view may limit the opportunities available to adults with intellectual disability both for a valued position in the community as well as for literacy instruction that is effective in assisting them to become more capable in negotiating their everyday lives.

Qualitative approaches to literacy research, such as participatory research, focus on everyday, local literacies in different contexts and in the lives of those who use them. In addition, for adults with intellectual disability such approaches embrace the notion that they are experts in their own lives. Thus, qualitative and specifically participatory research is likely to make a substantial contribution to this expanded notion of literacy for this group. Participatory research is likely to lead to better quality data about everyday literacy activities and meanings. In addition, the theoretical frames of a phenomenological sociology of impairment and a Deleuzoguattarian rhizomatic approach to *becoming* would appear to be useful in guiding participatory research to enable the voices of adults with intellectual disability to be heard and their stories to be told and valued.

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