


# Reframing Health Promotion for People With Intellectual Disabilities

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## Abstract

The World Health Organization calls for health promotion to expand beyond the health care system by considering social determinants of health, engaging multiple levels, targeting policy change, and including social action. This qualitative study embraces this holistic stance as a means to address the health disparities and inequities experienced by people with intellectual disabilities (ID) by supporting the development of interventions that consider components of social justice along with embracing this population's potential and acknowledging influences of the context. A content analysis of the data is presented to illustrate how an occupational viewpoint can promote positive health and well-being of people with ID. The four gerunds of Wilcock's *Occupational Perspective on Health*—doing, being, belonging, and becoming—are utilized and supported by the literature to offer actions that can be taken by health promotion professionals to address the health needs of people with ID.

## Keywords

disability / disabled persons; health and well-being, health care disparities; health promotion; marginalized populations; participatory action research (PAR); photography / photovoice

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The topic of health promotion for people with intellectual disabilities (ID) has become prevalent in recent literature, in part, as an effort to address the widespread health disparities and inequities currently experienced by this population. The causes of these differences continue to be studied and debated, but are generally attributed to insufficient preparation of health care professionals and limited health care delivery flexibility. Specifically, common causes are identified as negative provider attitudes and stigmatization, poor health practitioner preparation, diagnostic overshadowing, inaccessible medical facilities and equipment, and communication breakdowns between providers and patients with ID (Fisher, 2004; Iezzoni, 2011). As the focus of health care shifts beyond disease management to include education, prevention, and promotion, professionals need to seize this opportunity by exploring ways to expand health directives for people with ID, to address health as an integral part of life and “as a resource of everyday life, not the objective of living” (World Health Organization [WHO], 1986, p. 1).

Green and Kreuter (1999) defined health promotion as “any planned combination of educational, political, regulatory, and organizational supports for actions and conditions of living conducive to the health of individuals, groups, or communities” (p. 506). This broad definition leaves the actual interventions for health promotion open to interpretation, but at the same time, might limit the reader to apply

only traditional methods toward achieving health, for example, physical exercise and nutrition. Within the last decade, several health promotion programs have been developed to address the needs of people with disabilities (Abdullah & Horner-Johnson, 2006; Marks, Sisirak, & Heller, 2010; Ravesloot et al., 2006). The content of these programs tends to focus on this foundational health knowledge and individual health behavior change. Although health promotion approaches have been successful in facilitating health behavior changes in a variety of populations, the evidence supporting these theories in people with disabilities is sparse (Drum et al., 2009; Mallinson, Fischer, Rogers, Ehrlich-Jones, & Chang, 2009).

The Ottawa Charter for Health Promotion (OCHP) calls for health promotion to expand beyond the health care system and consider the social determinants of health by engaging multiple levels, targeting policy change, and including social action (WHO, 1986). By establishing effective interventions that influence multiple levels, health professionals can move beyond a focus on changing individual health

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behavior to acknowledging the dynamic interaction between social factors and individual behaviors (Peterson, Hammond, & Culley, 2009). Utilizing a broad approach to health promotion minimizes victim blaming by acknowledging the multiple forces that influence healthy behavior rather than just individual choices and/or behaviors (McLeroy, Bibeau, Steckler, & Glanz, 1988). Given the limitations many people with ID experience in decision making, this seems to be a relevant concern.

The OCHP defines health promotion as

the process of enabling people to increase control over, and to improve, their health. To reach a state of complete physical, mental, and social well-being, an individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment. (WHO, 1986, p. 1)

This is a more holistic and descriptive definition that goes beyond commercialized health aspects by considering the influence of environment, including emotion and social components, and linking health to capacity utilization and satisfaction. This document continues to expand the focus of health promotion by stressing the importance of social justice and its relation to health (Peterson et al., 2009) stating,

Health is created by caring for oneself and others, by being able to make decisions and have control over one's life circumstances, and by ensuring that the society one lives in creates conditions that allow the attainment of health by all of its members. (WHO, 1986, p. 1)

A thorough appreciation of the social determinants of health in people with ID requires identification of the needs and wants of the population, consideration of skills and experiences, and an acknowledgment of the influence of the environment in which they live, work, and play. Without this understanding, health promotion interventions stand little chance of being successful (Rimmer, 2006). For example, health professionals will be ineffective if they suggest attending a gym to increase activity without considering transportation needs or if they propose incorporation of vegetables without evaluating meal preparation skills.

The health promotion profession has long understood the value behind incorporating the priority population in the planning process. Green and Kreuter (1999) suggested that health promotion starts by engaging the Precede-Proceed model. This model offers several steps to assessing and developing interventions that address health and quality of life needs. The initial stages of the model, the Precede phases, focus on the identification and appraisal of the health determinants prior to program planning. This framework encourages beginning with the outcomes and asking the question *why* before *how*. Starting by identifying what precedes the outcomes allows the health promotion professional to direct education and behavior change methods to meet the needs of the priority population. The first step of this phase, the Social

Assessment, guides the planner to involve people from the priority population in a self-study to identify hopes, needs, and goals.

## Purpose

People with ID need health promotion programs aimed at risk factors and determinants specific to this population. Little research has been done that includes the perspective of this priority population. To address this concern, a qualitative, descriptive study was conducted to identify the perceptions of health in adults with ID. Information was gathered through observations and the direct elicitation of adults with ID. The study participants identified four themes: defining health, feeling connected, having something to do, and being part of the community. Details of these results are reported elsewhere (Cardell, 2013).

The purpose of this article is to acknowledge an alternate, or at least supplemental, direction for promoting the health of people with ID. By analyzing the data through the lens of occupational science, I suggest that the results support the proposal that inequities experienced by this group go beyond individual behaviors and health care delivery and are related to aspects of social justice. Implications for practice are considered and recommendations for the development of meaningful, holistic interventions are provided.

## Method

Successful utilization of conventional health-related data collection methods, such as questionnaires, self-reports, and journaling, requires complex cognitive skill and is therefore often difficult for people with ID. Besides being ineffective, researchers who use these methods risk highlighting participants' limitations, and contributing to feelings of inadequacy (Wang & Burris, 1997). The objective in designing this study was to choose a method that was both accessible and inclusive for the population's range of abilities. I chose to utilize photovoice after considering my priority population and the WHO's call to address health promotion through reciprocal participation and consideration of the environment, and across multiple levels of influence.

Photovoice is a qualitative method that utilizes photography to elicit information and empower participants to be self-advocates (Wang & Burris, 1997; Wang, Yi, Tao, & Carovano, 1998). Photographs, taken by the participants, are utilized to obtain thick descriptions and meaning of everyday experiences during group discussions. This is a participatory action research (PAR) method that considers the participants to be experts in their own lives with the ability to offer insight that professionals are often unable to access. The goals of this method are to identify the assets and concerns of the group, empower individuals through participation, and increase awareness in the public and stakeholders (Wang & Burris, 1997).

## Study Procedure

After approval from the Institutional Review Board and completed informed consent, I recruited a total of 25 adults with ID, all of who lived in the community with various levels of support. The majority of individuals lived with someone: 10 with parents, 2 with a spouse, and 11 with roommates (and assistance of staff). Only two individuals lived alone but did so with the support of part-time staff. The participants' ages ranged from 23 to 64 years ( $M = 33$ ), and 12 were men. The majority of individuals (16) were involved in some type of formal day program, 6 were employed at least part-time in the community, and 3 had no employment or structured services. No specific IQ range was identified during recruitment in an attempt to represent a range of abilities. No medical records were accessed to verify diagnosis because this was a PAR method and participants were recruited from several community agencies. For this reason, specific diagnoses of the individuals are unknown and irrelevant for the purposes of this study.

I followed the established steps of photovoice, with the exception of two additional components: (a) initial interviews and (b) participant observations. The details of the entire process have been documented elsewhere (Cardell, 2013). Individual interviews were included, as a part of the analysis phase, to allow each participant an opportunity to share their experiences and photographs with the researcher. Conducting interviews facilitated by the participants' photographs allowed me to collect rich data and negotiate the interpretation with my participants (Pink, 2007).

Traditionally, the photovoice method places the academic researcher in the role of a silent partner, facilitating the process, but not contributing beyond constructing the final written product. Because many people with ID often have difficulty with communication skills in both articulation of words and expression of ideas, I utilized participant observations, in conjunction with the visual methods, to assist the participants in telling their stories. These observations add the context in which to frame the participants' comments. This practice is in line with ethnographic methods (Angrosino, 2007) and allowed for a cocreated research experience and outcomes. The setting of the observation was chosen by the participant and generally occurred in the familiar, routine context of the participant's home, volunteer, or day program.

The individual interviews and the group discussion were initiated using a semistructured interview format. The participants were encouraged to discuss any relevant information related to the photographs or health. This method allowed the participants to be involved in the steps of analysis and the researcher to direct the questions in a way that allowed for richer description and deeper meaning (Creswell, 2007; Woodgate & Leach, 2010). The use of the photographs not only allowed me to elicit information about health but also gave me a glimpse into the lives of the study participants, events, and details I would have otherwise not been

exposed to during our interactions. The subjects in the photographs cued me into meaningful components of the participants' lives and broadened my understanding of their perspectives and the determinants of health.

## Analysis

The data for this study were gathered from multiple sources: groups, individual interviews, and observations. All interviews and group discussions were transcribed by the researcher verbatim and entered, along with field notes, into ATLAS.ti.6.2. This report includes a combination of data assembled from the participants' interviews (represented here with the use of pseudonyms) and from analysis of the field notes taken during participant interactions and observations, a total of 830 pages of text.

Goodley (1996) supported utilizing a narrative process to confront generalizations and opinions of people with disabilities by stating "... our 'truths' are quickly challenged by the personal narrative" (p. 335). There is only a brief description of the analysis process in the original photovoice articles; no details are present (Wang & Burris, 1997; Wang et al., 1998). Based on the information gained from these articles, I decided to use an inductive thematic analysis to identify the patterns of information that are related to the original inquiry. This recursive procedure requires examination of the entire dataset to discover themes of interest and offered a way to crosscheck the patterns in the data across the entire set of transcriptions and field notes (Morse & Field, 1995). The results composed during this first phase of analysis are reported elsewhere (Cardell, 2013).

My clinical experience as an occupational therapist (OT) includes nearly 25 years working in the community with people who have a variety of cognitive disabilities. When I set out to do this study, my intent was to gather information that would improve health promotion for this population, not from the perspective of an OT but from the perspective of the participants. After coconstructing results with the participants and reflecting on my experiences during the research observations and my clinical work, I concluded that there was a larger story that needed to be told. This compelled me to return to the literature and complete an additional step of analysis. After reexamining the related literature, I discovered that many of the aspects revealed in the data were similar to those discussed in the field of occupational science. In the reanalysis, I examined the data again utilizing content analysis to discover the details that align with an occupational viewpoint (Portney & Watkins, 2009). I applied the four interrelated segments identified in Wilcock's (2006) *Occupational Perspective of Health*—doing, being, belonging, and becoming—to the data for a retroductive content analysis by occupational health categories.

To increase the result's credibility and dependability, triangulation was created through the use of prolonged engagement, multiple methods (interviews, groups discussion, and

observations), and several analysis of the data (the researcher and participants; Creswell, 2007; Flick, 2006; Hergenrather, Rhodes, Cowan, Bardhoshi, & Pula, 2009; Portney & Watkins, 2009). The partnership in the research process and the use of the final groups served as forms of member checking, the traditional way of confirming results with the participants. Initial insights and procedural decisions were documented throughout the process via careful field notes and detailed memos. This audit trail made the decision process and conclusions transparent, increasing the dependability of the study (Creswell, 2007; Flick, 2006; Portney & Watkins, 2009).

## Results

The results of this study are presented below four headings, as Wilcock (2006) presented them, but the dynamic interaction Wilcock proposed among the four dimensions should be kept in mind. This separated representation is an effort to emphasize the distinct characteristics of each component and stress how they each affect health.

### Doing

What we do is at the heart of who we are. Think of how often you ask, "What do you do?" when becoming acquainted with someone. *Doing* includes goal-oriented activities that offer interaction, engagement, and productivity. It is through doing that individuals develop the skills needed to meet basic needs (Wilcock, 2006).

The participants described having something to do, or the lack thereof, as a determinant of health. Those participants who were doing during their day took photographs at the library, going on hikes, working at day programs, volunteering at community agency activities, and visiting with family. Many of them talked about the positive aspects of being busy, especially if the activity was productive, for example, making gifts for others, working, or volunteering. Quite a few participants took pictures of gardens and mentioned the satisfaction they felt when participating in the activity of gardening. When I asked the group how gardening was good for your health, the ideas of healthy food, along with exercise, nurturing, and being productive, were all mentioned:

- Sharla (S): My grandma has [a garden].  
 Jana (J): Vegetables!  
 Marilyn (M): You can plant vegetables, tomatoes, beans, carrots.  
 Brady (Br): I love to garden with my dad.  
 J: It's like exercise.  
 S: And you can pick all the vegetables and eat them.  
 Br: I love working in the garden because it makes me take care of plants and you get to grow things.

Although still considered doing, many of the participants stated much of their time was spent in sedentary activity. These tasks were generally nonproductive and offered limited engagement, for example, watching television and movies or going for a ride in the van. The majority of the individuals could identify that sedentary tasks were not health promoting and stated a preference for more active tasks like bowling, dancing, and sports.

Doing also includes the development and application of skills to meet daily needs. Skill development is vital to achieving the independence required to live in the community and to negotiating situations experienced in adulthood. In this study, those who received additional staff support outside of a day program were more inclined to be involved in some type of skill development than those without a daily program or those who just attended day services. Clients reported learning how to ride public transportation, manage health conditions, and complete household tasks.

The majority of the participants seemed to have a working knowledge of healthy lifestyle topics, but for many of them, a lack of daily living skills presented an obstacle to incorporating this information. Through cooperative review of the photographs, conversations, and observations, underdeveloped skills related to healthy lifestyle behaviors were most obvious in planning and preparing meals and making good choices concerning food and activity. Several people either stated the desire to learn to cook or spoke of making food choices (convenience foods) based on an inability to cook. Iris had a pantry that was so full of food, she was unable to close the doors. When I asked her why she had so much food, she stated she received a food box from the food bank each week. The food was accumulating because she was unsure what most of the products were and did not know how to prepare them. Before I left her apartment, she tried to give me a bag of fresh lettuce stating, "I have nothing to eat it with and I will just end up throwing it away."

The ability to make good, informed choices was difficult for many of the participants. Behaviors were observed that reflected a decreased ability to practice what they knew to be healthy. Discussions of healthy choices were often followed by recent examples of when they did not employ good decision making. Participants were often torn between choosing a healthy option or one they thought tasted good. After Josh identified healthy items on the menu at the restaurant where he works and the importance of making wise decisions, I questioned his choice to have french fries for lunch. He replied as follows:

- Josh (J): Cheese fries! Those are my favorites. Oh, they are with ranch dressing on them. Ohohohoh! You dip them in. Even better when it is hot and cheesy! And bacon bits on top. That is dressed up.  
 Author (A): Wow! Are those healthy for you?  
 J: Ha! What do you think?



- A: I think they are not.  
 J: You are right. I don't know, but you have choices to make, right?  
 A: Yep.  
 J: I choose cheese fries all the time.

Although some participants had evening and weekend staff available to assist with tasks and instruct in daily living skills, not all of the staff were effective. Brady showed me a photograph of a staff member lying on the couch. When I inquired about the purpose behind having staff in the evening, he replied as follows:

- Brady (Br): Um, they are usually laying [in the living room] watching TV and I am watching TV in my room.  
 Author (A): That doesn't sound very interesting. Why do they even come?  
 Br: Because, I want to learn to cook on my own.  
 A: You want to learn to cook on your own but you are watching a movie in your room while they watch TV [in the living room]. How does that help you learn to cook?  
 Br: Um, well sometimes I help [a different staff member] when she comes and cooks.

Another skill area that affected the participants' level of doing was difficulty with social participation outside of structured services. Planning social activities with friends is a task that can require a high level of cognitive performance. Organizing times, matching interests and abilities, and coordinating schedules take knowledge of your community and the capability to make appropriate decisions. Most of this study population stated limited experience doing these tasks, either secondary to inadequate knowledge or opportunity. The combination of limited planning abilities and a strong desire to *do* created a predicament for some of the participants. This dilemma not only negatively affected health by affecting both doing and belonging (discussed in more detail to follow) but also led some individuals to become involved in unsafe activities. A few of the participants told me stories about injuries that occurred while in the community, involvement with the police, and near-miss situations. In a desperate attempt to do, one participant decided to take a tour bus to a casino, approximately 90 minutes from her home. When she missed the bus, she solicited a ride from a man at the nearby gas station. This stranger agreed to drive her to the location, but once there abandoned her, leaving her with no transportation home. Although the problem of being stranded was apparent to her, at the time of the incident, she was unaware of the danger she placed herself in by accepting a ride from a stranger. She stated, "Well, I get that now. I just wanted something to do!"

## Being

*Being* has been defined as maintain your true self, finding meaning and purpose, and discovering and utilizing your capabilities (Wilcock, 2006). Hammell (2004) expanded on this definition by stating being involves opportunities to "reflect, be introspective or meditative, (re)discover the self, savor the moment, [and] appreciate nature, art, or music in a contemplative manner" (p. 301).

Acknowledging strengths and contributions promotes a sense of being by encouraging people to live a life that represents their true self. People with ID might require assistance to maximize their skills and recognize opportunities to contribute. Making the most of the abilities in people with ID was seen on several occasions during this study, mostly at the community agencies and during formal services, when staff members were able to match capabilities with activity demands. Clark, a participant who spoke infrequently and offered minimal eye contact, appeared to have limited abilities that would transfer to a vocation, yet his job at the day program was to keep the activity room clean. This task highlighted Clark's strengths of being observant and detail oriented. While reviewing a photograph of the activity room, he stated he loved attending the program. When asked why, he reported as follows:

- Clark (C): Work.  
 Author (A): What is your job here?  
 C: Cleaning.  
 A: I noticed you are always throwing things away. Are you in charge of keeping this room clean?  
 C: Yes.  
 A: You do a good job.  
 C: Yes, I do.

At a community fundraiser for Down's syndrome, Kevin was able to contribute and showcase his passion for music. He described this opportunity, to be true to himself and share his talents, as good for his health:

- Kevin (K): I was playing my guitar. I guess that's good for you. Having fun, singing, and showing your skills in front of everyone.  
 Author (A): So you like performing?  
 K: Yes, [even though] I can't sing very well but, I can play. Bob Dylan can't sing very well, but he does.

Unfortunately, an underappreciation for peoples' abilities was also experienced during this study, while I was in the recruitment phase. In an attempt to increase awareness of the study, I attended community activities where at times I was discouraged from recruiting participants. Group home staff members stated that the individuals did not have the ability

level required to take part in the study. Even when the inclusion criteria were explained and the minimal skill level was defined, the staff continued to doubt that participants would be able to fully participate. If staff members do not set high expectations for the people with whom they work, these individuals might miss out on opportunities to achieve their potential through being.

Utilizing the method of photovoice along with observations offered me a glimpse of the participants' true being. On entering their homes, the first thing each person did was offer me a tour. I interpreted this act, along with many photographs of bedrooms, belongings, talents, and awards, as an expression of pride and satisfaction in their being. Charles was proud of the photographs he took, several showing his bicycle, television, and athletic posters.

Charles (C): I took a lot of pictures. That is me, I am handsome. I did a good job, huh?

Author (A): Yes!

C: That's pretty. These are good pictures. I did a good job. I took a lot of pictures of my room.

A: You did fabulous!

C: Look at my stuff, what do you think of my room?

This research study supported the participants' sense of being by empowering them to contribute and by offering them an opportunity to discover something about themselves. Individuals displayed pride in their abilities by asking people to view their photographs and making statements such as "You will be amazed!" when introducing their slideshow. For several of the individuals, this study exposed a new talent in photography and sparked a desire to learn more about the camera and taking pictures.

Times to reflect and contemplate are also included in the concept of being. It is through this process that people define values, aspirations, goals, and dreams (Wilcock, 2006). This component of being was acknowledged through interactions with nature. The local mountain range symbolized a place for relaxation and time to think.

I love the fresh clean water, the smell of the pine trees and the sounds of the birds. You know, the birds relax me when they, they, they, they cheep and stuff. I took a picture of this because, um, it reminds me of a very healthy place to sit and, and think about things, about healthy reasons. Yeah a peaceful place where I can think and say "Hey this is what is not good for you or hey this is good for you."

A photograph of a rose was projected during a group discussion and the participants stated beauty was a catalyst to thinking and health.

Iris (I): It's pretty.

Jamie (J): It is nature.

Author (A): Do you think nature is good for your health?

I: Yes, it's nice to be around.

J: I like to look at nature stuff, and think about, the beauty of it.

When asked, "What do you do most days?" participants could identify activities they did on a weekly basis. Some of the tasks they named were seen in their photographs, but what might be just as telling were those things that were not seen in the photographs. Participants tended to take photographs of the things that were most important to them and although mentioned, they did not take as many pictures of the routine tasks, time-filling activities, or moments of boredom. As mentioned earlier, having something to do contributed to positive health but the effect is most powerful when meaning and purpose can be found in doing (Hasselkus, 2011). Meaning and purpose, as components of being, were often found through hobbies and community activities. Visiting the zoo, attending classes, knitting, making jewelry, and playing music were all present in the photographs and described as enjoyable. Samantha was not involved in formal day services, but found meaning and purpose by attending classes and events at the local Independent Living Center each day.

That impacts my health a lot because it helps me with daily living skills and gets me out of the house and be around people. Like for 4 to 6 weeks, they have a class and then after that class is done, they do something else.

Sadly, not all of the participants felt they had opportunities to utilize their capabilities or find meaning and purpose in daily life. On several occasions, Marilyn referred to being depressed to the point of being suicidal. Although there certainly could be many contributing factors to this emotion, Marilyn also complained often of being bored with her life. She attended a day program, but failed to see the meaning behind the activities offered there.

Marilyn (M): I'm depressed sometimes. I don't like [the day program]. I keep telling them and they don't listen.

Author (A): So what is it? Why don't you like it?

M: I don't know. Are they ever going to let me do something else? I don't understand why, how hard is it to work at [a grocery store]? Or get a job? Or how hard is it to bag groceries? I don't know why, it just makes me nuts.

A: So have you ever tried to apply for jobs on your own?

M: Yes, lots of times and they don't call me back or maybe I don't call them back. So I guess I will just stay at [the day program] forever.

Marilyn lacked the skill set to acquire a job on her own, but did not feel like she received the support she needed from the day program either. She was caught in a nonproductive cycle. Because she did not find meaning or purpose in the day program, she did not attend regularly, yet she was told the staff would assist her in finding a job when she demonstrated consistent attendance, a skill that reflects a reliable employee. Marilyn's frustration with the situation places her at risk for ill-health by affecting her being.

### *Belonging*

The word *belonging* describes mutual relationships along with feelings of connection and inclusion. The results of this study indicated that belonging was an important determinant to health for the participants and deserves further facilitation. Participants stressed the value of having a feeling of connections with people, animals, nature, and religion. Often the experiences of belonging occurred while participating in groups that shared common values. Special Olympics events, day program services, volunteer settings, religious activities, and family activities provided a sense of inclusion. Two individuals reported an extensive community on the Internet through social networking sites.

Sophie (S): I'm on [the website] for at least 2 hours a day.

Author (A): What do you do on there? Just read everyone's pages?

S: Yeah, I have over 600 friends.

Tomas stated he was close to his family, spending Sunday dinner with them every week, but he enjoyed living in his own apartment because of the connection he had with his friends.

Tomas (T): I [use to] live with my mom.

Author (A): Which do you like better?

T: Here.

A: Why is that?

T: 'Cuz I see my friends here.

Belonging most often referred to relationships with friends and staff. Although these relationships were important to the participants, they also expressed difficulties in maintaining these friendships and a sense of belonging. Friends often related to peers who attended the same community services. Although several individuals who attended community agencies together also lived in the same neighborhood, they rarely saw each other outside of the day services. Brady pointed out friends in one of his photographs of an outing with the day program.

Brady (Br): Yeah, he is my friend. Scott is my friend. Oke is my friend.

Author (A): They live close to here, don't they?

Br: Yeah.

A: Do you ever do anything with Scott or Oke on the weekends?

Br: Um, no, I just see them at [the day program].

Many of the individuals had difficulty fostering these relationships beyond structured services. They did not plan activities or initiate communication with friends, even though they lived only a few apartments away.

Staff members who had a sense of humor and were helpful, happy, and spontaneous were praised by the participants. These relationships were cherished, but the reality of staff turnover and reassignment was often difficult for the participants to understand and at times left them feeling deserted. Although most of the participants only had their cameras for a few weeks, several people took images displaying "old [previous] staff":

Sophie (S): That is a picture of my old staff, being goofy. Um, she's the best staff ever.

Author (A): Old staff?

S: She got transferred to a different house.

A: How do you feel about that?

S: I wasn't too happy, I was sad.

People with ID are often involved in relationships that are one-sided. Staff and family are often in a position to do for the person with ID, rather than do with or request from. Besides presenting an opportunity to discover new talents, participation in this study engaged the individuals in a collaborative process and revered what they had to offer. The level of excitement each time I interacted with the participants was palpable. Participants were aware of my status as a student and appreciated the opportunity to help me with my "homework." Questions about the status of the study, results, future opportunities, and what more could be done were constant.

Ryan (R): Did I help you with your project?

Author (A): You did.

R: Do you think your teacher is going to be happy with this?

A: I think she will be.

R: I think so too.

In general, literature supports the health benefits of having friends and a social network. Although conversations with participants also supported this notion, situations observed during this study indicate there might be a negative aspect to belonging. Some of the individuals attended a day program and then returned home in the evenings to a supervised living situation where their roommates were the same group of people. Although behavioral issues are common in people with ID, some of the incidences I witnessed involved arguments among individuals who spent a good portion of

the day together. Hasselkus (2011) spoke of overconnectedness as a possible deterrent to health. This concept is based on the idea that people need time for solitude, opportunities for being. Although anecdotal, these situations suggest that overconnectedness might be an area for future inquiry.

### Becoming

The process of *becoming* is continuous throughout life as we are constantly evolving into something different, positive or negative. The ideal process of becoming involves moving toward personal development and potential (Wilcock, 2006). For people with ID, this includes recognizing and utilizing talents, contributing to their community, having choice, and learning from daily experiences.

On the day I arrived to complete Sharla's interview, the staff stated it might not be the best day because she was angry and they were currently trying to control her behavior. Sharla was pacing the room, yelling, and attempting to hit those around her. Apparently, Sharla had chosen not to participate in the morning program and so, per protocol, she was not allowed to partake in her activity of choice (sitting in the sun) in the afternoon. Although it was not clear to me how or why she made that choice in the morning, one of her peers stated the activity Sharla refused was coloring. This could have been a contributing factor, indicating Sharla felt the demands of the task did not provide an opportunity to contribute and did not match her capabilities. Although the morning activity did not offer an ideal situation to encourage becoming, this situation presented the perfect opportunity for Sharla to experience the results of her choice. I observed the staff review the situation with her and offer her an opportunity to make another choice based on a different set of options: Did she want to take time to relax in the quiet area or did she want to meet with me to review her photographs? Sharla chose to meet with me, and the interview was completed without incident, in fact she became happy upon seeing her photographs. Offering choice, experiencing consequences, and highlighting abilities decreased Sharla's agitation and assisted her in her journey to becoming.

### Discussion

Achieving positive health is a continuous process affected by daily circumstances, the context, and life stages. This process has been described by many authors from a variety of disciplines. Wilcock's (2006) *Occupational Perspective of Health* asserts health can be achieved when people engage in an occupation that is based on meaningful pursuits that provide opportunity for growth, the use of capabilities, and the freedom to adapt to the context and individual choice. Wilcock, an OT, defines the term *occupation* as "all the things that people need, want, or are obliged to do; what it means to them: and its ever-present potential as an agent of change" (p. 9). The terms *doing*, *being*, *belonging*, and *becoming* are

used to illustrate how the use of occupation can promote health and well-being. These gerunds reflect the ever-incomplete nature of the process, while emphasizing the dynamic relationship among the four segments. They also symbolize actions that can be taken by people with ID and health promotion professionals.

Clark et al. (1997) found the use of an occupational perspective supported health and well-being in a population of well elderly. This study concluded there was a relationship between engagement in meaningful activity and health. As opposed to the control groups, one that had no intervention and one that participated in social activities, the group that engaged in meaningful activities received significant health benefits from the study. These tasks were deemed influential because they were relevant to the individuals' lives, context, and needs and included lessons on overcoming identified barriers, community resources, self efficacy, and internal locus of control.

The results reported here reflect Wilcock's (2006) occupational perspective that health is affected by the ability to do, be, belong, and become. They also support the use of an occupational perspective of health by aligning with the WHO's (1986) holistic definition of health promotion:

The process of enabling people to increase control over, and to improve, their health. To reach a state of complete physical, mental, and social well-being, an individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment. (p. 1)

Several of the aspects of health identified in this study aligned with this definition. The most relevant of these are skill development to meet daily needs, control achieved through choice and meaning in daily activity, realizing potential by utilizing talents and acknowledging goals, and inclusion in the community through positive social networks. These health characteristics demonstrate that health is affected by many aspects of life and beckon a reassessment of how health promotion is currently addressing the needs of this population. By utilizing only didactic lessons that review traditional nutrition and fitness knowledge, we might be missing the mark when it comes to promoting health for people with ID. In a study on health care in adults with ID by Parish, Moss, and Richman (2008), the majority of the participants had received standard health promotion information in the past. On a whole, the group could identify the importance of physical activity, proper nutrition, weight management, and follow-up physician visits. To address barriers to healthy lifestyles in this population, additional skills need to be addressed in the promotion of health. A holistic approach that addresses individual skill development as well as social determinants seems appropriate. Among the five health promotion actions identified by OCHP, creating supportive environments and developing personal skills correspond best with the outcomes of this study (WHO, 1986) and offer intervention alternatives for health promotion professionals.



Supportive environments can be created for people with ID first and foremost through acceptance. The health benefits of participating in positive social interactions have been reported by many researchers. In a meta-analysis of positive health predictors, social support was the factor studied most often, and results indicated that it was the second most powerful predictor, second only to the related concept of loneliness (Yarcheski, Mahon, Yarcheski, & Cannella, 2004). Being involved in reciprocal relationships, those based on give and take, contributes to self-worth by projecting respect and an assessment of competence (Hammell, 2004). Positive social interactions that accept assistance from someone or request help demonstrate confidence in their skills, value in what they have to offer, and acknowledge their significance. Incorporating reciprocal relationships and affirmative social interactions into the lives of people with ID is an important step to promoting health, one that asks them to do, encourages their being, promotes belonging, and fosters becoming.

Another method of providing an environment of support for people with ID is to address concerns regarding direct support providers. Two concerns seen in my study, frequent staff turnover and inadequate service provision, are exaggerated by the fact that frontline caregivers for people with ID are usually poorly paid, education requirements for employment are minimal (Powers & Powers, 2010), and services are often provided in the community or an individual's home where supervision and accountability are inadequate. These issues need to be addressed at an institutional and policy level. Health promotion professionals can influence institutional changes by designing health promotion educational programs that increase the skill level of direct caregivers and provide them with content to incorporate into their interactions with people with ID. Involvement in advocacy movements can strengthen efforts on a policy level and influence regulations related to service reimbursement.

Educational health promotion classes are generally didactic and have minimal exposure to interactive or experiential activities (Hodges & Videto, 2011; McKenzie, Neiger, & Thackeray, 2009). The basic tenet of doing is not only one that comes from an occupational perspective. This concept is also supported by the *Jakarta Declaration on Leading Health Promotion Into the 21st Century* (WHO, 1997), which states, "Health promotion is carried out by and with people, not on or to people" (p. 4). Bates, Cuvo, Miner, and Korabek (2001) explored instructional methods for people with ID and concluded that the best generalization of skills happened when participants were allowed opportunities to practice skills, both in simulated tasks and in the natural context of the activity. For health promotion interventions to be effective with this population, they must include hands-on, interactive components that include the development of personal skills specific to healthy lifestyle behaviors and meeting daily needs, such as preparing meals, planning leisure pursuits, obtaining employment, and developing social networks.

Personal development through an emphasis on active participation not only provides useful skills but can also enhance

health by promoting feelings of choice, meaning, and purpose. Hammell (2004) supported the use of an occupational perspective to address health by linking it to the components of quality of life, which she described as purpose, meaning, choice and control, self-worth, and occupation. These aspects were further supported by Christiansen (1999) when he suggested depression was the outcome of limited "opportunity to gain personal meaning from everyday activities" and could be averted by offering people the belief "that there is choice and control in their lives" (p. 555).

Most of these components are facets of self-determination, which has been recognized as a viable intervention to promote health for people with ID (Krahn, Hammond, & Turner, 2006). Choice making, a component of self-determination, contributes to control by acknowledging the ability to make choices and providing opportunities to learn from the consequences (Agran, Storey, & Krupp, 2010). Self-determination training is often included in educational programs of people with ID when they are in the school system, but the focus diminishes beyond this developmental period. Palmer (2010) suggested that by incorporating self-determination skill development throughout the life span, professionals can assist people with ID in achieving outcomes that enhance "a full range of capacities and opportunities" (p. 2). For people with disabilities to be active partners in their health care, autonomy should be encouraged in health promotion programs through skill training in self advocacy, decision making, assertive communication, and acquisition of knowledge (Wullink, Widdershoven, van Schroyen, Lantman-de Valk, Metsemakers, & Dinant, 2009).

## Conclusion

The OCHP stresses the importance of addressing issues of social justice through health promotion, stating health is achieved by,

Reducing differences in current health status and ensuring equal opportunities and resources to enable all people to achieve their fullest health potential. This includes a secure foundation in a supportive environment, access to information, life skills, and opportunities for making healthy choices. (WHO, 1986, p. 1)

Wilcock (2006) expanded social justice to include occupational justice, which encompasses equity, empowerment, and fairness that allow people to meet daily needs, develop potential, and achieve satisfaction. She continued by clarifying that this equity is not a call for everyone to be able to do identical things, but rather a need for a "justice of difference" (p. 247), which facilitates people to meet daily requirements by providing meaning and by matching opportunities with abilities, desires, and values. Along with addressing social determinants, health promotion interventions could be enhanced through an explicit inclusion of an occupational perspective. By including client-centered activities that tap into individual values and strengths, are inclusive, and focus

on possibilities health promotion, professionals send people with ID the message that we have confidence in their potential, see value in their contributions, acknowledge their desires for a meaningful, healthy life, and respect them as members of a just society.

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