

Self-advocacy and its impacts for adults with developmental disabilities

Thomas G. Ryan,
Sarah Griffiths
Nipissing University, Canada

The following review of literature illuminates self-advocacy from a North American transformational learning perspective via meaningful impacts, which arise for adults with developmental disabilities, as well as various communities and their members. For adults with developmental disabilities, increased leadership capabilities and the evolution of new self-concepts continue to be powerful examples of the impact of self-advocacy. For communities, a more prominent voice and personable research within the academic community, increased awareness for some boards and committee members, and the acknowledgement and support of local or online community members are broad examples of the impacts self-advocacy has on us.

Keywords: self-advocacy, developmental disabilities, transformational learning

Background

The purpose of this review of literature was to explore self-advocacy

for adults with Developmental Disabilities (DD) and highlight transformative elements. Aspects of self-advocacy and its impact on self-advocates, supports, and communities were examined. We examined self-advocacy as a construct; developed an improved understanding of the differences and connections between self-advocacy and self-determination, and explored the learning adults with DD experience as a result of self-advocacy. We then synthesized the impacts of self-advocacy on adults with DD, their supports, and community members as revealed in current literature.

Intellectual disability

Intellectual disability is another term used in reference to people with cognitive limitations. According to the American Association on Intellectual and Developmental Disabilities (AAIDD, 2013), an intellectual disability is "...a disability characterized by significant limitations both in **intellectual functioning** (reasoning, learning, problem solving) and in **adaptive behavior**, which covers a range of everyday social and practical skills . . . originates before the age of 18" (AAIDD, 2013). Used primarily in the United States, this is contrasted with the term DD, which is considered to be an umbrella term for disabilities that can be cognitive, physical, or both (AAIDD, 2013).

In Ontario, Canada, the term DD is the current term used by Developmental Service Providers (DSP) working in developmental services. The Ontario Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act (2008) stated,

A person has a developmental disability . . . if the person has the prescribed significant limitations in cognitive functioning and adaptive functioning and those limitations, (a) originated before the person reached 18 years of age; (b) are likely to be life-long in nature; and (c) affect areas of major life activity such as personal care, language skills, learning abilities, the capacity to live independently as an adult or any other prescribed activity . . ." (s. 3.1)

In contrast to the United States' use of the term, DD in Ontario shares a similar definition to that of learning disability in Britain and intellectual disability in the United States. For the purposes of this review the term

DD will be used to describe adults participating in self-advocacy groups.

An Exemplar: Malala Yousafzai

Recently, Malala Yousafzai, the young Pakistani woman shot in the head by the Taliban last year, addressed the United Nations (Vaidyanathan, 2013). Speaking at a special youth assembly, Malala advocated for education for children around the world and spoke out about the importance of education to countering terrorism and extremism (Vaidyanathan, 2013). She also presented a petition with more than three million signatures demanding education for all (Vaidyanathan, 2013). To quote Malala, “The terrorists thought that they would change my aims and stop my ambitions . . . but nothing changed in my life, except this: weakness, fear and hopelessness died. Strength, power and courage was born” (Vaidyanathan, 2013, para. 8). Reading about her keynote, one cannot help but be moved and inspired by her courage and her advocacy. Her words highlight a self-transformation borne of her belief in a cause important to her. Her actions, and others’ responses to her actions, demonstrate how one person’s aims may connect with the aims of others to begin collective action. Malala is an example of a self-advocate as well as an advocate for the children and youth worldwide without access to education that she represents.

Yet one does not need to read international news to find a reason to be uplifted or to be encouraged to speak up about an important cause. In Ontario, changes in the developmental services sector and an increase in the desire for agency accreditation are aligning to support the development of self-advocacy groups for and by adults with developmental disabilities. It appears that what started as a movement is leading to groups with organized and personalized purpose. Consequently, there is a need to explore the aspects of self-advocacy for adults with developmental disabilities and the impacts self-advocacy has on self-advocates, supports, and communities in greater depth.

Self-Advocacy Features

Exploring self-advocacy led to an intricate web of answers. Initially focused on only the educational aspects of self-advocacy, it quickly became apparent that defining self-advocacy, outlining its key features and offering an explanation of their educational importance to self-

advocacy would improve the clarity of this literature review. Central to self-advocacy is the concept of self-determination (Wehmeyer & Abery, 2013). The foundation self-determination forms for self-advocacy and their interdependence are critical to our research question which asks; what are the aspects of self-advocacy.

In a survey of self-advocacy groups across the United Kingdom, McNally (2003) asked respondents to describe what self-advocacy meant to each group; one group suggested:

Giving your views. Being listened to. Make our own choices. Able to make our own mistakes. Improving our life to be independent. We feel when we are treated as an adult and listened to [we are] . . . seen as an individual to make our own disions [sic] with or without Assistant [sic]. Then we can have our own houses, relationships and jobs. Our main thing is to be taken seriously and listened to. (p. 238)

This definition highlights the interconnectedness of self-determination and self-advocacy. It also demonstrates how voices previously not often heard are speaking out about a desire to make their own choices. When self-advocates are taken seriously and listened to as suggested, a dialogue that enables increased community engagement, thereby promoting the social model of disability and improving quality of life, may result. However, to do this requires a richer understanding of what self-advocacy is and what qualities contribute to its success.

Defining self-advocacy and types of self-advocacy

According to Schreiner (2007) self-advocacy is simply “the ability to speak up for what we want and need” (p. 300). Individual self-advocacy is speaking or acting for oneself and deciding what is best of oneself (Brandt, n.d.). Conversely, group self-advocacy is when individuals join together to advocate for a common cause (Brandt, n.d.). This may also be referred to as public advocacy if it increases awareness and/or educates others (ID Action Team, 2012).

A self-advocacy group can take on different forms. According to Crawley (1988, as cited in Brandt, n.d.), self-advocacy groups may have one of four different typologies. A self-advocacy group may be autonomous,

meaning that is independent from outside influence (Crawley, 1988, as cited in Brandt, n.d.). Or, a self-advocacy group may utilize a divisional model, whereby self-advocacy is promoted within an existing organization's structure (Crawley 1988, as cited in Brandt, n.d.). The third typology is the coalition model, which uses a cross-disability philosophy and works across disability groups (Crawley 1988, as cited in Brandt, n.d.). Finally, the service system model is another typology and is one that arose from service providers supporting self-advocacy groups within their own organizations (Crawley, 1988, as cited in Brandt, n.d.). Therefore, the importance of learning to make choices for oneself (be self-determined) is the key prerequisite for effective self-advocacy.

Self-determination and its differing perspectives

Self-determination is important to self-advocacy because it provides the self-advocate with the attitude, abilities and skills to identify personal goals and to take the initiative to reach them (ID Action Team, 2012, para. 3). Field and Hoffman (1994, as cited in Johnson, 1999) define self-determination as, “one’s ability to define and achieve goals based on a foundation of knowing and valuing oneself” (p. 164). Thus, defining self-determination and exploring different perspectives of its development becomes important to the topic of self-advocacy. Two such perspectives on self-determination are the social-ecological perspective (Walker et al., 2011) and causal agency theory (Wehmeyer & Abery, 2013).

The social-ecological perspective

The social-ecological perspective of self-determination described by Walker et al. (2011) indicates self-determination is a psychological construct that can be found within the broader theory of human agency. Human agency refers to our capacity to make choices and to impose or assert these choices in our lives (Walker et al., 2011). Those who may not have direct control over situations can still assert agency through proxy (Bandura, 2001, as cited in Walker et al., 2011). According to Bandura (2001, as cited in Walker et al., 2011), proxy agency is when, “ . . . people try by one means or another to get those who have access to resources or expertise . . . to act at their behest to secure the outcomes they desire” (p. 9). Grounded in human agency theories, the social-ecological perspective of self-determination considers human beings

to be active players in the events of their lives, whether through direct action or indirect action via proxy.

Another key aspect of the social-ecological perspective of self-determination is the recognition of the role environment plays in our choices through the use of person-environment interaction models (Walker et al., 2011). When a person interacts with his or her environment in a self-determined manner, the interaction is evenly distributed between enhancing the capacity of the person and changing the expectations of the environment (Walker et al., 2011). This can be impactful for self-advocacy because, if the interaction balances the individual with the environment, then skills in balancing rights with responsibilities and developing a solutions-focused approach to problem-solving can be learned through the development of self-determination skills (Wehmeyer & Abery, 2013). This may make the development and practice of self-advocacy skills easier to undertake for adults with DD.

Causal agency theory

Causal agency theory stems from a belief that there is a need to move beyond self-determination as a construct and to focus on the best ways to promote people living self-determined lives (Wehmeyer, 2004). This requires operationalizing three focal points: (a) enhancing people's skills that enable them to become more self-determined, (b) identifying and promoting opportunities, contexts and environments that promote enhanced self-determination, and (c) identifying the supports that can contribute to enhanced self-determination (Wehmeyer, 2004). Causal agency becomes the framework to explain how people become causal agents in their lives and, therefore, live in more self-determined ways (Wehmeyer, 2004).

Causal agency theory implies that the individual who makes or causes things to happen in his or her life does so for the purpose of causing an effect that will accomplish a specific end or initiate a change (Wehmeyer, 2004). Outcomes are dependent upon the person's capabilities and the challenges to self-determination that he or she faces (Wehmeyer, 2004). There are two types of capability: (a) causal capability that is the mental or physical capacity that enables a person to cause or make something happen, and (b) agentic capability that is the mental or physical capacity

that enables a person to direct causal action (Wehmeyer, 2004). Just as there are two types of capability, there are also two kinds of challenges to self-determination. One type of challenge is opportunities, which are challenges that provoke actions to achieve desired outcomes (Wehmeyer, 2004). The second type of challenges is threats, which are challenges that invoke self-determination in order to maintain a desired outcome (Wehmeyer, 2004). Causal agency theory is helpful for self-advocacy because it operationalizes self-determination. This places a focus on the active development of skills that can be of future assistance when developing self-advocacy capabilities.

While both the social-ecological model and causal agency theory consider those involved to be causal agents actively participating in their lives, the social-ecological model places an added emphasis on the interdependence between an individual and the environment to self-advocacy. Conversely, causal agency theory considers the environment from a more active view, citing challenges – opportunities or threats – as the contextual factor involved in self-determination. Both perspectives highlight the importance of decision-making and active participation to effective self-determination.

Self-determination and self-advocacy: relatedness

Van Reusen et al. (1994, as cited in Van Reusen, 1996) defined self-advocacy as, “... an individual’s ability to effectively communicate, convey, negotiate, or assert his or her interests, desires, needs and rights. It assumes the ability to make informed decisions. It also means taking responsibility for those decisions” (p. 50). The assumption of the ability to make informed decisions underscores the importance of self-determination to self-advocacy. The importance of decision-making to self-determination, and consequently to self-advocacy, is further supported by Johnson (1999) who noted that some of the most important components of self-determination are choice making, decision making, self-observation, self-awareness and self-knowledge. Thus, while self-determination is not self-advocacy and self-advocacy is not self-determination, the two appear to be inextricably linked.

The effects of self-determination and its required development of self-awareness and decision-making skills can be impactful in the lives of adults with developmental disabilities. For example, Heller et al. (2011) associated self-determination with enhanced empowerment outcomes,

health and psychological well-being and increased independence. In a study comparing self-determination levels with the quality of life of 182 adults worldwide with mild DD living in community environments, Lachapelle et al. (2005) found through the use of discriminant function analysis that when an individual possessed each essential characteristic of self-determination identified by the authors, he or she placed in the highest quality of life group. The identified essential characteristics of self-determination were autonomous functioning, self-regulation, psychological empowerment and self-realization (Lachapelle et al., 2005; Wehmeyer & Abery, 2013).

The self-realization noted by the authors above, coupled with the self-observation, self-awareness and self-knowledge noted by Johnson (1999) in discussing self-determination, connect with the ability to communicate and assert one's own interests, needs and rights noted in the previous definition of self-advocacy (Van Reusen et al., 1994, as cited in Van Reusen, 1996). Furthermore, the emphasis on self-regulation (Lachapelle et al., 2005) and decision-making (Johnson, 1999) found in self-determination links to the assumption in the definition of self-advocacy that people make their own informed decisions. As a result, self-determination and self-advocacy become interconnected on many levels, with self-determination providing a foundation upon which self-advocacy may develop.

Lastly, the interrelation between self-determination and self-advocacy skills need not be limited by the severity of a person's disability. In a study of 301 participants from 27 different support agencies in 10 states, Wehmeyer and Garner (2003) found that, while there was a low correlation between self-determination and IQ level, with self-determination being somewhat lower for individuals with more severe developmental disabilities, it was not low enough to suggest that IQ itself can be a strong predictor of higher self-determination. Furthermore, no correlation was made between autonomous functioning and self-determination in the study, regardless of the severity of an individual's disability (Wehmeyer & Garner, 2003). This may be because, according to Olney (2001), our ability to communicate expresses itself through words, behaviours and their communicative content without waiting for permission to be shared. Based upon observations of adults with severe DD, Olney (2001) realized six components of successful

communication, which the author refers to as communicative agency. These include, actions, self-regulation strategies, context or semiotics, collaboration, shared knowledge, and vocal communication (Olney, 2001). Even those of us with few verbal communication skills may combine these six components, due to the contextual and collaborative components, to achieve successful communication (Olney, 2001). Thus, continuing to provide opportunities to practice self-determination skills in a supportive communicative environment may also ensure that adults with more severe developmental disabilities are also included in the effort to develop self-determination skills and in self-advocacy initiatives.

Impacts of self-advocacy

Equipped with a deeper understanding of the aspects of self-advocacy for adults with developmental disabilities, DSPs may more clearly identify the impacts of self-advocacy on adults with DD, their supports, and communities. Examples of such impacts include enhanced leadership skills and self-transformation (self-perspective) for adults with DD (Caldwell, 2010). It is “a structural change in the way we see ourselves and our relationships” (Mezirow, 1978: 100). Perspective, perception and self-perspective are entwined and malleable. As well, research suggests that self-advocacy for adults with developmental disabilities impacts, not only adults with developmental disabilities, but their families and support staff (Caldwell, 2010). Ultimately, self-advocacy for adults with developmental disabilities impacts communities, including the academic community, boards or advisory bodies and the communities they represent, and local communities through projects and initiatives (Frawley & Bigby, 2011).

Impacts of self-advocacy on adults with DD

The impacts of self-advocacy for adults with DD can be seen directly in adults with DD themselves. An example of these impacts is the growth in leadership capabilities of adults with DD (Frawley & Bigby, 2011). Another impact of self-advocacy for adults with DD is a change in self-concept (Gilmartin & Slevin, 2009). This change in self-concept is demonstrative of transformational learning as part of self-advocacy development (Mezirow, 1978; 2000).

Increased leadership capabilities for adults with DD

The development of leadership capabilities is one impact of self-advocacy for adults with DD. Through semi-structured interviews with 13 leaders within the self-advocacy movement, Caldwell (2010) noted four primary themes, two of which directly relate to leadership: (a) the development of leadership skills, and (b) the availability of advanced leadership opportunities. Regarding the development of leadership capabilities, few leaders credited school experiences to building these skills, but rather credited volunteer opportunities, service on committees, experiences within the self-advocacy movement and leadership development workshops in assisting with the growth of leadership skills (Caldwell, 2010). It is these experiences within the self-advocacy movement that demonstrate the impact of enhanced leadership capabilities for adults with DD.

When discussing the second theme of the availability of advanced leadership opportunities, interviewees noted that few opportunities exist outside of the self-advocacy movement for leaders in the United States (Caldwell, 2010). These minimal opportunities are not limited to the U.S. Frawley and Bigby (2011) investigated the experiences of adults with DD on disability advisory boards in Australia. The participants in the study were the only 9 people (as of 2005) with a DD in Australia who were members of disability advisory bodies throughout the country (Frawley & Bigby, 2011). Furthermore, leadership development can be hindered in these limited existing opportunities. One of the intangible obstacles noted by study participants was the feeling that other members of the advisory body did not actively engage participants in conversations (Frawley & Bigby, 2011). As one participant noted, “it hasn’t always been smooth sailing because I have had to fight to get heard. Even now I don’t get heard” (Frawley & Bigby, 2011: 34). Consequently, while one impact of self-advocacy for adults with DD is the development of leadership capabilities, there is as of yet little room to exercise these skills outside of the self-advocacy movement or disability rights groups.

A third theme of note concerning the development of leadership capabilities for adults with DD is an interdependent quality of leadership that results from self-advocates’ experiences. Caldwell

(2010) revealed that leaders spoke in their interviews of embracing an interdependent approach to leadership; whereby they measured their leadership capability by the extent to which they assisted others in becoming leaders. A similar characteristic is addressed by Gilmartin and Slevin (2009) with regards to self-advocacy group participation. In their phenomenological study, the authors discuss how interdependence existed between group members. This was demonstrated when members would ensure that others who could not speak for themselves were heard in the course of meetings; for example by reading a recorded message or recording what somebody wanted to share on their behalf (Gilmartin & Slevin, 2009: 158). As a result, the theme of interdependence extends from self-advocacy leaders through to group members, impacting all participating self-advocates.

Transformative impacts for adults with developmental disabilities

Another significant power within self-advocacy for adults with developmental disabilities is the transformative (Mezirow, 2000) impact it can have on self-advocates. For many, these transformative aspects mean a change in self-concept resulting from membership in a self-advocacy group. Mezirow (2000) claimed that perspective transformation, which “refers to the transforming of a problematic frame of reference to make it more dependable in our adult life by generating opinions and interpretations that are more justified” (Mezirow, 2000: 20), was a powerful growth process. Often, this means reflecting on negative, or even discriminatory, experiences and transcending these experiences to develop a new personal identity (Gilmartin & Slevin, 2009). As one self-advocacy group member remarked, “the way people will treat you, it’s where they’re at in life, it’s true now, it’s not only us like, it’s everywhere in life” (Gilmartin & Slevin, 2009: 157).

Researchers, Beart, Hardy, and Buchan (2004) concluded, that a key theme in all interviews was the idea of “changing selves” (p. 94). Six categories emerged as contributing to this change in self-concept, including joining the self-advocacy group, learning and doing self-advocacy, identifying the aims of the group, and having a positive social environment (Beart et al., 2004). Most notable for transformation are the fifth and sixth categories: a change in self-concept and an

interlinking of one's personal identity with that of the group (Beart et al., 2004).

Changes in self-concept for self-advocates included discussion of experiences of discrimination, bulling and even physical abuse and, at times, prompted a comparison with the past that included reflections on negative and emotionally painful events (Beart et al., 2004). The authors note that membership in the self-advocacy group meant for members that some negative experiences were given new meaning and that reflections on past experiences were viewed in light of new information (Beart et al., 2004). To transcend these revisited experiences, members re-emphasized the importance of collective action and support (Beart et al., 2004). As one group member noted: "It would be suicidal if we did things on our own . . ." (Beart et al., 2004: 97). Others would manage their experiences by turning them into a means of helping and informing others using such media as newsletters or videos (Beart et al., 2004). Once more, the theme of interdependence and measuring personal success by the extent to which you contribute to another's growth is evident in the transformational impacts of self-advocacy.

The transformation of self-concept and the choices that result because of this change reflect elements of transformational learning. Previous discussion of Friere's (2000) theory of transformational learning highlighted the importance of praxis. Praxis is defined as, "reflection and action upon the world in order to transform it" (Friere, 2000: 51). The reflection upon negative experiences, transcendence of these experiences, and transformation of these experiences into ways to help others that is highlighted above provide a strong example of transformational learning based on a social emancipatory theory. It also demonstrates the transformative impact of self-advocacy on adults with DD.

Impacts of self-advocacy on supports

The impacts of self-advocacy for adults with DD are also felt by family members and other supports. Although research discusses family member involvement and knowledge of self-advocacy groups (Mitchell, 1997), this discussion centers primarily on the role family members play in validating a self-advocate's group membership (Caldwell, 2010). The

impacts on and importance of an advocacy advisor to self-advocates' growth and self-advocacy group development is a second theme in the research regarding the impacts of self-advocacy on supports.

Impacts of self-advocacy on family members

The impacts of self-advocacy for adults with DD on family members remain elusive. Mitchell (1997) noted that the experience of self-advocacy within the family is similar to the transitional process any family experiences when children move through adolescence and into adulthood. While co-researchers from Hackney People First noted that the most difficult thing about continuing to live with family was being allowed to be an adult, these co-researchers were also explicit in their belief that the self-advocacy group was for service issues and that discussions regarding home life should be a private matter (Mitchell, 1997).

In addition to a lack of discussion about family matters during the course of self-advocacy group meetings, information sharing with family members also appears to be limited. Mitchell (1997) found that self-advocacy group members would share the fact that they were a member in a group with family, as well as other general information. However, few specifics about the group were shared with parents (Mitchell, 1997). This suggested that determining the impacts of self-advocacy on family members requires utilizing direct research discussion with family members as opposed to indirect discussion with self-advocacy group participants. Additional research considering family impacts from the point of view of family members would assist in broadening the discussion in this area.

While the impact of self-advocacy on family members may require further investigation, the importance of family to positive self-advocacy experiences for adults with developmental disabilities is evident (Caldwell, 2010). In interviews with self-advocacy leaders, interviewees discussed how, outside of the self-advocacy movement, family influence was also important to their leadership development (Caldwell, 2010). When undergoing a change in self-concept, Beart et al. (2004) noted that an important need of self-advocacy group members was to have changed selves positively validated by others, such as family members. This validation helped group members to maintain their new self-

concepts (Beart et al., 2004). Therefore, one important impact of self-advocacy on family members is the ongoing positive impact they can have on their family member with a DD through encouragement and validation of self-advocacy group membership.

Impacts on supports

The greatest impact of self-advocacy for adults with developmental disabilities on supports is noted in particular for advocacy advisors. In a study of self-advocacy group formation and the role of the advocacy advisor, Cone (2000) notes that an advocacy advisor is somebody who helps start groups, teaches new group members about rights and responsibilities, teaches group members how to run the group, provides additional training opportunities, and helps arrange transportation for meetings. Competency areas of an effective advocacy advisor include: (a) facilitating group processes, (b) being a skilled trainer, (c) knowledge, belief and commitment to self-advocacy, (d) having access to community resources, (e) knowledge of service and political systems, (f) problem-solving and conflict resolution skills, and (g) developing action plans and grant writing abilities (Cone, 2000). In discussing the change in the role of the advocacy advisor as the self-advocacy group evolves, 27% of advisors stated that, while the initial activities they did focused on offering advice, running meetings and being the leader, this progressed to offering choices, being supportive and generating ideas (Cone, 2000). Thus, one impact of self-advocacy felt by advocacy advisors is the need to evolve along with the skill development of the group members. Gilmartin and Slevin (2009) illuminated this interdependence between self-advocacy group members and facilitators in their study of the effects of self-advocacy group participation.

Perhaps the greatest impact of self-advocacy on advocacy advisors is an increased opportunity to learn how to best support adults with DD. When summarizing the impacts of self-advocacy initiatives in two Albertan communities, Crocker (2005) shares that self-advocates felt the most useful staff support was when staff assisted with planning and organization, assisted with writing letters, and helped to ensure self-advocates understood what was said and that everyone involved in the initiative understood the purpose of the project. The use of the words assist and ensure demonstrate how self-advocates wish to take a

lead role in these activities, with staff providing secondary support as needed. This underscores the theme of person-centered support within self-advocacy while also demonstrating that a large impact on advocacy advisors and support staff is the desire of self-advocates that supports hold back from taking a direct role in activities and emphasize guidance, not direction.

Impacts of self-advocacy on communities

Self-advocacy for adults with DD also has many impacts on various communities. These include the academic community and also boards and the communities they serve (Frawley & Bigby, 2011). Field-based resources and reports also demonstrate that self-advocacy for adults with DD has localized impacts on the communities where projects and initiatives take place (Inclusion BC, 2010).

Academic communities and participatory research: impacts

The impacts of self-advocacy for adults with DD are evident in academic communities through the use of participatory research methods (Gilmartin & Slevin, 2009). One example of participatory research is Traustadottir's (2006) discussion of one person's experience with self-advocacy. Utilizing a collaborative life history approach, the author and participant highlight changes in access to opportunities for self-advocacy during the participant's life in both residential and independent living settings (Traustadottir, 2006). The collaborative life history approach can be helpful in understanding self-advocacy development because telling one's story is in itself an act of speaking up.

In a second example, Gilmartin and Slevin (2009) used a phenomenological approach in their study of the effects of participating in a self-advocacy group on group members; concluding that utilizing this participatory approach, "enabled and enhanced the ability of participants to participate in inclusive research" (p. 158).

In their study of inclusive academic conferences, Frawley, Bigby and Forsyth (2006) found that the degree of attention and effort that was given to inclusion at conferences was dependent upon having a champion that would support the process. Three strategies were noted as helpful in achieving inclusion. One strategy is to have a "consumer"

strand of the program during which accessible papers are delivered to an exclusive audience of consumers with additional time being allotted for questions and discussion (Frawley et al., 2006). A second strategy is to have a consumer/self-advocate day where there are Plain English presentations, exclusive activities, and workshops are run for and by people with developmental disabilities (Frawley et al., 2006). Thirdly, academic conferences may be offered as fully integrated events, with co-presentations and workshops run by local self-advocacy groups (Frawley et al., 2006). Regardless of the strategy used, partnerships between professional organizations and self-advocacy groups to support a joint forum are the authors' recommendation for ensuring success (Frawley et al., 2006). Depending on the strength of the partnership, the potential impacts on researchers, professional and self-advocates as an inclusive community are limitless.

Impacts of self-advocacy on boards and their respective communities

The impacts of self-advocacy can also be seen on boards and the respective communities they represent. In their study of adults with developmental disabilities participating on disability advisory bodies, Frawley and Bigby (2011) found that people with DD hold different political views and that these views influence civic participation. However, the impact of self-advocacy on these advisory bodies was limited, as representatives with developmental disabilities faced the tangible obstacles of long meetings, a failure to translate agendas, minutes and documents into plain English, and being inadequately briefed on issues to be discussed at the meetings (Frawley & Bigby, 2011). These experiences demonstrate how negative or limited impacts can be felt by board members and their respective communities if participation on advisory bodies is token participation, with minimal effort taken to provide a social environment that is collegial and supportive.

Conversely, when effort is made to provide a positive and supportive environment, the impact on board members and respective communities can be great. Through telephone surveys of board representatives with developmental disabilities, family member representatives, and traditional board representatives, Caldwell, Hauss, and Stark (2009) found that study participants felt the outcomes of

committee input can provide a good marker of a committee's value and importance. As one director/representative stated: "Is the advice utilized? . . . I know that for us we've got a number of initiatives going on that we would never have embarked on if it wasn't for this group telling us that this is what they wanted us to pay attention to" (Caldwell et al., 2009: 107). These words demonstrate, when input from self-advocates is valued, the impact of self-advocacy on the board is that new directions are undertaken and new possibilities are explored.

Impacts of self-advocacy on communities through local projects and initiatives

Self-advocacy also has impacts on communities through local projects and awareness initiatives. For example, self-advocates in communities throughout British Columbia organized and implemented projects in their communities as part of the Self-Advocates Seeding Innovation (SASI) project (Inclusion BC, 2010). In one project, a self-advocate mapped his community; interviewing community members about what they do and how they welcome people with disabilities into their establishments (Inclusion BC, 2010). These interviews and map were then turned into a guide book for others with disabilities to use to determine which places in their community are welcoming places to visit (Inclusion BC, 2010). This project represents a tool with potentially large impacts on community members and local business owners – a tool created by a self-advocate.

Another example of a local project undertaken through the SASI initiative is a partnership between a self-advocacy group and other community organizations to organize and host an employer appreciation awards and breakfast (Inclusion BC, 2010). Through this partnership, self-advocates engaged in discussion with business representatives, employment agencies, and community members about employment for adults with disabilities (Inclusion BC, 2010). The impact of this example of self-advocacy for adults with DD on the community is the assurance that self-advocates continue to play an active role in discussion of improved employment outcomes within their community.

The impacts of self-advocacy for adults with developmental disabilities on communities can also be seen in awareness initiatives or movements. For example, self-advocacy groups in two communities

in Alberta (Canada) created the *Broadening Your Horizons* initiative to demonstrate how individuals could become self-advocates and practice self-advocacy in their communities (Crocker, 2005). The initiative included *Abilities Awareness Week*, with a variety of workshops for business people designed to help them understand how to communicate with people with disabilities (Crocker, 2005). For example, one workshop included one self-advocate explaining how restaurants could improve their menus so that it was easier for people with developmental disabilities to understand them and, by extension, increase the restaurant's business (Crocker, 2005). This initiative had positive impacts on the interactions between self-advocates and fellow community members. As one self-advocate noted, "I was very proud to see that my community has been behind me and the things that I do" (Crocker, 2005: 15). Self-advocates are also impacting online communities. Ward and Meyer (1999) claim that large-scale self-advocacy advanced significantly during the early 1990s due to the increased use of email and other communication technologies. Today, self-advocacy continues to grow its online presence, impacting a greater number of online community members. This is demonstrated in another SASI project, where a website was able to expand its services (Inclusion BC, 2010). Due to the SASI initiative, the self-advocacy website selfadvocatenet.com was able to create an online space for self-advocacy groups to connect, share information and host their own WebPages (Inclusion BC, 2010). The impacts this may have on individual communities is unlimited, as self-advocacy groups throughout the world may find inspiration in the information and postings shared on this website which they can, in turn, use as starting points for initiatives in their own communities.

Social media is also a growing space for today's self-advocacy groups to share their message and impact communities. For example, the London, Ontario based self-advocacy group New Vision Advocates is one example of a self-advocacy group with their own Facebook page. Through this space, the group is able to share information about their mission, their events and services (i.e. presentations), at <http://www.facebook.com/#!/thenewvisionadvocates>. In today's social media age, self-advocacy has gone from being global via email, to social via our online networks. This could have new and exciting impacts via numerous shared online connections worldwide.

Conclusions and recommendations

Considering self-advocacy from a transformational learning perspective, meaningful impacts arise for adults with developmental disabilities as well as various communities and their members. For adults with developmental disabilities, increased leadership capabilities and the evolution of new self-concepts are powerful examples of the impacts of self-advocacy. For communities, a more prominent voice and personable research within the academic community, increased awareness for some boards and committee members, and the acknowledgement and support of local or online community members are broad examples of the impacts self-advocacy has on us all.

Recognising the importance of self-determination to the exercise of effective self-advocacy must also not be underestimated. Whether viewing self-determination from a social-ecological perspective (Walker et al., 2011) or through the use of causal agency theory (Wehmeyer, 2004), the importance of developing self-awareness and decision-making skills is key strong self-determination and, by extension, effective self-advocacy. As a result of their interdependence, it is important that one does not consider self-determination without considering its future implications for self-advocacy and, conversely, that one does not consider self-advocacy without acknowledging the important qualities of self-determination that serve as prerequisites for budding self-advocates.

The topic of self-advocacy for adults with developmental disabilities is not without its limitations. In considering the impacts of self-advocacy on family members, information was primarily focused on the validation self-advocates seek from family, with minimal information regarding family members' perspectives (Caldwell, 2010). Detailing these experiences and perspectives may be one area for future research consideration. Deepening our understanding of family members' opinions and experiences may promote the quality of interdependence noted in the social model of disability and further enable the efforts of self-advocates.

In a similar vein, research on the impacts of self-advocacy for adults with developmental disabilities on support staff centers on the experiences of advocacy advisors (Gilmartin & Slevin, 2009).

Considering Ontario's current context of establishing and maintaining person-centered services within developmental services, additional research regarding the impacts of self-advocacy on all support staff as well as their perspectives on self-advocacy for adults with developmental disabilities would be both current and helpful for the sector. Future research in this area may consider comparing and contrasting perspectives based on the type of position support staff hold, their length of employment to help develop an understanding of the factors that contribute to or detract from support staff's encouragement of self-advocacy for adults with developmental disabilities. This experience may demonstrate that support staff, in addition to self-advocates, can experience transformational learning and changes in self as a result of their involvement in self-advocacy groups for adults with DD.

References

- American Association on Intellectual and Developmental Disabilities. (2013) *Frequently asked questions on intellectual disability*, viewed August 12, 2013, <<http://aaidd.org/intellectual-disability/definition/faqs-on-intellectual-disability#.UdeBoWomPSg>>.
- Beart, S., Hardy, G., & Buchan, L. (2004) 'Changing selves: A grounded theory account of belonging to a self-advocacy group for people with intellectual disabilities', in *Journal of Applied Research in Intellectual Disabilities*, 17, 91-100.
- Brandt, J. M. (n.d.) *Creating a new self-advocacy organization – Imagine the possibilities: A discussion brief*. Unpublished manuscript. Partnership for People with Disabilities,
- Virginia Commonwealth University, Virginia, United States, viewed November 11, 2013, <http://www.aucd.org/docs/add/sa_summits/VBPD%20SALT%20Organization%20Discussion%20Brief%20FINAL.pdf>.
- Caldwell, J. (2010) 'Leadership development of individuals with developmental disabilities in the self-advocacy movement', in *Journal of Intellectual Disability Research*, 54: 11, 1004-1014.
- Caldwell, J., Hauss, S., & Stark, B. (2009) 'Participation of individuals with developmental disabilities and families on advisory boards and committees', in *Journal of Disability Policy Studies*, 20: 2, 101-109.
- Cone, A. A. (2000) 'Self-advocacy group advisor activities and their impact/ relation to self-advocacy group development', in *International Journal of Disability, Development and Education*, 47: 2, 137-154.
- Crocker, C. (2005) *The journey to self-advocacy*, viewed October 15, 2013, <<http://humanservices.alberta.ca/documents/pdd/pdd-central-journey-to->>

- self-advocacy.pdf>.
- Developmental Services Ontario. (2013) *The Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act*, viewed November 12, 2013 <<http://www.dsontario.ca/the-services-supports-to-promote-the-social-inclusion-of-persons-with-developmental-disabilities-act>>.
- Focus Accreditation. (2011) *Standards*, viewed October 15, 2014, <www.focusaccreditation.ca/standards>.
- Frawley, P., & Bigby, C. (2011) 'Inclusion in political and public life: The experiences of people with intellectual disability on government disability advisory bodies in Australia', in *Journal of Intellectual & Developmental Disability*, 36:1, 27-38.
- Frawley, P., Bigby, C., & Forsyth, H. (2006) 'Why are conferences "sometimes about us, without us?"', in *Journal of Intellectual & Developmental Disability*, 31: 4, 249-251.
- Friere, P. (2000) *Pedagogy of the oppressed: Thirtieth anniversary edition*. New York: The Continuum International Publishing Group, Inc.
- Gilmartin, A., & Slevin, E. (2009) 'Being a member of a self-advocacy group: experiences of intellectually disabled people', in *British Journal of Learning Disabilities*, 38, 152-159.
- Heller, T., Schindler, A., Palmer, S. B., Wehmeyer, M. L., Parent, W., Jenson, R., Abery, B. H., Geringer, W., Bacon, A., & O'Hara, D. M. (2011) 'Self-determination across the life-span: Issues and gaps', in *Exceptionality*, 19, 31-45.
- ID Action Team. (2012) *Self-Advocacy – Why It's Important*. (Issue Brief No. 2), viewed, December 12, 2014 <http://www.idaction.org/documents/cms/docs/Newsletter_Archives/2012-Issue-2.pdf>.
- Inclusion BC. (2010) *Self-advocates seeding innovation project*, viewed December 02, 2014 <http://www.inclusionbc.org/sites/default/files/uploads/SASI_booklet_for_web.pdf>.
- Johnson, J. R. (1999) 'Leadership and self-determination', in *Focus on Autism and other Developmental Disabilities*, 14: 1, 4-16.
- Lachapelle, Y., Wehmeyer, M. L., Haelwyck, M. C., Courbois, Y., Keith, K. D., Schalock, R., Verdugo, M. A., & Walsh, P. N. (2005) 'The relationship between quality of life and self-determination: An international study', in *Journal of Intellectual Disability Research*, 49: 10, 740-744.
- McNally, S. (2003) 'A survey of self-advocacy groups for people with learning disabilities in an English region', part two, in *Journal of Learning Disabilities*, 7: 3, 231-250.
- Mezirow, J. (1978) 'Perspective transformation', in *Adult Education Quarterly*, 28: 2, 100-110.
- Mezirow, J. (2000) 'Learning to think like an adult: Core concepts of

- transformation Theory, in J. R. Mezirow and Assoc. (Eds.), *Learning as transformation: Critical perspectives on a theory of progress*, 1-33. San Francisco: Jossey-Bass.
- Mitchell, P. (1997) 'The impact of self-advocacy on families', in *Disability & Society*, 12: 1, 43-56.
- New Vision Advocates. (n.d.) In *Facebook*. [Group page], viewed June 24, 2013, <<https://www.facebook.com/thenewvisionadvocates>>.
- Olney, M. F. (2001) 'Communication strategies of adults with severe disabilities: Supporting self-determination', in *Rehabilitation Counseling Bulletin*, 44: 2, 87-94.
- Schreiner, M. (2007) 'Effective self-advocacy: What students and special educators need to know', in *Intervention in School and Clinic*, 42: 5, 300-4.
- Services and Supports to Promote the Social Inclusion of People with Developmental Disabilities Act (2008) viewed September 22, 2013, <http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_08s14_e.htm>.
- Traustadottir, R (2006) 'Learning about self-advocacy from life history: A case study from the United States', in *British Journal of Learning Disabilities*, 34: 3, 175-180.
- Vaidyanathan, R. (2013) Shot Pakistan schoolgirl Malala Yousafzai addresses UN. (July 12). *BBC News*, viewed August 27, 2013, <<http://www.bbc.co.uk/>>
- Walker, H. M., Calkins, C., Wehmeyer, M. L., Walker, L., Bacon, A., Palmer, S. B., Jesien, G. S., Nygren, M. S., Gotto, G. S., Abery, B. H., & Johnson, D. R. (2011) 'A social-ecological approach to promote self-determination', in *Exceptionality*, 19, 6-18.
- Ward, M.J., & Meyer. R. N. (1999) 'Self-determination for people with developmental disabilities and autism: Two self-advocates perspectives', in *Focus on Autism and Other Developmental Disabilities*, 14: 3, 133-139.
- Wehmeyer, M. L. (2004) 'Beyond self-determination: Causal agency theory', in *Journal of Development and Physical Disabilities*, 16: 4, 337-359.
- Wehmeyer, M. L., & Garner, N. W. (2003) 'The impact of personal characteristics of people with intellectual and developmental disability on self-determination and autonomous function', in *Journal of Applied Research in Intellectual Disabilities*, 16, 255-265.
- Wehmeyer, M.L., & Abery, B. (2013) 'Self-determination and choice', in *Intellectual and Developmental Disabilities*, 51: 5, 399-411.

About the Authors

Dr. Thomas G. Ryan is Professor of Education, Graduate Studies and a special educator who volunteers in his community supporting adult

learning. North Bay, Ontario, Canada.

Email: thomasr@nipissingu.ca

Ms. Sarah Griffiths is a graduate of Nipissing's M.Ed., program and currently is a LEG Up! Instructor at Kitchener Waterloo Habilitation. In the past she was an instructor of Literacy and Continuing Education at District School Board of Niagara - Life Skills Curriculum Developer/Facilitator at Options Niagara, Ontario, Canada.

Email: sgriffiths@kwhab.ca

Contact details

*Nipissing University,
Faculty of Education,
100 College Drive,
North Bay, Ontario,
P1B 8L7
Canada*