

# Impact

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**Feature Issue on Supporting  
Wellness for Adults with Intellectual  
and Developmental Disabilities**

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Connie Lewis, People First member and co-facilitator for the 14 Weeks to a Healthier You program in Missoula, Montana, grows healthy food in her community garden. See story on page 19. Photo courtesy of Steven Begleiter Photography.

## **Advocating for Quality, Inclusive Wellness Opportunities in Our Communities**

by Jana Peterson-Besse

Participation in programs that promote health and wellness, such as those that promote physical activity, nutrition, tobacco cessation, or mindfulness, is an important opportunity for individuals with intellectual and developmental disabilities. Maintaining good health, strength, and function over time can help a person maximize independence and self-determination. Just as important, these activities are enjoyable for many people. And, participation in inclusive community activities of this type builds friendships and community networks, improving well-being.

There are many options for engaging in wellness activities in communities, and disability should not exclude a person from participation. However, in reality there are too few wellness opportunities that are of high quality and truly inclusive. This article aims to help readers advocate for inclusive wellness opportunities in their communities by providing a list of key characteristics of quality, inclusive programs, as well as a set of tips for individuals with disabilities and their families seeking to advocate for and create inclusive wellness opportunities.

[Besse, continued on page 34]

### **From the Editors**

*Wellness is a rapidly growing area of focus for people across the U.S. The popularity of health advice segments on TV news and talk shows, of high tech fitness tracking devices and apparel, and of stress management and meditation workshops are a few of the indicators of a growing interest in whole-person well-being. For individuals with intellectual and developmental disabilities, the benefits of attending to wellness are at least as great as those experienced by the rest of the population. But the opportunities to access wellness activities and resources are not necessarily as available.*

*This Impact issue presents wellness as touching all areas of life for individuals with disabilities – physical, social, vocational, spiritual, emotional, psychological – with choice-making and inclusion as keys. It offers ways in which disability service providers, health and wellness professionals, community fitness and recreation programs, employers, advocates, individuals with disabilities, and their families can help ensure that opportunities to choose and engage in wellness activities are as available to individuals with disabilities as to anyone else. And it shares examples of those leading the way in supporting attention to life areas that are essential to everyone's well-being – healthy activity, social connections, pleasure and meaning, supportive relationships, and participation in health care.*

### **What's Inside**

Overview Articles  
Program and Personal Profiles  
How-To Articles  
Resources

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# From Wellness to Flourishing for People with Intellectual and Developmental Disabilities

by Lynda Anderson and James Flowers

Wellness has been described as “multi-dimensional, positive health, possessed by the individual” (Corbin & Pangrazi, 2001). Wellness is more than physical health, however. A person who experiences optimum wellness also has mental, emotional, social, vocational, and spiritual health, and the opportunity to know about and choose activities that support overall wellness. The importance of wellness for people with intellectual and developmental disabilities (IDD) was identified by the U.S. Surgeon General (2005)

*A person who has optimum wellness also has mental, emotional, social, vocational, and spiritual health, and the opportunity to choose activities that support wellness.*

when he noted that people with IDD need to have the opportunity to “protect, preserve and improve their health in the same ways as everyone else” (p. v).

## Changing Models of Wellness

For much of the 20th century, the medical model was the primary approach in addressing the health of people with IDD. The medical model is an individualist perspective of disability that sees deficit or inability to function as a problem inherent in the individual (although not necessarily the fault of the individual) (Brandt & Pope, 1997). Health promotion was mainly focused on preventing disability and little thought was given to the health and wellness needs of people with disabilities. Beginning in the mid-20th century, new models of talking

about disability emerged, thanks in part to the Disability Rights Movement and the work of dedicated families and self-advocates. The models began to move away from solely focusing on individual impairment or deficit, and towards biopsychosocial models in which the importance of the impact of biological, emotional, and environmental issues on health and well-being is acknowledged (Krahn, Putnam, Drum & Powers, 2006). There is now a greater understanding that these forces interact to affect the ability of individuals to maintain as high a level of health and well-being as possible.

In the past three decades there has been increased attention to health promotion and improving the health of people with IDD (Anderson, et al, 2013). In general, these efforts have focused on physical activity and nutrition. However, supporting optimal wellness that encompasses not only the physical health, but all areas of human functioning, including mental and emotional health, spirituality, meaningful activities, life purpose, financial health, and sexuality, needs greater attention. Physical activity and nutrition are a critical piece of health and wellness, however, health promotion for people with IDD needs to address these other areas of wellness in order to support flourishing.

## Supporting Flourishing

*Flourishing* means “to be filled with positive emotion and to be functioning well psychologically and socially” (Keyes, 2002, p. 210). Supporting flourishing means supporting several dimensions of personal functioning. Positive psychological functioning, which encompasses things such as having a purpose in life, having autonomy, and experiencing personal growth (Keyes, 2005), is one dimension. Feeling social acceptance, contributing to society, and being

integrated into society are examples of the second dimension of personal flourishing. Emotional well-being, which encompasses self-identified quality-of-life and a positive outlook, is the third dimension of flourishing (Keyes, 2005).

What gives each of us a sense of well-being or the ability to flourish is unique and is individually defined. While there may be some specific needs related to health and wellness for people with IDD (such as addressing co-existing conditions, physical or sensory accessibility needs, or medications a person might be required to take), the meaning of optimal health and ways of achieving that for individuals with IDD are just as unique as for any other person.

Persons with IDD may need more tailored support in identifying their wellness goals and aspirations. This identification and planning process may require allocation of staff time or otherwise intentional support from personal caregivers. For individuals living in residential or supportive living arrangements, in particular, the attainment of individual wellness goals may be contingent on sufficient buy-in from both support staff and organizational leaders. This might include the intentional inclusion of volunteers in providing opportunities to develop meaningful unpaid relationships with community members and inclusion in community activities that support flourishing (e.g., an exercise class or participation in a faith community). It may also include an organizational focus on wellness (including for employees), or a demonstrated flexibility in adapting organizational regulations to meet the wellness goals of individuals served.

## Areas in Need of More Attention

Moving the support of flourishing for adults with IDD forward requires that some areas of wellness in relation to

people with IDD need to be further addressed in wellness research and program development. For example, having a meaningful vocation, whether it is paid employment or some unpaid activity, is associated with both better health and a higher quality of life. Meaningful employment should be considered as an important factor in optimal health and wellness in both health and employment program development and research.

The need for intimacy is natural part of the human experience that is often overlooked when thinking about supporting the health and wellness of people with IDD. Maslow's seminal work on human motivation (1943) describes a hierarchy of needs that all people experience and how the drive to meet those needs creates individual motivation. Wellness can be thought of as residing in the individual attainment of higher needs such as love/belonging, esteem, and self-actualization. To support people with disabilities in achieving love, esteem, and self-actualization, practitioners, researchers, and community members must be willing to engage in conversations that recognize the need for intimacy and be willing to support healthy relationships.

Having positive social support has been shown to be an important factor in health. People with little social support experience greater rates of chronic disease and premature death. People with IDD are often socially isolated and have limited contact with people other than paid caregivers. To flourish, having social connections in which one both receives and gives support to people who care about us is critical, as is having a sense of belonging among a community of people beyond paid caregivers (Amado, Stancliffe, McCarron & McCallion, 2013). However, creating social connections is overlooked in many health and wellness interventions for people with IDD despite the high levels of isolation.

Having a connection to nature is an important aspect of wellness and flourishing that is gaining greater attention for people with and without disabilities. Studies have shown that connection to

nature – even things as simple as walks in a park – can have both physical and mental health benefits such as lowering blood pressure, improving mental health, and reducing pain (Hartig, Mitchell, DeVries & Frumkin, 2014). While this is a growing area in wellness and disability research, finding ways to support connections to nature and opportunities to be outdoors can be beneficial and are worth considering in wellness interventions.

Perhaps the central factor underlying optimal wellness or flourishing is autonomy. People with IDD generally have little opportunity to exercise self-determination or autonomy in relation to their health and wellness. Often, increases in independence have been associated with greater health concerns such as obesity. However, it has been demonstrated in some interventions that, given adequate training and support, adults with IDD do choose health-promoting behavior (Wullink, et al., 2009). This remains an under-addressed area of research, program development, and translation into practice for both for individuals with IDD and caregivers and support staff. Including people with IDD in leadership roles in developing and leading opportunities for wellness interventions is an important step in promoting autonomy.

Autonomy goes beyond personal aspirations to having a greater voice in policies and research that directly affect one's life. Researchers, service providers, policymakers, and self-advocates need to work together to support integrated models of research that value wellness, and research as determined by disability advocacy groups (Krahn, et al., 2006). Moving forward, researchers and funders must develop more collaborative partnerships with individuals with IDD, disability service organizations, and community health and wellness agencies (e.g., YMCAs) that will have the greatest impact in terms of supporting wellness for persons with intellectual and developmental disabilities.

## Conclusion

Efforts to address the health disparities experienced by people with IDD over the past three decades have played an important role in the growing efforts to improve access to health and wellness activities for everyone. However, to promote optimal wellness, or flourishing, more needs to be done to address all the areas of the human experience. Access to physical activity and a nutritious diet are fundamental to good health, but spirituality, social connectedness, intimacy, connections with nature, economic opportunity, and autonomy are also important aspects of overall wellness that need to be addressed when thinking about health and wellness policies and programs. Supporting individuals with IDD to grow in each of these areas is the key to supporting them to flourish.

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## What Wellness Means to Me: Reflections from Three Self-Advocates

*For each person, the meaning of wellness and how they work it out in their own lives is unique. In this article, three leaders in the self-advocacy movement talk about how wellness is part of their daily lives.*

### Tia Nelis: Walking for Wellness

#### What does wellness mean to you?

Learning about how to be healthy instead of being told to be healthy. It includes experiencing different kinds of healthy food, but not being forced to do it. You have to want to do it instead of being forced to do it. Sometime places where people with disabilities live are forcing diets and forcing exercise, and that won't work. Teach people about different foods and let them taste different things, and let them come to the conclusion of what they want to do. Sometimes if one person has a health issue then that is forced on everyone. That's not right. It means having other people supporting you to be healthy and active.

#### How did you get started walking as part of being healthy?

I started with my friend and co-worker, Renae. She asked if I wanted to walk with her. She also helped me try different foods and let me ask her questions on what I was eating. She is the first person who helped me a lot when I first started. And she was the best support; she was there for me, and still is even though she does not work with me anymore. I counted on her; she didn't make me feel bad and she cheered me on. She told me how proud she was of me when I shared with her my progress. She asked if I wanted to try different foods that she was eating. Sometimes I liked it and sometimes I did not. I tried to find the things that were healthy and that I liked.

#### How much do you walk?

I walk halfway to work and it is about 3.5 miles each day. Sometimes I walk more.



*Tia Nelis (right) and Beth Terrill were among the 8,000-plus participants in the 32nd Annual Dan Gibbons Turkey Trot, a 5K walk/run held on Thanksgiving 2015 to raise money to feed area families in need.*

By the time I get home it is usually 3 to 4 miles. If I cannot walk outside I can go to the Y and use the treadmill, but I really like being outside. I have a certain route that I know.

Another coworker walks all the way to work. I tried that and it was too much. So I figured out if I walked from the train station to a certain landmark my Apple Watch tells me how much I have done. Then I take the train the rest of the way to work. Depending on the weather, I either get some or parts of my walk in. I'd rather be outside than inside and I prefer walking with a partner, but that is not always possible so I made up my mind that I have to do it alone.

#### Did you have a wellness goal?

I had a goal on how much weight I wanted to lose so I would set this with my co-worker and I'd try to do it. I have lost 52 pounds.

#### How does the Apple Watch help you?

On the Apple Watch it has exercise rings that are different colors (standing and movement) and I try to fill up all three circles each day. If I walk halfway to

work the 30 minute one is full. I can tell how much I have done and I get a weekly progress report. I get information on how much I have burned, and that kind of stuff is helpful. It is hard to tell without it, and the visual helps me to see it.

#### What are the benefits you have seen besides just losing weight?

My breathing has improved. I can walk further than I used to be able to do. I am trying new things and I found out I like new things, new experiences, new foods. I have also influenced others at work to go walking with me. I have gone down six pants sizes since I started walking!

#### Do you have tips and suggestions for others who want to be healthier?

If you could figure out a way to mix up a variety of healthy foods then you won't get bored eating healthy. It is important that you don't have to eat the same thing every day. My nutritionist helps with that. I take pictures with my iPhone of what I am eating and then show it to the nutritionist and she tells me if anything needs to change, like I need more protein or that is a good portion or that's a

little too much. Having a simple picture is helpful in letting me see what I am eating. It was easy to help me remember to add green to my plate. I also learned about variety in what I drink and I don't drink soda any more but I pick from things like unsweet tea with Stevia, water with Stevia, and other stuff. Keep it simple.

Tia Nelis lives in Chicago, where she works as a Self-Advocacy Specialist with the Institute on Disability and Human Development, University of Illinois at Chicago.

### **Liz Weintraub: Living Happy**

#### **What does wellness mean to you?**

How I am healthy and how my mind is. How happy I am as a person.

#### **How does your employer support your wellness?**

I am a much happier person now that I am working for AUCD [Association of University Centers on Disability]. Doing the kinds of things that I really want to do helps me and my wellness. For example, when I do my weekly program, *Tuesdays with Liz* [a YouTube interview series from AUCD hosted by Liz], I feel it in my body how happy I am. When I am out of a "box," not seen as only a self-advocate, I can do more and am challenged beyond advocacy. I can do MUCH more and when people allow me to do that, I am happy.

I work with lots of active people. Sometimes at work we will take a walk together. One time we participated in a challenge about walking steps. We usually have a fun day every spring to do something as a group that is active. We also get together for lunch and sometimes the topic of healthy foods will come up or other stuff that helps wellness. Like this week we talked about our pets and their importance in our lives – about how they make us happy.

Wellness is a part of your mind, and if you are happy it helps your wellness. I feel like I am happy at work. Getting more hours at work makes me happy.

I remember when I was in New Jersey and lived in a private institution. I was in a horrible workshop and I was not happy there. When I was unhappy I had

lots of health problems, even seizures. It was all in my mind and when I got out and got new opportunities and became happy, my seizures are all gone.

#### **How do others support your wellness?**

Being involved in advocacy was not enough. Being known nationally was not enough. At family events I would cry a lot even though the events were not sad. Everyone there was married and had their own lives and I was afraid I'd be alone without a husband and my own life. Getting married was a big step in turning this around and it made me happy. Phil and I have our own life and we are there to support one another and make each other happy. So my family and husband really help to make me happy and when I am happy I am well.

I do Yoga on Thursday nights every week (sometimes I miss because of work or other responsibilities). It really helps because it is a "me time." I do so much for everyone else all of the time and I benefit from having time just for me. Yoga is for me and I stretch my body. Yoga is also something I do just with myself, I am with me, I connect with me. I don't have to talk.

Another thing that is very important to my wellness is getting sleep. When I do



For Liz Weintraub, practicing Yoga gives her "me time," which is important for her wellness.

not get enough sleep it is hard. I cannot concentrate. Those days after a bad night's sleep are hard. So I try to get enough sleep; I go to bed at a reasonable time.

So for me, happiness, a husband, a job I love, sleep, and "me time" are keys to my wellness.

Liz Weintraub works as an Advocacy Specialist for the Association of University Centers on Disability in Silver Spring, Maryland.

### **Beth Terrill: Getting Fit with My Fitbit**

My doctor said I have to exercise more to lose weight. She said if I don't lose weight, I could get diabetes. I don't want to take medicine. I am working hard to lose weight. My doctor said I should try not to eat a lot of things that are white like bread, pasta, and cereal. If I eat something that is white I should only eat as much as could fit in my one hand. I am trying to eat more fruit and vegetables. I am trying to exercise more. My Fitbit helps me to exercise. Staff help me to:

- Check how far I have walked each day by helping me plug my Fitbit into the computer.
- Set new goals on my Fitbit when I have success.
- Set up contests with my friends who have Fitbits. We set the same weekly goal and we see who reaches the goal first. Everyday my Fitbit gives me an update.
- Set up a contest with my sister, who lives far away, to get us to both exercise more.
- When I look at my Fitbit on my wrist it reminds me to walk more.
- Now that I have a Fitbit I walk to work.
- I am looking into an adapted Fitbit that will let me use it in the pool when I swim.
- Sometimes I have trouble sleeping and my staff can look at my Fitbit to see how long I sleep each night or if I wake up a lot.

Beth Terrill lives in Elmhurst, Illinois, working as a high school mailroom assistant and park district child care worker.

## SELECT a Lifetime of Physical Activity

by James H. Rimmer

While there is a strong and urgent need to promote higher levels of physical activity among all Americans, there is a particularly compelling need to address the low rates of physical activity among many people with intellectual and developmental disabilities (IDD). A recent study by Havercamp and Scott (2015) found the risk of physical inactivity was 4.5 times higher compared to a group who had no disability. Unfortunately, many people with IDD have less access to many of the more engaging types of physical activity that increase the likelihood of long-term adherence to this important health behavior.

It's time for individuals with IDD to have the opportunity to SELECT a physical activity program that will result in a *lifetime* of regular activity. The following are six critical characteristics of such a program, which are presented in the SELECT model in Figure 1:

- **Social Engagement.** The *S* in SELECT refers to the most important element of physical activity: Social engagement. No one likes to do things alone when it comes to movement-related behavior, which is why games, sports, and dance were created thousands of years ago. The incorporation of social engagement in exercise routines will lead to greater acceptance and adherence of regular exercise among people with IDD.
- **The Enjoyment Factor.** *E* stands for Enjoyment. If an activity is not enjoyable (e.g., riding a stationary bike alone in a room), it is almost guaranteed to fail after the novelty wears off. Even games like the Wii can become quite boring and meaningless after a few months and result in short-term use and long-term failure.
- **Learning Something New.** The *L* in SELECT characterizes the nature and importance of self-discovery. Learning a new activity (e.g., Yoga movements, dance routine, sport) or improving an old one (e.g., tennis,

golf) in a socially dynamic, enjoyable setting is highly gratifying to most people and can keep many people with and without IDD engaged in the activity for many years. Golfers, tennis players, line dancers, and many other physical activity groups are constantly searching for ways to learn something new to enhance their performance. This makes learning the third most critical element behind social engagement and enjoyment. When thinking about physical activities for adults with IDD, consider the types of activities where the skills can be broken down into small enough steps so that there is a sense of learning and accomplishment. Everyone likes to feel that sense of joy when they finally get the routine or movement pattern correct.

- **Exploration a Key to Discovery.** *E* is for Exploration. For people with IDD, tapping into our “explorer” instinct is necessary for maintaining a strong desire to be physically active. Many people are able to sustain low to high intensity exercise for longer periods if they perform them in new, enriching environments that are visually appealing. Many “explorers” bike through different neighborhoods or trails, visit malls to view new store displays or sale items, or walk through a range of neighborhoods to view different homes and parks (often driving to the location).
- **Friendly Competition.** *C* is for Competition. Elite athletes are not the only ones who are motivated to exercise through sport. Many people enjoy competing against themselves, such as trying to reach a target number of steps per day and beating the previous month's goal, or competing in a group against other opponents. Competition can also be at a very high level such as participating in the Special Olympics. Team sports such as

basketball, golf, and softball are often performed because of the competitive nature of the game and the enjoyment element associated with winning.

- **Task Completion.** Finally, the *T* stands for Task completion. High responders to exercise are generally categorized as “task completers.” They like to check things off their list, daily exercise and doing chores being two of the major ones. Some people naturally engage in physical activity by completing daily routines (e.g., shopping, cleaning, chores), while others start the day with a regular exercise routine (e.g., going to the fitness center, walking, jogging). People with IDD also like to be “task completers,” so engaging in a daily bout of exercise at the same time of day, preferably in the morning when energy is fresh, is a great way to build in lifetime physical activity.

We may have gotten it wrong by suggesting to people with IDD and other groups that the only approach to obtaining regular exercise across a lifetime is by purchasing a stationary bike or joining a fitness center. While this may work in the short-term, without multiple opportunities to hit a number of SELECT “buttons,” long-term adherence to regular physical activity will be a challenge.

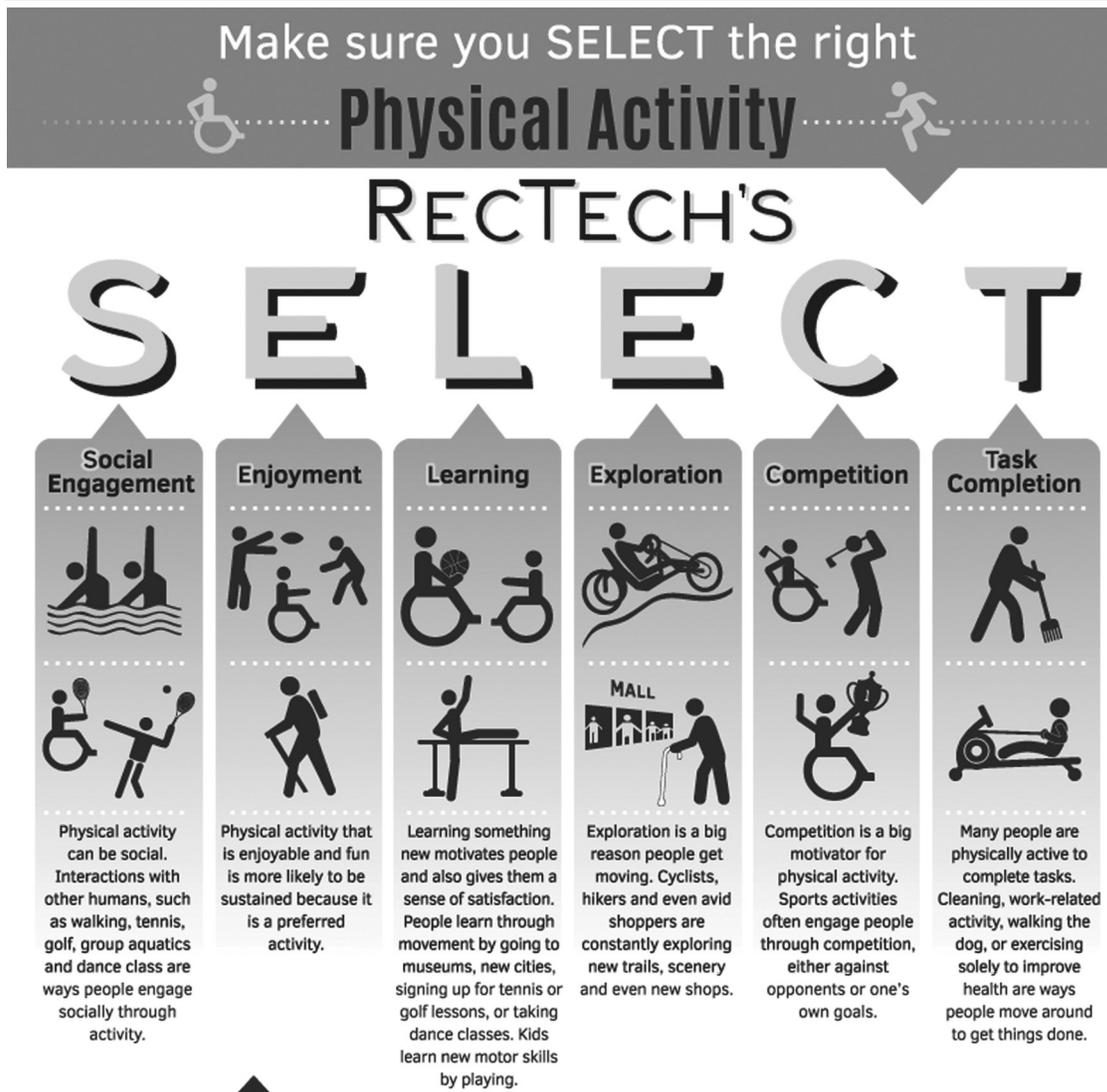
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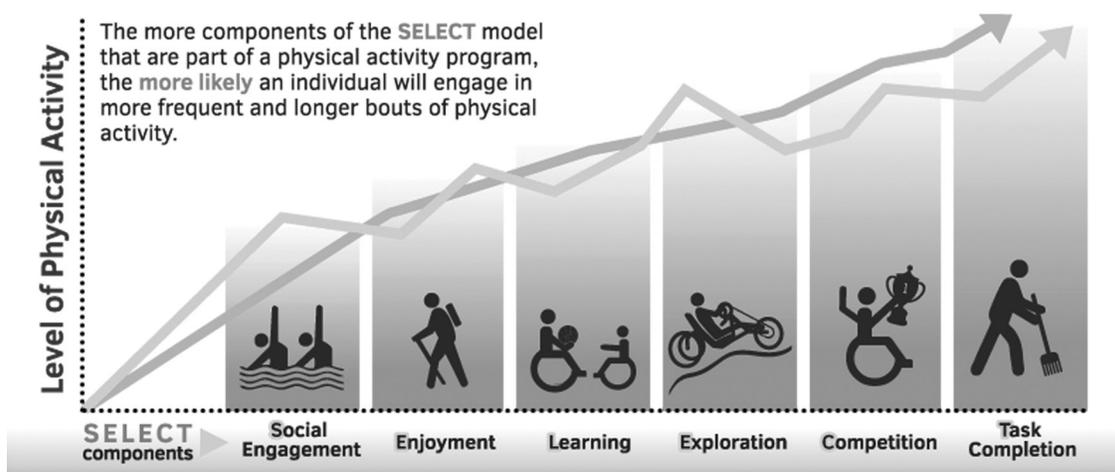
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Figure 1: SELECT Model of Physical Activity



Understanding the 6 components of the **SELECT** model is integral in promoting more physical activity in people with disabilities.



# Workplace Wellness Programs and People with Disabilities: A Summary of Current Laws

by Linda Carter Batiste and Melanie Whetzel

Wellness programs seem to be popping up in workplaces all over the United States. At least part of the reason is some major changes in the past few years related to the health care benefits employers must provide. To keep the costs of these benefits down, many employers are implementing wellness programs in the hopes of creating healthier workforces and reducing the use of medical insurance. In general, wellness programs help encourage employees to

*If an employer has a wellness program, that employer has a duty under the ADA to provide reasonable accommodations so employees with disabilities have the opportunity to participate and benefit.*

address health risks, get in better shape, and hopefully avoid the onset of many preventable diseases.

## Current Laws and Legal Challenges

Not surprisingly, employers who implement wellness programs need to be aware of the laws that might apply. First, the Health Insurance Portability and Accountability Act (HIPAA), as amended by the Patient Protection and Affordable Care Act (ACA), has several provisions that promote and regulate wellness programs. The ACA generally prohibits discriminating against participants and beneficiaries of health care plans in premiums, benefits, or eligibility based on health. However, there's an exception to this general rule that allows employers

to offer premium discounts for employees who participate in wellness programs (for more information, see <http://www.dol.gov/ebsa/healthreform/regulations/wellnessprograms.html>). In addition, the Equal Employment Opportunity Commission (EEOC) has been weighing in on how federal employment laws apply to wellness programs, especially regarding the collection and storage of medical information and how offering incentives for participation in the programs affects the voluntariness of the programs. One of the laws the EEOC has addressed is the Genetic Information Nondiscrimination Act (GINA). Under GINA, employers can gather genetic information as part of a wellness program as long as providing the information is voluntary. According to GINA regulations, that means employers cannot condition the receipt of incentives on whether an employee provides the genetic information.

The other law the EEOC is currently looking at regarding its relationship to wellness programs is the Americans with Disabilities Act (ADA), which is the focus of the rest of this article. The ADA is a federal civil rights law that prohibits discrimination on the basis of disability, and also requires employers to provide reasonable accommodations so employees with disabilities can perform their jobs and enjoy equal benefits of employment. The ADA also regulates when employers can obtain medical information from employees and requires that all medical information be kept confidential. Under the ADA, employers are allowed to ask employees medical questions or require them to take medical examinations as part of the wellness program only if participation in the program is voluntary.

One unanswered question is whether offering incentives to employees to participate in a wellness program, as allowed under the ACA, affects whether the

program is voluntary under the ADA. The EEOC recently issued proposed regulations to answer this question (for more information, see [http://www.eeoc.gov/laws/regulations/qanda\\_nprm\\_wellness.cfm](http://www.eeoc.gov/laws/regulations/qanda_nprm_wellness.cfm)).

## Making Programs Inclusive

Regardless of what the EEOC's final regulations say about offering incentives, there is no question that if an employer has a wellness program, that employer has a duty under the ADA to provide reasonable accommodations so employees with disabilities have the opportunity to participate in and benefit from the program. In most cases, it's an employee's (or an employee's representative's) responsibility to request an accommodation. However, an employer may need to ask an employee whether he or she needs an accommodation

*With simple changes, employers can make wellness programs more inclusive of all employees, increasing participation.*

when the employer knows the employee has a disability and may need an accommodation to participate in the wellness program, but the disability prevents the employee from making the request. This situation can come up for employees with intellectual and developmental disabilities who may not understand their rights under the ADA or what types of accommodations an employer might offer. For wellness programs to be effective, all employees must be able to participate, so making wellness programs

accessible and providing accommodations for employees with disabilities not only helps with legal compliance, but also helps employers meet the goals of their wellness programs.

In Table 1 are some tips and examples to help insure that employees with intellectual and developmental disabilities are included in workplace wellness programs. If an employer is aware that a specific employee may need additional accommodations, the employer should

talk with the employee one on one. With some simple changes, employers can make their wellness programs more inclusive of all employees, increasing participation and hopefully leading to a healthier workforce. This, after all, is the ultimate goal of wellness programs.

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**Table 1: Tips and Accommodations to Ensure Inclusive Workplace Wellness Programs**

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### Disseminating Information About the Wellness Program

- **General Tip:** The first step to successful participation in a wellness program is making sure all employees are aware of the program. Some employees with intellectual or developmental disabilities may need information in a different manner than other employees. Employers may want to initially offer information in the usual manner – via intranet, written materials, emails, meetings – and offer to follow up with any employees needing more information.
- **Accommodation Example:** An employee with autism was unable to effectively retain information in meetings. The employer discussed accommodations with him, and they agreed that he could record upcoming meetings about the new wellness program so he could listen later by himself. In another situation, an employer made sure all printed material was available in an accessible format for screen readers for an employee with a vision impairment.

### Promoting Exercise

- **General Tip:** Many wellness programs promote exercise, sometimes specific exercises such as walking, going to a gymnasium, or taking an exercise class. In some cases, these exercise programs may need to be modified so employees with disabilities can participate. Also, some employees with intellectual or developmental disabilities may need extra guidance before they are able to participate.
- **Accommodation Example:** An employee with fetal alcohol syndrome was having trouble participating in an exercise class offered by her employer. The employer provided a temporary trainer/mentor to help her follow the instructor. After the trainer left, the employee was given a headset/recording with instructions for participating in the class. The employee liked wearing the headset because it looked like she was listening to music like other employees.

### Tracking Progress

- **General Tip:** As part of a wellness program, employers often provide tools for tracking progress, such as online tracking systems and handheld electronic devices. In some instances, employees with intellectual or developmental disabilities may be unable to use these systems or devices. Employers should be prepared to offer alternatives, such as paper tracking systems or easy-to-operate devices.
- **Accommodation Example:** An employee with cerebral palsy was able to participate in a walking program by using an accessible pedal machine. However, he was unable to use the pedometer his employer provided to track his miles because of his fine motor limitations and the small buttons on the pedometer. His employer provided him with a large-button pedometer.

### Educating About Nutrition

- **General Tip:** Educating employees about good nutrition can be an important part of a wellness program. Once the education is provided, employees are generally on their own to apply the information and make good food choices. For some employees with intellectual or developmental disabilities, it can be difficult to retain and apply this information, so employers may want to provide materials these employees can keep with them.
- **Accommodation Example:** An employee with Down syndrome signed up for a nutrition class, but had trouble understanding the information that was presented. His employer asked the instructor to provide pictures of the types of food she was recommending employees eat. The employee with Down syndrome was able to keep these pictures with him when making food choices.

### Setting Health Goals

- **General Tip:** Many wellness programs provide incentives based on employees reaching certain health goals. For some employees it may be impossible to meet the goals because of their disabilities. When this happens, employers should set attainable goals for employees based on their specific situations.
  - **Accommodation Example:** An employee with Prader-Willi syndrome was unable to meet one of the goals of her employer's wellness program – having a 35 inch waist – and therefore was not going to qualify for a reduction in her insurance premium. Her employer modified her goal, changing it to a two inch reduction from her current waist measurement.
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## Moving From Fear to Fullness: How Martial Arts Changed My Life

by Nathan Perry

*For Nathan Perry, learning martial arts has been an important part of wellness across all areas of his life, from self-defense to social connections. In this interview he talks about his experience, including the challenges he's faced and lessons learned.*

**You do a lot of things to have health and wellness in your life. One of the things you do is karate. How did you get started doing that?**

I got involved in karate originally for learning self-defense and how to take care of myself. Before I started taking martial arts, I lived in fear because I ran

*I went in to learn how to defend myself, but was also able to get physical exercise, have social interaction with people, be out in the community, lose weight, and feel much better about myself.*

into some trouble in my neighborhood with some shady people. I was attacked just right outside the house. Someone came up behind me and gave me a bloody nose and black eye and chased me around the neighborhood. I didn't know what to do. I was screaming, "Help, help" and no one helped. So I realized I need to know how to defend myself.

When I started learning self-defense, I became much more confident that I know how to handle a situation that doesn't feel right. I can do stuff that's really simple to diffuse a situation that

I had no idea about before. Like one of the things that just never dawned on me is that if somebody's following you, cross the street or go into a building. There are all sorts of different tactics to take care of a situation without having to use any physical interventions. Learning how to read people and be aware of your surroundings was helpful. We don't pay attention to where we're going and what's around us. Usually there's some kind of warning or something that leads up to something happening. Rarely does it just come out of the blue. As far as the physical martial arts, I've also learned how to do a do a lot of pressure locks – using pressure points on people to control their movement – and how to disarm someone if they're coming at you with a knife.

**In karate there's a belt system. Can you explain what that is?**

You go in as a white belt, for beginner. And then you take classes a couple times a week and within a month or so go to yellow belt. Then you go into more intensive training for three, four, five months and you go for the orange belt. And then your training gets even more intense, and you stay in that for about five or six months and go to green belt. And then the belts are spaced out longer because the skills are harder.

**How long have you been doing this and what belts do you have?**

I've been doing karate off and on for the last six or seven years. I have several belts in different styles. I was a green belt in Shorin Ryu karate. I'm an orange belt in Shotokan karate. I'm just starting Tae Kwan Do and Hapkideo in the next couple of weeks.

**So you went in with a specific need that was met – you wanted to feel**

**safer, be safer, in your neighborhood. Did you get other benefits out of participating?**

I got a lot of benefits. It filled a social void in my life. It had the exercise component. I met people there, one of whom became my girlfriend. I learned how to defend myself. And in the dojo – the school – as a whole we would do things outside the dojo too. Like we went to a Japanese lantern festival and did demonstrations. So I went in to learn how to defend myself, but was also able to get physical exercise, have social interaction with people, be out in the community, lose weight, and feel much better about myself.

**Are there some things you've learned in martial arts that you're now taking into other areas of your life?**

I have learned to trust my gut on things. I've also learned not to immediately trust people. That was kind of hard for me because I used to think everyone was good. Life circumstances have taught me not to immediately trust people. It now takes time for me to warm up to people. So when I first meet people, depending on their body language, what they say, how they look, I might be a little cautious until I actually get to know them. And I was also very controlling and had to learn to let things go, and be okay with myself. Karate helped with that.

**How has it helped you learn to let things go, and be okay with yourself?**

I had done Shorin Ryu karate for a few years when I had a falling out with my *sensei*, my instructor, and I wound up leaving. I went to another school where I tried Shotokan style and it just didn't work right for me. Then I went into Tae Kwon Do trying to start over. I went in with the wrong view of things, the view that I'm a green belt in karate and



*Nathan Perry has practiced martial arts for a half dozen years, finding both rewards and challenges in the process.*

can do more advanced stuff in Tae Kwon Do, and that backfired on me. I actually hurt my arm and leg. And also I was really, really hard on myself. I thought this has got to get done this way, this has to be perfect – I thought the whole setting had to be perfect for me. After trying Tae Kwon Do for awhile in a setting that was really beyond my skill level, it wiped me out. I got discouraged and quit again. I decided at that point in time that I was done with martial arts altogether.

But every once in awhile something would come back to me. You know, Nathan, you used to be a lot healthier when you were in martial arts. You used to meet a lot more people when you were in martial arts. You were a lot more relaxed when you were in martial arts. About three weeks ago I was talking on the phone with one of my support staff and I was upset because I was lonely, and wasn't meeting anybody, and was bored. I had nothing going on in my life. And we went out for a walk to talk about that, and he said, "Nathan, I think you really need to think about getting back into martial arts." And so I thought about it, and decided that if I go back into it I'll start this time as a beginner in Tae Kwon Do and Hapkiedo because they're different than what I had learned before as a green belt. And the reason Tae Kwon Do and Hapkiedo didn't take

off for me before was that I was pushing too hard and taking more advanced classes when the foundation wasn't there for me to be taking advanced classes. So I'll start out as a beginner this time and do that for a couple months, then move up the natural rank.

**It sounds like there was a lot of problem-solving going on, a lot of learning what works for you and what doesn't. That was hard, wasn't it?**

It was hard.

**What's next for you in martial arts?**

I'm restarting it in the next two or three weeks. My goal going into it this time is whatever happens, happens. Just be okay with yourself and let things progress naturally instead of trying to influence everything and control everything. So I'll take it one day at a time. I've also learned, painfully, not to push myself so I don't injure myself, because I had to have physical therapy from the injuries. I had to learn I'm not 22 anymore and have to take that into account.

**Through all your journey you've had to be open to not only learning new things, but also be open to things not playing out exactly as you thought they would.**

Yes, and it can be really hard to be open to everything, to accepting your limitations, and to things not being exactly as you want them to be. You have to work through that and get over that to move forward and better yourself.

One of the things I struggle with is that I have depression. And depression lots of times just zaps everything out of me and I just stay in bed and don't do anything. There have been times when all I would do is go to work and come home and go to bed, go to work and come home and go to bed. I also have autism, and depression and autism go hand in hand. In the winter depression is especially bad for me. This winter I became bitter with myself because I'd see my family doing things, and my nephew who's 17 and has a girlfriend out doing things, and here I am not wanting to do anything. At times that gets tiring. So I finally got mad one day and was talking to my support person and was upset with myself and saying this just isn't working. And he brought up the idea of getting back into martial arts. By doing that, hopefully I'll be able to meet some people. And getting exercise will help with the depression symptoms. And I'll be involved in the community as a whole again. And I'm hoping I'll have a nice group of friends come out of martial arts.

This time I'm also taking two different kids of karate, and they're the more popular types that have lots of schools where they're taught. So if something doesn't work out for me at one school I have lots of options for going somewhere else. I'll have a Plan B this time.

**Is there anything in particular out of the lessons you've learned that might be helpful to others?**

Take it one day at a time. Be open to suggestions. Don't beat yourself up. Give it time. And be willing to try a new thing.

*Nathan Perry works as an Information Technology Specialist at the Institute on Community Integration, University of Minnesota, Minneapolis.*

## The Flourishing Through Leisure Model: Supporting Well-Being Through Leisure

by Linda Heyne and Lynn Anderson

Leisure is a source of well-being for many people, and a powerful force for positive change in a person's life. Leisure offers diverse choices for participation, including arts and culture, hobbies, socializing, sports, volunteering, and nature-based activities, among many others. Through leisure, people experience positive emotions, which link directly to health and well-being (Fredrickson, 2009). Leisure can fulfill creative-expressive needs and help people derive purpose and meaning in their lives, which can lead to personal development and self-determination. Leisure also provides opportunities for social relationships, a key contributor to happiness (Seligman, 2002).

Leisure participation for the purpose of well-being is at the heart of the profession of therapeutic recreation. This article describes a practice model used in therapeutic recreation called the Flourishing through Leisure Model: An Ecological Extension of the Leisure and Well-Being Model (Anderson & Heyne, 2012). Based on the Leisure and Well-Being Model (Carruthers & Hood, 2007; Hood & Carruthers, 2007), a social model of disability, and recent discoveries in positive psychology, the Flourishing through Leisure Model follows a strengths orientation. That is, instead of developing services based on a person's disability or deficits, services are built around the person's unique strengths, goals, aspirations, and dreams. An ecological perspective is also used because resources in a person's environment are important sources of support for leisure participation and strengthening well-being.

### Overview of the Model

The left side of the Flourishing through Leisure Model (see Figure 1) shows what the therapeutic recreation specialist does, and the right side shows the outcomes the participant experiences (see the labels at

the bottom of the model). The interactive arrow at the bottom indicates that the therapeutic process is driven by the participant's goals, dreams, and aspirations, a key aspect of the strengths approach.

The left half of the model looks at the person in their environment. Here, two focus areas guide the services provided by the therapeutic recreation specialist: personal strengths of the participant (represented by the image of the person) and environmental resources (represented by the image of the house). As such, the therapeutic recreation specialist helps participants enhance their experience of leisure and build internal strengths while tapping environmental resources to support the participant's progress toward greater well-being.

The right half of the model shows the outcomes of therapeutic recreation services, depicted by a flower emerging from the rich combination of personal strengths and environmental resources. The outcomes manifest as enhanced leisure experiences and positive change across the domains of well-being. These outcomes, in which the participant experiences successful, satisfying, and productive engagement with their life, lead to a flourishing life.

### The Leisure Experience

To enhance a participant's leisure experience, the therapeutic recreation specialist facilitates the development of leisure skills and knowledge within the individual. Change within leisure environments is also facilitated to support the development of those skills and knowledge. For example, the therapeutic recreation specialist can assist participants in clarifying their leisure interests and talents, then help them find a club or other community setting where those interests and talents may be pursued. The therapeutic recreation specialist may also help the

community setting become more accessible or inclusive. Further, a participant might discover he or she has the character strengths of kindness and generosity, and the therapeutic recreation specialist can help find a volunteer placement at a local agency where the individual can exercise those strengths.

When leisure experiences are enhanced, other strengths and resources develop as well, as implied by the interactive arrow that extends vertically through the leisure and well-being domains. For example, enjoyable participation in a fun run can boost a person's physical fitness (physical domain), provide an opportunity to meet new people (social domain), and enable a person to contribute to a charitable organization (spiritual domain).

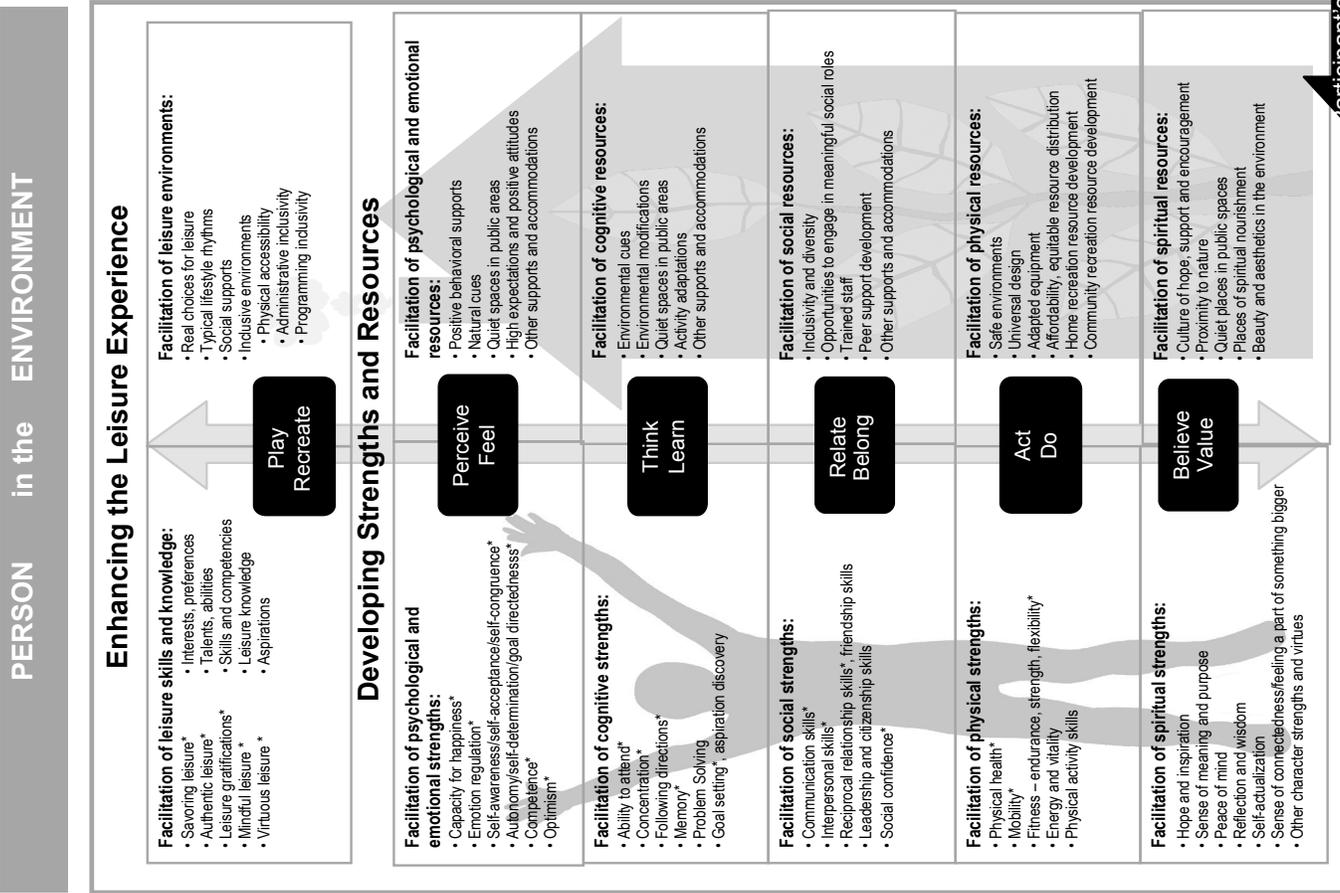
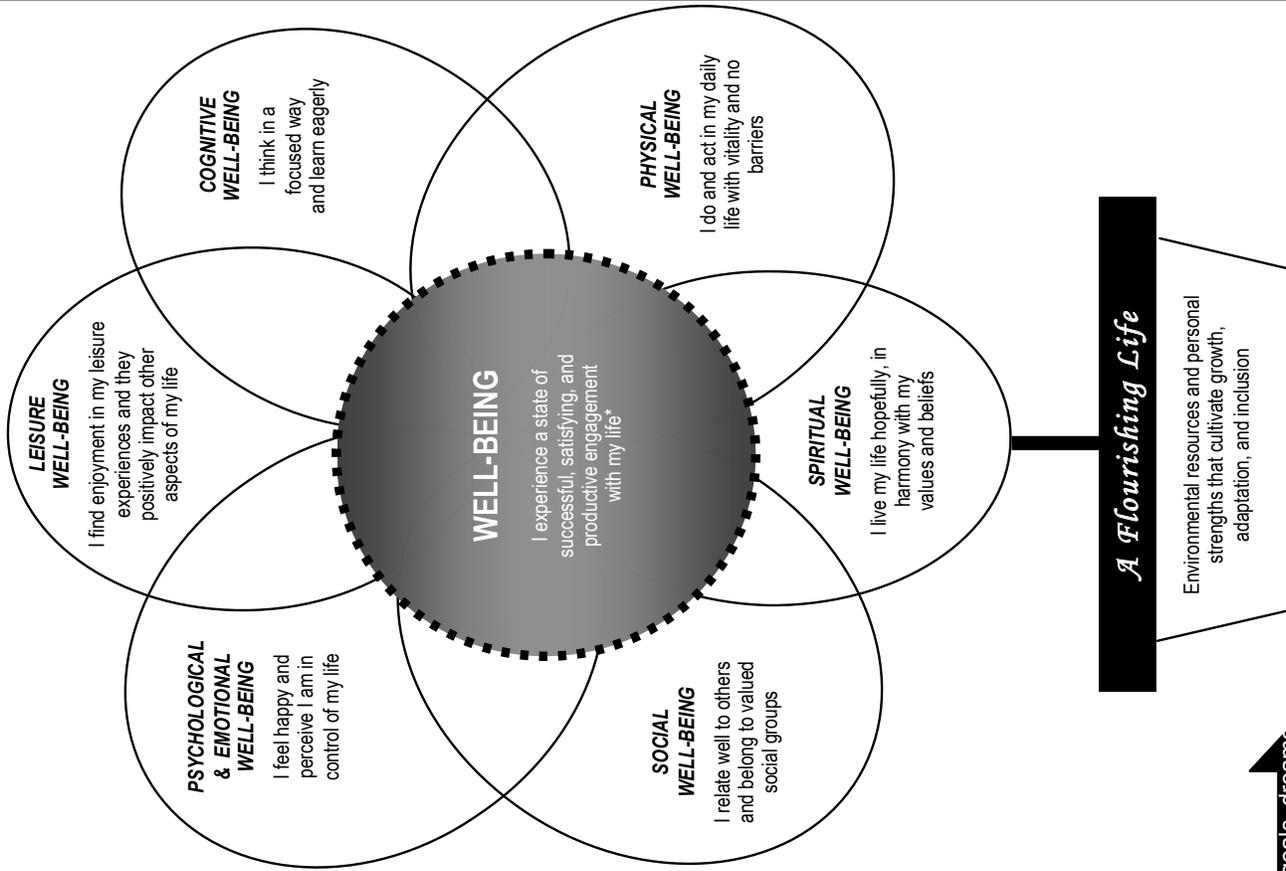
### Dimensions of Well-Being

Besides leisure, the Flourishing through Leisure Model encompasses five dimensions of well-being: psychological/emotional, cognitive, social, physical, and spiritual. This section briefly describes each dimension and provides practical examples of their application using the model. In each instance, leisure is used as a context to enhance well-being. Please refer to the model for examples of personal strengths (e.g., leisure interests, interpersonal skills) and environmental resources (e.g., adapted equipment, universal design) within each dimension of well-being:

- *Psychological/emotional.* Psychological and emotional strengths help us perceive the world around us, and feel and regulate a range of emotions. Someone who experiences well-being in this area would be able to experience happiness and feel in control of their life. As an example of building on personal strengths and drawing

[Heyne & Anderson, continued on page 33]

Figure 1: Flourishing Through Leisure Model



Participant's goals, dreams, and aspirations

What the Therapeutic Recreation Specialist Does

\*From the Leisure and Well-Being Model (Carruthers & Hood, 2007; Hood & Carruthers, 2007)

## Flourishing and Spirituality: Healing and Wholeness Without Perfection

by Bill Gaventa and Erik W. Carter

Being or becoming “well” is not necessarily about minimizing sickness or eliminating disease. Nor should it be conflated with the absence or healing of a disability, despite prevailing stereotypes out of both the medical model and some religious traditions. Theologians and clergy these days often make a distinction between “healing” and “cure,” noting that healing can occur even if a particular condition is not cured. Wellness, like healing, involves moving toward a healthier physical, mental, and spiritual way of living. Wellness is a journey. To be

support to pursue those that matter most to you. But it also entails embracing all of what we have – our strengths, needs, limits, and gifts alike – and then living whole lives that do not rest on being perfect. Such lives are full of “spirit.” They are characterized by a positive sense of one’s identity; by doing things that are meaningful and enriching; by enjoying strong connections with people, places, and whatever is sacred or holy in one’s life; by having a sense of purpose; and by making a difference in the lives of others. These are aspects of what many call “spirituality.” It can be expressed through a community of faith, but it does not have to be. Spirituality is not so much a set of beliefs as it is a relationship – with oneself, others, God, tradition, and future. In the quality of life model that pays the most substantial attention to the place and prominence of spirituality, quality of life is about being, becoming, and belonging (Quality of Life Research Unit, n.d.).

In the past three decades, research at the intersection of spirituality and wellness has burgeoned. Hundreds of studies (Koenig, King & Carson, 2012) affirm what so many people can speak to first hand – spirituality and various indicators of flourishing often accompany one another. This connection is also evident among people with IDD. In their interviews with young people with disabilities, Liu and colleagues (2014) learned that thriving included the friendships young people forged within their congregations, the sense of belonging that came from membership in a faith community, and the opportunities they had to worship and serve alongside others. Biggs and Carter (in press) reported a similar pattern in their study involving almost 400 young people with disabilities – faith and quality of life were strongly correlated with one another. The importance of spiritual expression is not

limited to just a handful of individuals. In a national survey, nearly 90% of adults with significant disabilities considered their faith to be an important aspect of their lives (NOD, 2004) and almost half of adults with IDD in another national study attended a place of worship at least once in the past month (Carter et al., in press). Supporting the spiritual lives of people with IDD appears to be an important element of enabling people to thrive.

How, then, might we tap the spiritual dimensions of people’s lives in their journey toward wellness? It starts first with listening to and supporting well the wishes, dreams, needs, and preferences of each individual. One can do that through one or more spiritual assessment processes, some of which have been developed specifically for and with people with IDD (see the Web site of the Collaborative on Faith and Disability at <http://faithanddisability.org/resources/webinars-and-online-trainings>). If we learn that a spiritual community, tradition, and religious identity is important to someone, then supporting these things well is simply a matter of good person-centered practices (see position statements by TASH, the Arc, and the American Association on Intellectual and Developmental Disabilities). And the forms these supports take might vary widely – from tapping into the network of people within their congregation to help find just the right job (Gaventa, Allen, Kleinert & Carter, 2014), to enabling them to serve others in their community, to supporting their time with friends with whom they share the deepest of connections, to providing space for them to explore or express things that matter most.

The efforts of congregations are also essential to ensuring people with IDD who want to be part of a faith community actually receive the invitations,

*Spirituality and flourishing can be intimately linked. Supporting people well on their journey toward both is an important aspect of providing the very best services and supports.*

well and doing really well on that journey is, one might say, to flourish with or in spite of one’s limitations.

In her wonderful book, *Flourish: People with Disabilities Living Lives of Passion*, Karin Meiberg Schwier (2012) shares the life stories of a number of people with intellectual and developmental disabilities (IDD) who are seen as flourishing, on their own and in community with others. She names reflections on how to help flourishing happen by paying attention to the “spice of life,” “journeys of discovery,” “identifying passions,” “building on interests,” “picking up the pieces,” and “promoting passions.” Passion, belonging, and purpose emerge as key themes throughout these stories.

Flourishing is partly about knowing all of one’s options and having sufficient

encouragement, and supports needed to participate in valued ways. However, many congregation members feel reluctant or ill-prepared to extend hospitality in this direction – they are unsure what to say, unsure what to offer, and unsure where to begin. And uncertainty almost always leads to avoidance. Here is where the growing number of new resources can be so helpful for congregations that want to be welcoming, but wonder where to start (see <http://www.faithanddisability.org> for a searchable database of resources). Professionals steeped in the world of disability can also be effective advocates and guides for congregations.

Spirituality and flourishing can be intimately linked. Supporting people well on their journey toward both is an important aspect of providing the very best services and supports to people with intellectual and developmental disabilities.

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Morgan Vice (striped dress) surrounded by friends at the church she attends.

## Church Means Lots of Things to Morgan

Morgan keeps a calendar beside her bed. Every evening, before she says her bedtime prayers, she marks the current day with an X, and then writes down her schedule for the next day. Monday through Friday is routinely marked "School, Home." Saturdays are marked "Breakfast." If she has a special event coming up, she will mark it ahead so she can count down the days. On Saturday evenings, she looks up at me and says, "Church, C-H-U-R-C-H." But for all of us, church is more than just a Sunday thing.

Morgan looks forward to seeing her teachers and friends. Our church holds regular Buddy Breaks, Vacation Bible School, and socials throughout the year, giving her lots of opportunities to stay connected with friends. When asked what she likes about church, one answer is, "Lots of friends. Lots of stuffs about Jesus." Beyond worship, religious education, and social events, she enjoys the church library, the fitness center, and piano lessons through their music program. Morgan is currently learning various jobs at our

church through her school-to-work program. Now that she is in her final year of school services, we are realizing how precious these continued connections will become to Morgan, and all of our family.

Morgan is on the autism spectrum, and she sometimes thinks the world revolves around her. When Morgan's Sunday School teacher told her that her husband had the same birthday as her, she said, "Oh no, that's not right. That's Morgan's birthday." Through church, she not only learns how to serve others, but prayer is also very important to her. When Morgan knows someone is hurting, she is quick to say a prayer, right then and there: "Dear Lord, please make it all better. Take care of it." It touches people. She is quick to pray out loud for herself, too. When asked what Jesus does when she prays, Morgan replied, "Jesus loves Morgan." In other words, she knows who's got her back.

But you never quite know what she will say. She has her introvert side, so sometimes when she is ready to leave a gathering, she'll announce to everyone, "What time is it? Too many friends. I'm done!" It's a nice problem to have.

Contributed by Morgan Vice and by Tammy Vice, Hendersonville, Tennessee

# Friendship Matters! Improving Health and Well-Being by Supporting Relationships

by Angela Novak Amado, Elizabeth Pell, and Kim Zoeller

Friendships help us cope with life. Research in the general population shows that having friends positively impacts health and well-being. Humans are such social animals that loneliness can increase stress, lead to depression, and even shorten our lives (Perry, 2014).

Who your friends are matters, too. In terms of health impact, all friendships are not the same. Friendships that have a more positive impact on health are those with people beyond one's spouse or other family members (Kroenke, et al., 2006).

## Connecting Friendship and Health

The National Core Indicators (NCI)<sup>™</sup> program is an effort by state developmental disability agencies to evaluate their performance using a nationally validated set of measures. NCI measures areas including employment, rights, service planning, community inclusion, choice, health, and safety. Currently, 42 states (including the District of Columbia) participate. For this article we examined data from the 2013-14 NCI Adult Consumer Survey to see if life experiences that contribute to overall health and well-being differ by friendship types for people with intellectual and developmental disabilities. The data reveal significant differences in many areas between adults with intellectual and developmental disabilities whose friendships are with family and/or paid staff only (i.e., *limited* friendships) and those who have friendships with people beyond paid staff or family (i.e., *expanded* friendships), including other people with disabilities and general community members.

In 2013-14, 17 percent of adults with intellectual and developmental disabilities receiving publicly-funded services reported having limited friendships; 76 percent reported having expanded friendships (NCI, 2015). NCI data showed that people with expanded friendships had better life experiences than those with limited friendships.

Differences between friendship types were found in employment, choice of job, choice of where to live, and extent of community integration. Some of the life experiences in which NCI data show differences between friendship types are displayed in Table 1.

Those with expanded friendships were more likely to have a mild level of intellectual disability, to use speech to communicate, to get around without mobility aids, and to live with family/relatives, or in their own or shared apartments, than those with more limited friendship networks. The differences reported are statistically significant.

Further research is required to understand the relationship between the personal characteristics examined and the friendship experiences (including their effects on each other). However, these findings do suggest differences in important life experiences for people who have expanded friendships.

## Prioritizing Relationships

Supporting people with intellectual and developmental disabilities requires constant discovery and conversation about what is really important to them. This is especially relevant when focusing on relationships and supporting people to build their own social networks. Everyone has a personal definition of what they want their social network to look like. People with intellectual and developmental disabilities are no different, but they may need support to discover the possibilities.

One way in which agencies can evaluate their performance and improve in this area is using the Personal Outcomes Measures<sup>®</sup> developed by The Council on Quality and Leadership (CQL). For more than 40 years, CQL has been a leader in the development of progressive and innovative strategies to advance quality of life outcomes for people with disabilities; their methods

have been used for agency accreditation and for quality improvement.

The Personal Outcome Measures<sup>®</sup> can provide a guide for discussion with people, and the opportunity to measure progress towards personal goals. Focusing attention on the following Personal Outcome Measures<sup>®</sup> is key to advancing relationships and social networks:

- People have friends.
- People have intimate relationships.
- People are connected to natural support networks.
- People participate in the life of the community.
- People interact with other members of the community.
- People perform different social roles.
- People are respected.

(CQL, 2012, p. 13)

Members of a person's support team should strive to consistently offer opportunities that expose the person to people, places, and groups that may result in fulfilling experiences. One empowering approach and support in this area is to look at building "social capital." Several years ago, CQL raised the bar for organizations to embrace the concepts and values of "social capital," the interconnectedness and trust associated with reciprocal relationships. A large body of research tells us that when people, in general, have more social capital they lead happier and healthier lives.

Taking note to document people's priorities for the above Personal Outcome Measures<sup>®</sup> (whether one uses the CQL system or not), as well as identifying strategies that the team will pursue for expanding social capital, are key. It is necessary to fully understand that as people have more life experiences, their priorities may change. Therefore, frequent conversations about relationships and social networks are important to continue successfully supporting people.

**Table 1. Experiences by Friendship Type**

|                             | Held community job in past 2 weeks | Volunteers in community | Chose job or had some input | Chose or had input into where to live | Can see friends whenever want to | Integrated exercise | Integrated entertainment |
|-----------------------------|------------------------------------|-------------------------|-----------------------------|---------------------------------------|----------------------------------|---------------------|--------------------------|
| <b>Limited friendships</b>  | 15%                                | 25%                     | 80%                         | 55%                                   | 69%                              | 55%                 | 67%                      |
| <b>Expanded friendships</b> | 22%                                | 32%                     | 85%                         | 65%                                   | 80%                              | 63%                 | 75%                      |

Note: Data from National Core Indicators (NCI)<sup>™</sup> (2015). *Adult consumer survey 2013-14 final report*. Retrieved from [http://www.nationalcoreindicators.org/upload/core-indicators/4\\_23\\_15\\_2013-14\\_ACS\\_508.pdf](http://www.nationalcoreindicators.org/upload/core-indicators/4_23_15_2013-14_ACS_508.pdf).

### Supporting Expanded Friendships

Clearly, expanding friendships has a positive effect on people's lives. But how do you do it? There are some basic strategies that many have used to support friendship development between individuals with and without disabilities. Many are summarized in a free workbook, *Friends* (see <http://rtc.umn.edu/friends>). They include these three basic approaches and seven specific strategies and questions:

- 1) *Connecting people through their interests and gifts*
  - a. After identifying a person's interests, where are community members who share those same interests?
  - b. After identifying the gifts an individual has – both things they do well and what others receive from knowing them – where are people who would appreciate receiving those gifts?
- 2) *Connecting in one-to-one relationships*
  - a. Where could someone be found who would like to get to know this person?
  - b. Which community members who are on the periphery of the person's life could befriend the person in a deeper relationship?
- 3) *Finding places of community membership and belonging*
  - a. Where are associations, groups, and clubs that would enjoy having this person as a member?
  - b. Where are community places that would be welcoming?
  - c. For individuals who do things that may seem challenging, where are places they would fit in just the way they are?

Engaging in pursuing these strategies and working on connecting people with other community members have revealed many policy and practice implications.

For provider agencies, factors that play a major role in success in community building include the commitment of the executive director, the person-centered values of the agency as a whole, and how the agency defines its role in relation to community. Agencies that have been successful in this arena have incorporated community building into staff job descriptions and individual service plan goals, developed structures for ongoing staff training and problem-solving, put evaluation systems in place to determine success, and developed a culture of perseverance and persistence. Staff have come to embrace their role as community builders, and some agencies have generated community-wide efforts. When agencies serve multiple individuals in one location such as a group home, effective strategies have included figuring out ways to support one-to-one connections with community members. Staff have developed skills in asking community members to get involved, and have shifted the focus from simply participating in activities in the community to searching out the people who can get more deeply connected.

Policies at the local, state and federal levels can also be more supportive of social inclusion. There are requirements in regulatory and funding streams for "community participation," but these unfortunately often result only in physical presence or community activities, rather than true relationships, community membership, and belonging. Although services

are governed by regulations that require community integration and promoting natural supports, some staff use regulations about confidentiality and data privacy to inhibit introductions to community members. This apparent conflict should be resolved.

### Conclusion

Friendships are key to health and quality of life for everyone. Supporting individuals with intellectual and developmental disabilities in this arena is a new frontier for many in the services system, but it is critical and exciting both for those individuals and our communities.

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## Learning Together About Health Promotion: A Community Partnership in Montana

by Andrea Dahl

Over the years, many programs have been established that promote improved weight and nutrition for people with disabilities. However, few have been written so that people with intellectual and developmental disabilities (IDD) could fully comprehend what was being taught. Many communities offer programs to prevent diabetes and heart disease through their county health departments, but the materials are written in a way that is not accessible for people who are living with IDD. As a result, very few are participating in the such programs.

An important role I have as an employee of Summit Independent Living Center (ILC) in Missoula, Montana, is as a chapter advisor for Missoula Valley People First, a self-advocacy organization for people with IDD. In the past, some People First members have participated in weight loss programs in their community. They have found it challenging when the program includes written materials to follow, and some programs promote dietary habits that are not truly healthy or realistic to maintain in the long run. They need support to learn the vocabulary and develop some basic skills for activities used in programs, such as diet and activity logging. If People First members had a class where they could learn healthier eating habits, they would be able to reach their goals and maintain them afterwards. A new program was needed in our community that teaches the basics of healthy eating habits and exercise in a way that can be easily understood.

The Summit ILC has collaborated with the Rural Institute for Inclusive Communities (RIIC), University of Montana, on several health promotion programs, including: a) a program to develop individualized health portfolios to improve outcomes of medical appointments; b) the Have Healthy Teeth (HHT) program that supported healthy choices in oral hygiene routines; and c) the Women Be Healthy (WBH) program that teaches



Wayne and Tiffany (center), are People First members who completed the 14 Weeks to a Healthier You class in Missoula, Montana this past summer. It was co-facilitated by Andrea Dahl (right) of Summit ILC, and Connie Lewis (left) of People First.

about women's health. Participants in the health portfolio program still use their portfolios today, HHT graduates report fewer cavities and gum issues after their dental check-ups, and WBH graduates are scheduling routine women's health exams. Our latest collaboration is on adopting a health education program focused on nutrition and physical activity for implementation in Montana.

The *14 Weeks to a Healthier You* facilitated program is focused on both fitness and nutrition at a comprehensible level. It originally was developed by the National Center on Health, Physical Activity, and Disability (NCHPAD) as an online program (see <http://www.nchpad.org/14weeks/>). Developers evaluated the online version and saw a need to develop it further for use with people with IDD. They worked with the Illinois Disability and Health Program to create a facilitator manual with tools and resources to teach persons with IDD how to make healthy physical activity and nutrition choices.

Last year, the Montana Disability and Health Program, a partnership of the RIIC and the state health department, organized a workgroup to review the *14 Weeks* facilitator manual and plan a one-day training that prepared myself

and my co-facilitator, Connie Lewis, to go through the program with local People First members. Each week of class with the People First members, our group covered a physical activity and a nutrition topic, and we noted what education tools worked and did not work. We tailored it for use with people who have IDD in Montana. In week one, we started with basic information on physical activity and on food labels. Each week's physical activity topics built on one another, from breathing exercises, to aerobic activity, to strength and flexibility training; nutrition topics built from hydration to healthy food choices and habits (fruits, vegetables, fiber, protein, carbohydrates, fats, salt, calcium, eating breakfast, portion control, healthy snacks). Each week's exercise videos showed basic, adaptable exercises for people who are mobile, have limited mobility or use a wheelchair. They featured peers with IDD performing the exercises and are fun. The activities and worksheets helped break down the nutrition guidelines and food labels into information participants could use to make healthier eating choices. And the peer support that developed around the nutrition topics carried over to support healthy choices by participants as they're in the community.

In their feedback on this adaptation of the program, People First members noted that they learned that stretching, when done on a regular basis, will help get rid of the “flab,” which they appreciate. They learned the importance of balanced nutritional meals to improve their health. They learned together how fast food is convenient, yet should be avoided in daily eating habits. They learned that they

can accomplish more when their body is healthy. And they are beginning to see that they have more possibilities in life if they include exercise and healthy eating in their daily living.

As next steps, we are sharing what we learned about the program to improve it for implementation with people who have IDD throughout the state. We also are meeting with health educators at

programs like the community Diabetes Prevention Program to identify options for graduates of the *14 Weeks* program to continue learning about and having support to lead healthy lives.

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Connie Lewis (right), People First member and staffer at the University of Montana Rural Institute for Inclusive Communities, is joined in the community garden by Andrea Dahl. They co-facilitate the *14 Weeks to a Healthier You* program in Missoula.

## ***It's All About Healthy Eating and Exercise***

by Connie Lewis

*Hi! My name is Connie Lewis. I am an Administrative Assistant with the University of Montana Rural Institute for Inclusive Communities. I answer phones, run photocopiers and fax machine, and make sure we have supplies if we need them. Those are just some things I do.*

*Also, I am the secretary for Missoula Valley People First Chapter and for the Home Owners Association Board for the condos where I live. So for these two organizations, I write the minutes. My hobbies are reading, sewing by hand, gardening, crochet, and cooking in the kitchen at home and at my church that I attend. I've been in TOPS (Taking Off Pounds Sensibly) for several years because I need to improve my own health with better eating habits and exercise.*

*This year the Montana Disability and Health Program is doing a program called 14 Weeks to a Healthier You. The organizing committee decided to have a People First member co-facilitate the class. Because of my organization skills and my knowledge from attending TOPS meetings, I was recruited to help Andrea Dahl facilitate these meetings. I had to start by attending a couple of planning meetings of the organizing committee and a full day of facilitator training. Our job was to review the program and give recommendations on what changes we needed to make in the program. We also suggested some incentives that we could give out when people accomplished a goal. I thought if people accomplished something from doing this*

*class, they should get an incentive. That's why I suggested incentives like passes to the Y and local gyms and pools.*

*We started our weekly meetings in July. We had them on Mondays from 4:00 until 5:00 p.m. Every Friday Andrea and I coordinated what we would talk about in the meetings, and I reminded people about our meetings by giving a call to them on Saturday or Sunday.*

*I want to help people learn about ways to be healthier. When you do the 14 Weeks program, you can do exercises sitting in a chair or standing up. There are low, moderate, and intense exercises to do. You do what fits for you. You learn not to overdo it and start out slow and work up the intensity of your exercise routine. For example, if you are not a usual walker start with 10 minutes a day and work up. From the class, I learned that drinking water helps all your organs work. I've been trying to drink more water. Water is always healthier than soda pop. You gain weight with soda pop. A healthy amount of water is eight glasses (8 ounces) a day.*

*This program will help people to be better at making healthier choices. They can lose weight. Weight gain can cause a lot of problems. When you have more weight on your body, it can make it harder to walk, tie your shoes or even go up and down stairs. The more health problems you have going on in your life, the more you could decrease your lifespan. I think if people improve their health, their lives would be longer and better.*

Contributed by Connie Lewis, University of Montana Rural Institute for Inclusive Communities, Missoula. She may be reached at [cjlewis@mso.umt.edu](mailto:cjlewis@mso.umt.edu) or 406/243-4620. Photo courtesy of Steven Begleiter Photography.

## Including Wellness in Individual Service Plans

by Meg Traci

Birthdays, New Year's Day and other events set annual occasions for many people to commit to health and wellness goals. The annual service or person-centered planning process can work in this way, setting the occasion for individuals with intellectual and developmental disabilities (IDD) to set health and wellness goals, and organize Home and Community Based Services (HCBS) and supports to meet those goals. Person-centered planning empowers individuals to have goals that address multiple dimensions of health and wellness, and support a self-determined and satisfying life.

States partner with the Centers for Medicare and Medicaid Services (CMS) to provide HCBS programs such as case management, HCBS waivers, and Community First Choice (CFC) programs. These programs support individuals' participation in community life. In a growing number of states, these programs are flexible enough to support approaches to health and wellness. They can support fitness club memberships, health education classes, wellness coordination, and home modifications. These programs complement the Medicaid and Medicare programs that reimburse for needed and preventive health care and for medical transportation and medical escort services. Individuals can set and organize for both health care and health and wellness goals and objectives in their person-centered plans.

This article offers a series of questions and suggestions designed for use in person-centered health and wellness planning. They're adapted from a guide developed by community partners in Montana titled, *Montana Community First Choice (CFC): Health Supports Planning Guide* (Traci, Hoffman, Monson, & Driggers, 2014) and expanded here to include additional resources available in all states. This information can help identify health and wellness goals and objectives to be included in individual service plans for issues related to the following areas:

- Health monitoring and care coordination
- Serious health concerns
- Chronic condition management
- Preventive care
- Health promotion

The suggestions address considerations of pressing or acute health care needs first, and then focus on healthy lifestyle planning and health promotion.

### Health Monitoring and Care Coordination

An initial question to ask in the process of person-centered planning for health and wellness is in the area of health monitoring and care coordination for acute and chronic conditions. The question is whether the individual will need assistance to access health care professionals in order to better monitor their personal health and to coordinate their health care. They can review the following list of health care professionals to identify which ones they need to see, and think about what supports they need to access these professionals. Additionally, they can consider whether they want any of these professionals to help them identify their health and wellness goals and objectives for their person-centered plan. The list is as follows:

- Primary care physician
- Mental health professional (counselor, psychologist, psychiatrist, licensed social worker)
- Dentist
- Vision specialist (optometrist or ophthalmologist)
- Hearing specialist or audiologist
- Physical, occupational, and/or speech therapists
- Other health care specialists (e.g., psychiatrist, dietitian)

There are a number of resources to support health care providers to deliver care to individuals with IDD and to be a

part of the supports in their plan. Among them is *Health Care for Adults with Intellectual and Developmental Disabilities: Toolkit for Primary Care Providers*, published by the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities at <http://vkc.mc.vanderbilt.edu/etoolkit>.

### Serious Health Concerns

Another question that can be asked as part of the person-centered planning process is whether the individual would like to consult a health care provider, such as their primary care physician or a nurse, about any serious health concerns at that time. To make this decision, the individual should take time to think about the concerns they have (for example heart attack or stroke, undiagnosed diabetes, medication side effects, pain, weight management) and make a list of these concerns. Then they can work with their health care provider to identify related supports for inclusion in their person-centered plan. A health checklist may help them think about all of their possible health concerns. One such checklist that can be adapted for use in various settings is *Personal Support Plan Health Care Checklist and Risk Worksheet* developed by the Montana Department of Public Health and Human Services. It can be accessed online at <http://dphhs.mt.gov/Portals/85/dsd/documents/DDP/Forms/PSP/PSPHealthcareChecklist.pdf>.

Another area of health-related planning for serious health concerns is an Advance Directive (also known as a Living Will), which allows an individual to document their wishes regarding end-of-life care. Does the individual need help to develop an Advance Directive? A member of the National Disability Rights Network in each state can provide information about how Advance Directives work in the state where the individual lives. To find the Disability Rights Network member directory, visit <http://www.ndrn.org/en/ndrn-member-agencies.html> and select the state. A wide range of resources

on end-of-life planning for individuals with IDD can also be found on the Quality Mall Web site (<http://www.qualitymall.org>) of the Research and Training Center on Community Living at the University of Minnesota. In the section titled, “Grief, Loss and End-of-Life” (under “Life and Future Planning”) are a number of planning/discussion resources.

### Chronic Condition Management

For individuals with chronic conditions, part of their wellness planning will need to include any assistance they need to manage chronic conditions and maximize their independence and quality of life. Below is a list of some specific chronic conditions with example management objectives to support that planning process. The individual can review the list and identify supports needed to address any conditions they might have:

- Diabetes: Develop, review, and follow diabetes management plan
- Cancer: Start or continue treatment; seek follow-up care if in remission
- Asthma: Develop, review, and follow asthma management plan
- Arthritis: Develop, review, and follow pain management plan
- Mental health or substance abuse problem: Develop, review, and follow behavioral health management plan
- Emphysema, chronic bronchitis, or COPD: Develop, review, and follow respiratory management plan
- Heart disease, irregular heart rate, or angina: Develop, review, and follow heart health management plan
- High blood pressure: Develop, review, and follow control plan
- Skin Condition (eczema, psoriasis): Develop, review and follow skin care and monitoring plan
- Chronic Pain: Develop, review, and follow pain management plan
- Other Chronic Conditions: Urinary tract infections, pressure sores, gum disease, menstrual pain, other?

There are widely available resources that can help with managing many

chronic conditions, and can be useful in planning for that management. They include the online SuperTracker (<http://www.cnpp.usda.gov/supertracker>) from the U.S. Department of Agriculture; it’s a state-of-the-art resource designed to assist individuals as they make changes in their life to reduce their risk of chronic disease and maintain a healthy weight. Another resource is the Web site of the National Center on Health, Physical Activity and Disability (NCHPAD) (<http://www.nchpad.org>), which has extensive resources on adaptations and suggestions for physical activity that can help people with many different types of disabilities manage their health and wellness. And lastly, managing stress is often an important part of managing chronic conditions, and the American Psychological Association has a helpful tip sheet on stress at <http://www.apa.org/helpcenter/stress-tips.aspx>.

In addition, if an individual’s chronic condition led to an emergency room visit in the past year, part of the planning process can be asking if the individual and their doctor can identify supports to help reduce or avoid the need for urgent or emergent care in the coming year. These supports could include education on managing the chronic condition, staff training, care or wellness coordination, and rewards or incentives for managing their condition successfully.

### Preventive Care

Person-centered wellness planning also includes keeping track of preventive care screening recommendations, and asking whether the individual needs help to access preventive health care in the coming year. That care can include oral health screenings, mammograms, pap smears, colorectal cancer screening, bone density screening, prostate exams, and immunizations, among others. For current recommendations, a useful resource is *The Guide to Clinical Preventive Services* from the U.S. Department of Health and Human Services at <http://www.ahrq.gov/professionals/clinicians-providers/guidelines-recommendations/guide/index.html>. The booklet, *Making*

*Preventive Health Care Work for You: A Resource Guide for People with Physical Disabilities*, published by the Center for Disability Issues and the Health Professions, has information to help people with disabilities get the most from preventive health care visits. It is available at <http://webhost.westernu.edu/hfcdhp/wp-content/uploads/Preventive-Health-Care.pdf>.

### Health Promotion

Lastly, there are community resources, including health education programs, that individuals with disabilities can join to promote their health. In shaping a person-centered plan, one question to ask is what programs or activities the individual wants to participate in this year, and what supports and preparation they’ll need to access these community resources. Some health education/wellness programs that are available in most states include those offered by clinics, hospitals, community organizations, national associations, and disability organizations in areas such as diabetes prevention and management, arthritis management, fall prevention, tobacco cessation, weight management, alcohol/drug abuse prevention, exercise promotion, healthy cooking and eating, sexual health, and violence prevention. Local health departments can provide information on health education classes. Contacts for departments can be found at <http://naccho.org/about/LHD/copy-of-index.cfm> or from the NACCHO Health and Disability program at [disability@naccho.org](mailto:disability@naccho.org). Centers for independent living may also have programs tailored to specific needs of individuals with disabilities. For a list of centers nationwide see <http://www.ilru.org/projects/cil-net/cil-center-and-association-directory>.

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## Modeling Health and Wellness in Minnesota: Living Well Disability Services

by Toni Gillen

According to DATA2010 (CDC, 2015), people with disabilities are more likely to have high blood pressure, be overweight, lack fitness activities and social-emotional support, use tobacco, and lack regular medical tests. The data reinforces the need for health and wellness activities for people with disabilities. Physical exercise, good nutrition, stress management and social support are important for everyone, including people with disabilities who may have a thinner margin of health.

Since 2008, Living Well Disability Services has worked to transform the delivery of services for people impacted by disabilities to one that models health

*Self-advocates served by Living Well report improved physical health, regular engagement with people in the community, and a reduced sense of isolation and loneliness.*

and wellness. The goal is straightforward: to improve the overall quality of life for people with disabilities.

The 43-year-old private, nonprofit organization, founded as Dakota's Children in West St. Paul, Minnesota, serves a broad spectrum of individuals in the region who have intellectual, developmental, and physical disabilities such as cerebral palsy, Down syndrome, multiple sclerosis, autism, and brain injury. These may be complicated by health issues related to aging, diabetes, anxiety, Alzheimer's, and medical fragility.



The Living Well Disability Services menu system incorporates fresh and whole foods naturally lower in salt and fat, as prepared here by (left to right) Adam, Tim, Living Well Disability Services Advocate Devin, Jordan, and Jordan's mom Julie.

### The Wellness Program's Beginning

Living Well began its health and wellness programming with individuals living in group home settings. The multi-faceted program started with the creation of a seasonally-based menu system for all Living Well Disability Services group homes. The menu system incorporates fresh and whole foods naturally lower in salt and fat. Nutritious meals are enhanced with produce from gardens planted at group homes by residents with the support of volunteer Master Gardeners. Access to local farmer's markets and Crop Share programs was also researched and included in the process to implement the new healthy and nutritious menu system.

A holistic approach to wellness drove expansion of offerings to include individualized exercise programs, animal-assisted interactions, music therapy, and volunteerism. Exercise and diet are integral parts of targeted plans and support for weight loss, one of the key indicators of success for a focused wellness program.

Therapeutic use of animals has shown that the presence of a pet can decrease heart rate and blood pressure significantly. Music therapy interventions are also designed to promote overall wellness through managing stress, alleviating pain, expressing feelings, enhancing memory, and improving communication.

For people with disabilities who choose to move toward greater independence, an intentional focus on volunteerism increases overall quality of life. Friendships and social skills gained through volunteerism help to increase natural and informal supports available.

With a desire to create a culture of wellness, employees play a critical role in the success of the wellness program. The organization reinforces healthy habits and behaviors, and recognizes employees for being wellness partners with people they support. A health and wellness coaching program pairing people served with employees, in conjunction with "Ways to Wellness" at Woodwinds

Hospital, provides an opportunity for active partnerships. The 12-week partnership includes goal setting, attending wellness and nutrition training, and exercising together. Employees facilitate engagement, and the partners motivate and inspire each other to make healthy changes that last a lifetime.

Wellness services were expanded in 2014 to those receiving Home and Community Based Services (HCBS) wherever they live: in their own home or their family's home. The program content and approach was modified to make it easy for a family to get started. For example, individuals and their family members attend nutrition and cooking classes to develop skills to implement a family-based wellness program. Comprehensive wellness kits include instructions and tools to help families integrate health and wellness activities into their daily routines.

### **The Impact of Wellness Programming**

In 2014, doctors seeing people served by Living Well reported that 91% of the people they examined experience good to excellent health. Annual satisfaction surveys include responses from self-advocates who report improved physical health, regular engagement with people in the community, and a reduced sense of isolation and loneliness. Individuals have made progress in reducing their need for some medications, increasing their mobility and overall fitness, and reducing health-related crises.

Program success served as an inspiration when Dakota Communities changed its name to Living Well Disability Services, and developed a new mission and vision, in August, 2013. The wellness program results have been shared both locally and nationally. Living Well Disability Services is a founding partner of Altair, an Accountable Care Organization (ACO)-type collaborative with five other Minnesota nonprofit organizations serving people with intellectual and developmental disabilities. Based on program results, the members of Altair have selected the Living Well Disability

Services health and wellness process as a best practice to be replicated across all member agencies.

### **Future Directions for the Program**

Maximizing health for people with disabilities is a key determinant in the level of independence possible and the amount of support needed throughout their lives. In particular, improving overall wellness, including building social supports in the community, improves the likelihood of success for those who wish to increase their independence.

All elements of the health and wellness program are reviewed and renewed each year to incorporate best practices and new learnings. A complete revision of the healthy menu system was introduced in 2015, incorporating changes that streamline meal preparation and reduce cooking time. In addition, all recipes have been evaluated for affordability. Upcoming program additions will include mind/body wellness interventions designed specifically for people with intellectual and developmental disabilities. They'll include activities that target sight, smell, touch, and sound, and promote a greater concept of self, increased environment awareness, and emotional well-being. Data will be collected to evaluate the effectiveness of these interventions on social, emotional, and physical health and wellness.

The Living Well Disability Services approach to wellness will continue to assist individuals with disabilities to express their aspirations, expand their options, develop non-paid relationships, and increase healthy choices in order to live as independently as possible and be engaged in the community.

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*John's commitment to health and wellness is paying off for himself, and for others whose lives he touches.*

### **John's Road to Wellness**

*John had difficulty with his steadiness and walking due to his disability. He began to experience falls. It was at this time that his case manager helped find him a more supported living environment at Living Well Disability Services.*

*When he moved into his Living Well Disability Services home, the Occupational Therapist on staff created a program to help him regain some mobility and move toward the goal of returning to work at the VA Medical Center. John suffered setbacks, needed a walker, and became dependent on oxygen. Early disability retirement was a difficult decision. "I really didn't want to say goodbye. I wanted to be around all of those very nice people. I was very sad that I had to stop," he says. In spite of setbacks, John did not give up on his health. In his words, "This isn't the end!"*

*Through the organization's wellness programming, he began doing exercises in his home and got a membership at the YMCA. The Living Well Disability Services wellness approach is holistic in that it embraces the person's overall well-being, so John also received help setting up a volunteer position with the VA unit where he had worked, allowing him to stay connected with his community. "I continue to work on my strength, stamina and walking," says John. Through self-determination and a personal commitment to health and wellness, John continues to live a fulfilling life and make a difference in the lives of others.*

Contributed by Rich Stoebe, Living Well Disability Services, Eagan, Minnesota

## HealthMatters Kentucky: A Multi-Level Approach to Building Health Promotion Capacity

by Lindsey Catherine Mullis and Kathy Sheppard-Jones

We all recognize that healthy lifestyle choices are beneficial for everyone. However, startling national data show that people with intellectual and developmental disabilities (IDD) are disadvantaged in regards to health and wellness outcomes (National Core Indicators™, 2014). Unfortunately for Kentucky, those disparities are even higher, with over 70% of those on Kentucky's Supports for Community Living Medicaid waiver being overweight or obese, and only 14% engaging in at least 30 minutes of moderate physical activity three days a week. These statistics resulted in a call to action for Kentucky. HealthMatters Kentucky, as a part of larger scale-up initiative, is a health promotion program aimed at improving health and health promotion of people with IDD throughout the state.

A combination of stakeholder engagement, purposeful planning, community input, training, and resource development is resulting in increased opportunities and knowledge that is positively impacting health outcomes for people with IDD in Kentucky. Partners in this collaborative include the Human Development Institute (HDI) at the University of Kentucky, Kentucky's University Center for Excellence in Developmental Disabilities; the Kentucky Division of Developmental and Intellectual Disabilities; provider agencies supporting individuals with IDD around the state; and the Rehabilitation Research and Training Center on Developmental Disabilities and Health (RRTCDD), University of Illinois at Chicago. The power of the collaboration is that it addresses, and helps ameliorate, the disconnect that can occur between academia, state policymakers, and community organizations, harnessing the combined strategies utilized by these entities to enable successful statewide health promotion scale-up efforts.

In December 2010, recommendations were made to the state on the critical need to improve health outcomes for



For participants in HealthMatters Kentucky, exercising with others supports physical and social wellness.

Kentucky. That spring, HDI provided a training opportunity for university staff and faculty, agency providers, state trainers, and students using the evidence-based HealthMatters curriculum developed at RRTCDD (Marks, Sisirak, & Chang, 2013; Marks, Sisiark, & Heller, 2010). This unique training audience started conversations about what could be done, and how various partners could work together. In January 2012, HDI was able to offer mini-grants to 12 organizations that devised projects or plans to incorporate health and wellness into their communities, using their own unique strengths and interests. Some developed community gardens; others offered weekly health programming. The next step was to offer health education that highlighted a model of peer coaching. Nineteen organizations engaged in this program, impacting over 100 people who received their services, while also starting dialogues with staff around health and wellness. In 2013, an amended Supports for Community Living waiver went into effect that included a new focus on health objectives. In the following months, the collaborations and powerful data of successful health promotion programming

provided the fuel to create a new position at HDI for a statewide health and wellness coordinator, with the first objective of implementing a statewide scale-up of the HealthMatters program.

The purpose of this scale-up is to test and describe an innovative framework to ensure sustainable adoption of HealthMatters by local service providers, and to demonstrate how tailored frameworks can be used to scale-up a health promotion program across a network of service providers. In addition, as part of a research study with the RRTCDD the scale-up will not only have a positive impact on health outcomes for people with IDD in Kentucky, but in other states as well through the larger overall reach of the HealthMatters scale-up initiative.

To date there are 15 organizations from all corners of the state taking part in HealthMatters Kentucky. Participants with IDD are in groups that range in size from as small as six to over 50 as several organizations are offering programming for all agency personnel. A part of the HealthMatters Kentucky agreement is that each location develop an onsite wellness committee. This component is critical for sustainability efforts to develop

a culture of healthy behavior change within the organization. The committee is comprised of at least three staff members as well as self-advocates, community leaders, executive administration, and local health professionals. Meetings are held regularly to discuss health and wellness goals along with identification of resources needed to achieve those goals that go above and beyond the scope of the HealthMatters programming.

The role of the health and wellness coordinator is to assist with training efforts for the scale-up and to offer support to the initiative. Helpful resources are routinely made available at the initiative Web site (<http://www.wellness4ky.org>) including supplemental lessons and activity ideas, health messages, success stories, and motivational resources. The biggest challenge has revolved around the idea of adapting exercises or level of programming. The solution has been to support the ground-up approach of always starting at the same level while thinking outside the box and then adapting accordingly to meet individual needs. This applies to individuals with or without disabilities, especially regarding health. For example, one person might want to lose weight as a health goal while another might want to gain strength and independence. Healthy living is unique to each person, and HealthMatters Kentucky supports people in learning what it means to them to be healthy, and how to take the steps to live that healthy lifestyle.

One of the most interesting points to come out of this venture has been the dynamic between staff and participants with IDD. Everyone can benefit from health promotion programming that includes learning how to make healthy choices and be successful in working towards individualized health goals. The most successful programming efforts have been at the locations where the staff are included in the healthy culture change. Some locations have “biggest loser” contests with both staff and participant winners losing over 50 pounds in 12 weeks, while others provide a pedometer daily-steps challenge for the entire organization. Several have created

walking, gardening, or cooking groups that include staff and the local community. It is this component of inclusion and equality in leading a healthy lifestyle that truly makes for remarkable changes.

Examples of expansions at the individual level include the information from the wellness committees based on the HealthMatters programming that is being communicated to case managers and support coordinators. The individual goals are being incorporated into the recommendations made to the support team for individual support plans (plans of care) to support people in pursuing their healthy lifestyle goals.

Kentucky was the first state to start the HealthMatters scale-up and the inspiring successes have prompted other states to follow, including Alaska, Illinois,

and Missouri. There are sure to be more positive health outcomes to come.

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*Matthew reviewing the HealthMessages material.*

### **Coaching Peers to be Healthy: Matthew's Story**

*Matthew Spire is a former HealthMessages peer coach in Kentucky. The Peer to Peer HealthMessages program, developed at the Department of Disability and Human Development, University of Illinois, Chicago, is an evidence-informed program that equips people with intellectual and developmental disabilities to be Healthy Lifestyle Coaches (HLCs). As HLCs, they share the 12-week HealthMessages program with others who have disabilities, encouraging and educating them to exercise, eat right, and lead a healthy lifestyle.*

*Matthew was a HLC during a pilot testing of the program in Kentucky. He taught three classes a day to 10 of his peers. He takes pride in the positive impact he had on 30 people, and beyond.*

*Matthew started his HealthMessages classes with 5-10 minutes of physical warm up, like jumping jacks and other exercises. He did this because he wanted to “make sure the group was awake and ready to learn about health.” His favorite part of the programming was “getting people to eat healthier foods.” His classes went so well that he was invited to give a presentation about them at the University of Kentucky’s Human Development Institute, impressing the crowd with his knowledge and enthusiasm.*

*Matthew currently lives in a staffed residence where he continues to take his HLC role seriously by telling his roommates not to eat too many chips because of the high sodium. He routinely reminds his friends about the high sugar content in soft drinks, and leads by example, saying, “I drink 5-8 glasses of water each day.”*

*Matthew became interested in being a HLC because he knew that he was able to accomplish health goals that his peers had not, and he would be good at helping them be successful. He enjoyed teaching about health, saying “It was a lot of fun!” and that his peers really listened to him. Matthew would love to continue teaching the courses on a regular basis if the opportunity arises. In the meantime, he keeps reminding those around him how to make healthy choices.*

Contributed by Lindsey Mullis, Human Development Institute, University of Kentucky, Lexington

## The Role of Direct Support Professionals in Promoting Health and Wellness

by Meg Traci and Tom Seekins

Direct Support Professionals (DSPs) can, and do, play important roles in maintaining the health and wellness of persons with intellectual and developmental disabilities (IDD). How they fulfill that role is influenced by the commitment of service provider organizations to wellness for both those they support and those they employ. This article looks at specific ways that wellness for persons with IDD, and wellness for DSPs, are connected and can be supported.

### How DSPs Can Support Others' Wellness

DSPs can assist individuals with IDD to stay on track in following established routines that support health and wellness. They can help prioritize healthy activities over less healthy activities, especially when stressors disrupt routines (e.g., if dinner is running late, the

*These kinds of initiatives could facilitate DSP fulfillment of wellness roles and responsibilities for others, as well as their own well-being.*

walk following dinner can still happen, but perhaps it's a shorter walk). DSPs can assist individuals with IDD to monitor for, and recognize, important changes in their physical, behavioral, and psychological status. When there are concerns, DSPs can help individuals address those concerns. Experienced DSPs know that sudden changes in behavior (e.g., anger, aggression) are often signs of a health problem (e.g., pain, hunger, too little sleep, depression) and should be treated as such. Finally, when healthy

routines get disrupted, DSPs can help individuals reestablish those routines.

Some of the specific ways that DSPs can partner with individuals with IDD to support health or wellness goals and objectives are the following:

- Routinely review expected outcomes of the individual's service plan related to health and wellness, including basic information on short-term goal(s).
- Review possible activities to support short-term goal fulfillment, including who else should be included in the activities and where they'll take place.
- Review options for scheduling or rescheduling activities.
- Assist the individual to plan for, and receive, meaningful rewards or acknowledgments as they achieve milestones in health and wellness goals.
- Assist with the ongoing recording and tracking of health and wellness activity and progress.

### Wellness and DSP Turnover

Some of our early research on DSPs and the health and wellness of persons with IDD showed that turnover of DSPs contributed to increased limitations due to secondary and other health conditions among persons with IDD affected by those staffing changes (Traci, Seekins, & Seninger, 2001). Specifically, individuals with IDD experienced increased limitation due to psychological, social interaction, hygiene, allergy, memory, and balance problems, as well as injuries due to accidents or seizures. These findings were consistent with other research showing that adequate personal assistance services were associated with better health outcomes, such as fewer pressure sores and infections, better fitness, and uninterrupted sleep (Kaye, Chapman, Newcomer & Harrington, 2006; Kay, Harrington, & LaPlante, 2010; LaPlante,

Kay, Kang, & Harrington, 2004; Rimmer & Rowland, 2008; and Nosek, Fuhrer & Potter, 1995). Increasing DSP stability, and the communications and routines they support, is an essential part of sustaining health and wellness of individuals with IDD.

One approach to reducing turnover is to attend to the health and wellness of DSPs by creating a culture of wellness in service provider agencies. In Montana, for example, we have promoted health and wellness resources to DSPs, including models to increase their access to health insurance and better pay, and awareness of public health programs such as the Quit Line, cancer screening programs, and health education classes. Recently, we have begun promoting Worksite Wellness as a comprehensive approach to improve the health and wellness of DSPs because a reduction in absenteeism, and an increase in staff retention, are among the demonstrated outcomes of comprehensive Worksite Wellness programs (U.S. HHS, 2015; Baicker, Cutler & Song, 2010). We see this approach as a possible means for increasing stability in the DSP workforce, thereby improving health and wellness for the individuals they support.

The Montana Worksite Health Promotion Coalition gives employers bronze, silver, and gold awards in recognition of excellence in Worksite Wellness programs at three levels: basic, enhanced, and comprehensive (award criteria and more information is available at <http://mahcp.org/montana-worksite-wellness/>). With our partners, we have begun to ask, "What if service provider organizations that support individuals with IDD were counted among those employers?" Consider, for example, the potential to integrate health and wellness training resources for staff into existing DSP training systems. (For ideas of how this might work, see information on NIOSH's Total Worker Health®,

available at <http://www.cdc.gov/niosh/twh/totalhealth.html>, and the CDC Workplace Health Promotion toolkit, available at <http://www.cdc.gov/workplacehealthpromotion/index.html>). These kinds of initiatives could link service organizations to a community's culture of wellness in ways that would facilitate DSPs' fulfillment of wellness roles and responsibilities for others, as well as their own well-being.

### **The Role of Supervision and Training**

Another component of assisting DSPs to provide stable health and wellness support for individuals with IDD is training and supervision of DSPs.

## ***Designing effective and principled guidance to support DSP performance in these areas is very much the work of our time.***

Within the *National Frontline Supervisor Competencies* (Sedlezky, Reinke, Larson, & Hewitt, 2013) are 16 competencies specifically dedicated to supporting the health and wellness of persons with IDD. In most of the health and wellness competencies, frontline supervisors are to provide guidance to DSPs on their roles and responsibilities related to the following items:

- Individualized risk management in all areas of health and safety (e.g., assist with maintaining assistive technologies such as eye glasses, mobility and communication devices).
- Medication administration (e.g., maintain current training on medication administration).
- Health monitoring, documentation, and response (e.g., support routine use of paper or electronic activity logs for exercise, sleep, food intake, water consumption, etc).

- Infection control (e.g., follow hand-washing and sick leave policy).
- Health communications (e.g., post menus in accessible formats and read food labels, explaining as necessary).
- Patient rights and protection, including end-of-life care (e.g., know and represent organizational policies to health care providers).
- Emergency preparedness and response (e.g., support individuals to participate in fire drills and other emergency exercises).
- Culturally-competent health care for persons with IDD (e.g., support consistent, repeated use of health care provider instructions in plain language and with illustrations as needed).
- Support plans designed to promote wellness (e.g., communicate daily progress on goals and objectives).
- Behavioral and environmental arrangements to increase healthy choices (e.g., help plan and prepare healthy food options; arrange environment to promote sleep hygiene).
- Community-based health promoting activities and social support (e.g., support walks or hikes with friends).

Designing effective and principled guidance to support DSP performance in these areas is very much the work of our time. For instance, the agenda set forth in the Affordable Care Act to improve health care outcomes has increased the readiness of health care practitioners to partner with disability stakeholders on the health of persons with IDD, as well as on clinical-community linkages (to learn more on such linkages see the Agency for Healthcare Quality and Research at <http://www.ahrq.gov/professionals/prevention-chronic-care/improve/community/index.html>). Investments in health care systems to strengthen these linkages are leading to a variety of care management and care coordination resources that may support the competencies of frontline supervisors and their capacity to provide effective and principled guidance to DSPs.

### **Conclusion**

The roles and activities of DSPs have evolved as a complex and core set of supports for self-determination, freedom, and choice within community service systems. Integrating evidence-based, health management and promotion knowledge into effective guidance for DSPs should build on this foundation. In combination with adopting Worksite Wellness programs, these approaches can support persons with IDD to be well, strengthen service provider organizations' capacity to recruit and retain DSPs, and contribute to development of community health and wellness resources.

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## Less is More: Preventing Polypharmacy in Individuals with Intellectual Disabilities

by Christopher Selph and Briana Cosca

Individuals with intellectual disabilities, like the general population, will likely experience a variety of illnesses or conditions during their lives, including chronic conditions. Those with multiple conditions often take multiple medications, and as the number of medications increases, they have an increased risk for drug interactions, side effects, and non-adherence to their treatment regimen (Hovstadius & Petersson, 2012). While multiple medications may be necessary, taking too many medications could result in harm.

### **Polypharmacy and Its Prevention**

The term *polypharmacy* means the use of more medications than is medically necessary. Unnecessary medications may lead to harm without providing additional benefit. Each medication added to a person's regimen has potential side effects and drug interactions, which may lead to more doctor visits.

To lower the risk of polypharmacy, a discussion between the individual with an intellectual disability and their health care providers about the potential risks and benefits of each new medication is important. People with intellectual disabilities have different levels of impairment, and health care providers should deliver individualized patient-centered care. An individual may experience decreased communication, self-care, social skills, use of community services, or self-direction (DiPiro et al., 2014). Because a complete assessment of an individual is crucial before safely adding medications, using best practices in interviewing patients with intellectual disabilities is very important in obtaining accurate information (see AAIDD's *Guidelines for Interviewing People with Disabilities* at <https://aaid.org/docs/default-source/sis-docs/sisguidelinesforinterviewing.pdf>).

While some prescribers may not have time for a complete discussion, a

pharmacist can help an individual with any concerns about new and multiple medications. Pharmacists usually see people regularly, and may see them more frequently than their physician. This rapport allows pharmacists to ask questions about self-care and home life. A pharmacist often has time to ask about side effects in a casual setting when an individual picks up their medication. With access to an individual's full medication list, the pharmacist checks for drug interactions when a medication is added. The availability of a pharmacist allows people to check-in with their concerns, and as a member of the health care community, a pharmacist can direct people to other needed community resources.

Preventing polypharmacy is better than treating it because stopping a medication can be difficult. Pharmacists have a key role in this prevention. Individuals with intellectual disabilities and caregivers also play an active role by discussing the person's medication profile with their physician periodically. This allows the doctor and patient to verify all the medications are still needed.

### **Medications for Mental Illnesses**

Individuals with intellectual disabilities experience certain mental illnesses at equal or greater rates than the general population (National Down Syndrome Society, 2012; Center for Autism and Related Disabilities, 2015; Scott & Havercamp, 2014). Common problems include conditions such as anxiety, behavioral issues, and depression. Classes of medications commonly prescribed for mental illnesses include antidepressants, antipsychotics, and benzodiazepines. These medications are effective, but also have side effects (see Table 1). Some side effects disappear with continued use, but others persist or worsen with long-term

treatment. Taking multiple medications increases the risk of side effects. Individuals may have even more profound reactions when taking several medications because many have similar side effects. Also, medications may interact, leading to altered drug concentrations in the body. Lower drug concentrations can decrease a medicine's effectiveness, while higher concentrations may cause adverse reactions or toxic effects.

### **Medications for Neurological Disorders**

Individuals with intellectual disabilities can also develop neurological disorders, such as Alzheimer's disease, other dementia, epilepsy or other seizure disorders. Several classes of medications are used for various neurological disorders, for example cholinesterase inhibitors for Alzheimer's disease and anticonvulsant medications for epilepsy. As with medications for mental illnesses, medications for neurological disorders may also cause side effects (see Table 1).

Alzheimer's disease and dementia treatments can only slow the progression of the disease. While side effects from cholinesterase inhibitors usually resolve after three weeks of treatment (DiPiro et al., 2014), new medications may be needed as the disease worsens. The addition of new medications may increase side effects or result in drug interactions. When new medications are added, individuals should be monitored for adverse effects as well as for changes in medication effectiveness.

Anticonvulsant medications not only have a variety of side effects (see Table 1), but sometimes require additional laboratory testing. The blood concentrations of many anticonvulsant medications are periodically measured to insure that the medication dose is appropriate for the individual. If the anticonvulsant medication's concentration is too high, it

may have toxic effects. If the concentration is too low, the anticonvulsant medication may not work and seizures could occur. Side effects from anticonvulsant medications may occur even if the blood concentration of the medication is in the correct range. If side effects occur, the dose may need to be changed or the medication may need to be switched to another medicine. Some individuals will require more than one anticonvulsant medication or higher doses to control seizures. Each of these cases may increase the person's risk for side effects or drug interactions.

### Minimizing Side Effects

If a medication is the likely cause of a side effect, the health care provider and their patient should discuss other options for treatment. Sometimes side effects can be minimized. For example, some medications cause sedation; these can be taken before bedtime as a way to minimize problems from that side effect. Other medications cause insomnia and these should be taken early in the person's day. If a person feels nauseous after taking a medication, they may be able to take future doses with food. Constipation and diarrhea are problems that may

warrant switching medications if they limit a person's day-to-day activities. Individuals with constipation may need to increase fiber intake, try a laxative, or switch medications. Some medications cause profound weight gain. Individuals should monitor their weight often when starting these medications, so they can know if weight gain occurs. They may need to adjust diet and activity level, but to prevent excessive weight gain a medication change may be necessary.

While these basic solutions may decrease side effects, individuals should visit their health care provider if the side effects persist. The physician may switch medications, change medication doses, or provide education on non-pharmacological methods to lower side effects.

**Table 1: Commonly Used Medications and Their Side Effects**

#### Medications Causing Sedation (DiPiro et al., 2014)

- **Tricyclic Antidepressants:** All medications in this class
- **Other Antidepressants:** Trazodone, Remeron (mirtazapine)
- **Antipsychotics:** Thorazine (chlorpromazine), Mellaril (thioridazine), Clozaril (clozapine), Zyprexa (olanzapine), Seroquel (quetiapine), Risperdal (risperidone), Geodon (ziprasidone)
- **Anticonvulsants:** Tegretol (carbamazepine), Ethosuximide, Keppra (levetiracetam), Trileptol (oxcarbazepine), Phenobarbital, Dilantin (phenytoin), Depakene (valproic acid)
- **Benzodiazepines:** All medications in this class

#### Medications Causing Insomnia (DiPiro et al., 2014)

- **Antidepressants:** Wellbutrin (bupropion), Zoloft (sertraline), Prozac (fluoxetine), Paxil (paroxetine), Effexor (venlafaxine)
- **Alzheimer's/dementia medications:** Cholinesterase inhibitors (all medications in this class)

#### Medications Causing Nausea (DiPiro et al., 2014)

- **Anticonvulsants:** Tegretol (carbamazepine), Ethosuximide, Vimpat (lacosamide), Trileptol (oxcarbazepine)
- **Alzheimer's/dementia medications:** Cholinesterase inhibitors (all medications in this class)

#### Medications Causing Constipation (DiPiro et al., 2014)

- **Antipsychotics:** Clozaril (clozapine), Zyprexa (olanzapine), Mellaril (thioridazine), Thorazine (chlorpromazine)
- **Alzheimer's/dementia medications:** Namenda (memantine)

#### Medications Causing Diarrhea (DiPiro et al., 2014)

- **SSRI Antidepressants:** Zoloft (sertraline), Paxil (paroxetine)
- **Alzheimer's/dementia medications:** Cholinesterase inhibitors (all medications in this class)

#### Medications Causing Weight Gain (Bray & Ryan, 2012)

- **Tricyclic Antidepressants:** Nortriptyline, Amitriptyline, Doxepin
- **SSRI Antidepressants:** Paxil (paroxetine), Lexapro (escitalopram)
- **Other Antidepressants:** Remeron (mirtazapine)
- **Antipsychotics or Mood Stabilizers:** Lithium, Zyprexa (olanzapine), Clozaril (clozapine), Risperdal (risperidone)
- **Anticonvulsants:** Tegretol (carbamazepine), Depakene (valproic acid), Depakote (divalproex)

### Conclusion

Polypharmacy can occur in all populations, not just in individuals with intellectual disabilities. However, people with multiple medical conditions often take multiple medications, which increases the risk of side effects and drug interactions. Communication between health care providers, caregivers, and the individual will help identify problems early and prevent polypharmacy.

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## Aging and End of Life: Helping the Spiritual Tasks of People with Disabilities Come Alive

by Bill Gaventa

Dealing with aging, death, grief, and end-of-life issues with people with intellectual disabilities is a growing challenge in services and supports. It is a challenge brought on, in some ways, by success in terms of effective health supports in that people with intellectual disabilities are living longer into old age. But the challenges are many:

- Dealing with decline and death seems like the antithesis to the values of growth and development, such as independence, productivity, inclusion and self-determination, that are at the core of so many services and supports.

*Dealing with decline and death seems like the antithesis to the values of growth and development, such as independence, productivity, inclusion, and self-determination.*

- Loss of ability and decline to death may seem to staff and caregivers like a “double injustice,” adding the “Why?” of death to the “Why” of disability in the first place. For younger staff without personal life experience with death and loss, this can be even harder; and for all staff and carers, it may feel like “failure” in their responsibility. That can be compounded in systems where normal deaths get investigated as if they were a “critical incident” or evidence of abuse or neglect.
- As in any relational system, intense feelings about responsibility and care can be part of the mix between people with disabilities, their friends, families or relatives, and professional caregivers.

- Until recently, there has been little attention to the ways that people with intellectual disabilities experience and process grief and loss, a paradox given the amount of loss that they have to deal with in so many areas of their life, including staff and caregiver turnover. People worry about their capacity “to understand,” yet rather than taking more time and attention to help that happen, the pressure is to move on quickly. There is pressure in agencies to fill the empty beds, to get back to the programs and plans, rather than recognizing the power of relationships.

Those same challenges can present opportunities to do the following:

- Re-vision the end of life not as decline but as journey, and to give people as much choice and control as possible in the final stages of life.
- Focus on the importance of relationships, and remember connections to the past, present, and future relationships. “Remember” is about connections with important relationships, and “re-remembering” can be about helping people get connected again to relationships and communities of which they have been members.
- Build new communities of caregiving and meaning around a person in the latter stages of life.
- Pay attention to the importance of spirituality in people’s lives, what is most important to them, the cultural and religious rituals that are part of old age and death, and the opportunities to participate in and practice spiritual connections.
- Re-vision the core values of independence, moving from “Who am I?” to “Who have I been?”; of productivity, moving from “Why am I” to “What difference have I made with my life?”; and of inclusion, moving from

“Whose am I?” to “Whose have I been? Who will remember me, and how will I be remembered?”.

In a resource manual called, *The Challenges of Aging: Retrieving Spiritual Traditions in the Long-Term Care of the Elderly*, the Park Ridge Center in Chicago identified five tasks of aging common to all major spiritual traditions (Park Ridge Center, 1999):

- Reaffirm covenant obligations to community.
- Blessing...how have you been a blessing and given your blessing?
- Honor, respect and appreciation for aging and the elder.
- Maintaining and growing faith in face of loss.
- Reconciliation of discordant experiences (e.g., letting go, reunion, forgiving).

As we think about adapting those tasks to and with adults with intellectual disabilities, the remainder of this article outlines some ways we might do so.

### **Reaffirming Covenant Obligations to Community**

Of what communities has someone been a part? What has been important to them about those communities? What might they want to do in those communities? So, for example, would people like to revisit places they have lived in their lives? Would they find it meaningful to make a photo album of places and people that have been important to them? Would they like to volunteer somewhere? If they have never had the chance to join a desired faith community, could this now happen? For example, there are powerful stories in the state where I live, New Jersey, of people with intellectual disabilities being able to have the bar or bat mitzvah

they never had, or having the chance to be confirmed or baptized. Those relationships also need to be built to avoid the crisis of “who to call?” when someone in residential services is suddenly hospitalized with life-threatening illnesses or dies. Clergy and spiritual communities can respond, but that response is so much better if a person is known to a given faith community.

### ***Giving and Receiving Blessing***

Service providers have gotten better at identifying the key strengths and gifts of individuals with intellectual disabilities as well as their needs or deficits. This is a time to focus on those gifts and

*Can we help people participate in rituals of loss and mourning, or develop new rituals in service systems where grief and loss have often been unacknowledged and unrecognized?*

strengths. How can we celebrate and honor them for those gifts? Could they give them to others, such as by writing or telling their life stories to younger professionals or others? Could we help individuals think about what they want others to have when they die (i.e., make a will, and think about who would like valued possessions as a keepsake, something to remember them by)? One chaplain at a small residential facility started a practice of identifying key strengths in each person, and then developing a “Certificate of Appreciation” for that person and their gifts that was presented to each individual and their family at the annual plan review. Not only did those certificates start ending up in frames

and on their walls, but they changed the ways that others saw the people with whom they worked.

### ***Restoring Honor to Aging***

Many cultures see the elderly as those to be honored, in stark contrast to some modern culture that sees aging as curse. As people with intellectual disabilities age, how might professionals and caregivers honor them? We could ask for their blessing, in a variety of ways. We can help turn records and charts into life stories. One agency is doing just that with Power Point presentations and scrapbooks that are turning a team of consumers into speakers and presenters at workshops. We can re-vision “consumers” as “survivors and veterans” of endlessly changing service systems, and honor them as we would any veterans. We can also do so by restoring mutuality to the relationship between professional and “client” by finding ways to tell and thank them for what “they” have meant to us, and how they have helped us. Professionals all know people with intellectual disabilities who touch deep parts of their own lives and values, and have provided part of their own sense of calling and vocation. We need to share that appreciation with others as they age, as we would with other elders who have been our teachers or mentors.

### ***Maintaining Faith in the Face of Loss***

How do we help people prepare for and deal with the losses they have – losses of relationships and losses of their own health or vitality? Can we help people participate in rituals of loss and mourning, or develop new ones in service systems where grief and loss have often been unacknowledged and unrecognized? Many elderly people get more involved with religious communities. Can we help that happen, and build supports that will be there at the end of life? And, can we find new and creative ways to help people express their own grief and develop their own form of understanding;

for example, the book *Am I Going to Die?* in the *Books Beyond Words* series ([www.rcpsych.ac.uk/bbw](http://www.rcpsych.ac.uk/bbw)) is one creative way to help people understand both facts and feelings, loss and mourning.

### ***Reconciliation***

Are there old relationships that need to be renewed as people get older? Or connections with families, old friends, or former staff that need to be “re-membered?” For the rest of us, “reunions” become more important in old age. Can we work with people with intellectual disabilities to see if there are people they want to see, or need to see? Many old institutions where people lived were terrible places and times; so is war. But people who have survived and gone their separate ways to better lives often choose and seek the opportunity to have reunions, or to revisit those places and relationships that shaped their lives.

### ***Summary***

Support and service agencies, families and other caregivers, and individuals can develop their own creative ways to address these tasks of aging and end-of-life planning with people who have intellectual disabilities. The challenges can indeed become opportunities.

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## Resources on Wellness and Individuals with Intellectual, Developmental, and Other Disabilities

The following resources from around the country may be of interest to *Impact* readers.

- **National Center on Health, Physical Activity and Disability (<http://www.nchpad.org/>).** NCHPAD seeks to help people with disability and other chronic health conditions increase participation in all types of physical and social activities, including fitness and aquatic activities, recreational and sports programs, adaptive equipment usage, and more. Its Web site features extensive resources and services for individuals with disabilities, fitness and health professionals, care providers, and others. Among the online resources are how-to videos on inclusive and adapted exercise; fact sheets describing physical activity, exercise, and health considerations for individuals with specific disabilities and chronic conditions; and resources for fitness centers to use in assessing and correcting barriers to participation by people with disabilities.
- **Retaining Employees in Your Worksite Wellness Program.** This free guide for employers discusses the importance of attending to health and wellness for all employees, including employees with disabilities. It offers guidance in providing the right program accommodations and incentives to increase enrollment by employees with disabilities, improving employees' health and the company's bottom line. Published by the U.S. Office of Disability Employment Policy and available at <http://www.dol.gov/odep/research/WellnessToolkit.pdf>.
- **Inclusive Fitness Coalition (<http://incfit.org>).** The Inclusive Fitness Coalition is a group of organizations and individuals representing a cross-section of the disability rights, sports, health/fitness and civil rights communities. It works to

create a unified effort to increase access to and participation in physical activity for youth, adults and seniors with physical, cognitive, and sensory disabilities. Its Web site includes resources for fitness organizations and professionals on topics including improving fitness center accessibility and how to become a Certified Inclusive Fitness Trainer, as well as information on coalition membership for organizations and individuals.

- **HealthMatters™ Program (<http://healthmattersprogram.org>).** This program, based at the RRTC on Developmental Disabilities and Health (<http://rrtcadd.org>), University of Illinois at Chicago, is a partnership with community organizations nationwide that aims to improve the health of people with developmental disabilities. Its goals are to develop and share tools for health promotion research, service learning, and training; support health promotion program development, implementation, and evaluation; and disseminate and integrate evidence-based health promotion services for people with developmental disabilities. Among the resources on its Web site are manuals for the evidence-based HealthMatters™ curriculum, online training opportunities, and community partner profiles.
- **Impact: Feature Issue on Sexuality and People with Intellectual, Developmental and Other Disabilities.** This issue of *Impact* explores the question, "What does it mean to affirm and support a positive, healthy sexuality for individuals with disabilities?" Its articles cover topics ranging from sexuality education in the home and school, to personal stories of dating and marriage, to legal and ethical issues for staff and agencies providing services for people with disabilities. The goal of this issue is to provide information and inspiration that further support the right and opportunity for people

with intellectual, developmental, and other disabilities to understand and express this essential dimension of human life. Published by the Institute on Community Integration, University of Minnesota, and available at <https://ici.umn.edu/products/impact/232/232.pdf> or in a text-only version at <https://ici.umn.edu/products/impact/232/default.html>.

- **American Association on Health and Disability: Health Promotion Resource Center for People with Disabilities (<http://www.aahd.us/resource-center/>).** The Health Promotion Resource Center provides visitors with information about multiple aspects of health promotion and wellness for people with disabilities. It includes abstracts of published research on topics related to disability and health, resources on best practice, fact sheets and Power Points on a range of topics related to health and disability, health and disability state resources, disparities data, and a link to the *Disability and Health Journal*.
- **Mental Health for People with Intellectual Disability: The Impact of Stress and Social Support.** By Haleigh M. Scott and Susan M. Havercamp. The authors of this journal article utilized data from the National Core Indicators to examine the impact of stress and social support on the mental health of adults with intellectual disability. Correlations were found between stress and mental illness, and between lack of social support and mental illness. The importance of considering these factors in the prevention, diagnosis, and treatment of mental health among people with intellectual disabilities is discussed. Published in the *American Journal on Intellectual and Developmental Disabilities* (Vol. 119, No. 6, 552-564) and available at <http://aaidjournals.org/doi/pdf/10.1352/1944-7558-119.6.552>.

- **Removing Barriers to Health Clubs and Fitness Facilities: A Guide for Accommodating All Members, Including People with Disabilities and Older Adults.** This guide provides strategies for making a health club's facility and services more accessible to people with disabilities and older adults. Illustrations demonstrate how barriers in the physical environment can be removed and how exercise equipment and programs can be designed to create a welcoming facility. Topics include how to market fitness programs in an accessible manner, incorporating universal design into the facility, recommendations for assisting people with disabilities, and guidelines for selecting equipment. Developed by the North Carolina Office on Disability and Health

and The Center for Universal Design. Available at [http://fpg.unc.edu/sites/fpg.unc.edu/files/resources/other-resources/NCODH\\_RemovingBarriersToHealthClubs.pdf](http://fpg.unc.edu/sites/fpg.unc.edu/files/resources/other-resources/NCODH_RemovingBarriersToHealthClubs.pdf).

- **Supporting the Expression of Spirituality for Persons with Intellectual Disabilities.** This free guide published by the Volunteers of America can be used to identify whether or not spirituality and/or congregational involvement are considered a valued outcome for an individual with an intellectual disability and, if so, how services and supports might be directed toward helping them attain this outcome. Available at <http://faithanddisability.org/wp-content/uploads/2015/02/RESOURCE-GUIDE.pdf>.

- **My Health Passport for Hospital/Clinic Visits ([http://flfcic.fmhi.usf.edu/docs/FCIC\\_Health\\_Passport\\_Form\\_Typeable\\_English.pdf](http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_English.pdf)).** Published by the Florida Center for Inclusive Communities, this is a document that individuals with disabilities can fill out and take with them to the clinic or hospital. It tells health care professionals important information about the individual, such as how they communicate; how they express pain and distress; mobility needs; how to best assist them with personal care; sensitivities to noise, light, food; and medical history.

[Heyne & Anderson, continued from page 12]

from environmental supports, a participant could increase self-awareness and calmness by participating in a community Yoga or meditation class.

- **Cognitive.** Cognitive strengths are those that help us think and learn. Someone who experiences cognitive well-being would be able to think in a focused way and learn eagerly. Applying the model, a participant who wishes to enhance memory could go to a crafts store and purchase materials to create a reminiscence scrapbook or go to the library to find music that triggers pleasant memories of past experiences.
- **Social.** Social strengths are those that help us relate to others and belong to valued social groups. Leisure provides a natural setting for the development of social connections and community inclusion. For example, a participant who wishes to build interpersonal skills and make friends could take part in a neighborhood social club built around a common interest (e.g., reading, hiking, dancing) or join a local community center.

- **Physical.** Physical strengths are those that help the participant “act” and “do” in their daily life with no barriers. Physical activity has been shown to be one of the more effective contributors to happiness and well-being (e.g., to elevate mood, reduce stress, improve cardiovascular health). A participant who wishes to gain physical fitness could join a fitness club or be matched with a walking or workout buddy.
- **Spiritual.** Spirituality is defined as having strong and coherent beliefs about the higher purpose and meaning of life (Seligman, 2002). As an example in this area, a person who wishes to cultivate hope and a sense of connectedness could spend time in a nature or a wilderness area, find a faith community, or develop a regular Yoga or meditation practice.

### Conclusion

This article presents a model for how leisure can positively impact a person's well-being across several dimensions.

When optimally facilitated within the person and their environment, an enjoyable leisure experience has the power to motivate a participant toward personal well-being, fulfilling leisure, community engagement, and a flourishing life.

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[Besse, continued from page 1]

### **Characteristics of Quality Wellness Programs**

How do you know if a program is a quality wellness program for people with intellectual and developmental disabilities? Several sets of guidelines for inclusive community wellness programs have been created. The following list draws upon those published by The Expert Panel on Disability and Health Promotion Interventions (Drum et al., 2009) and the Center on Disability at the Public Health Institute (Kraus & Jans, 2014):

- 1) **Programs should be accessible.** Accessibility of the physical space and any equipment is important. Programs that include equipment should include universal design features so that all individuals, including those using wheelchairs, can utilize the equipment. In addition, programs should be socially and programatically accessible, and accessible in communication for people with intellectual disabilities and limitations in hearing or vision. Wellness program staff should be welcoming, respectful, and inclusive, and programs should allow for accommodations.
- 2) **Programs should be flexible to fit the needs of the individual.** Under the Americans with Disabilities Act, you have the right to reasonable accommodations to meet essential eligibility requirements for participation. Program accommodations should be tailored to specific needs of the individual. Quality programs will welcome input and be proactive in response.
- 3) **Programs should provide and/or allow for supports that are appropriate to the individual participant.** Support is a vital part of maintaining healthy behaviors, which is not unique to people with disabilities! Quality programs will allow for and welcome supports needed for an individual to participate fully. Participate in a program with a family member or friend, bring support staff, or look for programs that offer personal

trainers, health coaches, mentors, or other individuals who could support participation and help individuals overcome barriers.

- 4) **Programs should be inclusive and welcoming to all participants.** All programs should seek to be inclusive, rather than creating separate or segregated programs specifically for people with disabilities. Programs should be welcoming of all people, and program staff should receive training to increase knowledge and skills related to supporting participation of individuals with disabilities.
- 5) **Programs should allow for choice by the individual participating.** Participating in wellness should enhance and support self-determination. It is important that an individual choose to participate in activities that are enjoyable! Support and encouragement – not prescription – help individuals make healthy choices.
- 6) **Programs should be affordable to people with disabilities and their families or caregivers.** To increase affordability, advocate for the program or facility to let support staff enter without a fee. Inquire about scholarships or reduced fees at your Y, public recreation facility or other program in which you participate.
- 7) **Programs should expressly commit to including people with disabilities as a cornerstone of their organizational mission.** Ideal programs clearly state inclusion of all people, including people with disabilities, in their program mission or objectives. They involve people with diverse abilities and disabilities in their planning, seek out people with disabilities through their marketing, and engage in outreach and communication that includes people with disabilities.

There are wellness programs that seek inclusion by design, especially related to sports and recreation. You may be interested in looking for organizations such as these in your community. They include Special Olympics

Unified Sports and inclusive outdoor recreation programs. A growing number of organizations seek to be inclusive of people of all abilities in their “fun run” fundraising events by putting on accessible run, walk, and roll events. Some company human resources groups are also seeking greater accessibility with wellness activities, such as lunchtime run, walk, and roll clubs. These activities still may not be fully accessible for all

*While seeking quality, inclusive programs and positive supports for participation, remember that wellness should not be found only as part of a “program.”*

people with intellectual and developmental disability, so even if you find welcoming and inclusive wellness opportunities, communication and advocacy regarding your needs is always important.

### **Advocating for More Inclusive Programs**

In reality, participating in wellness activities in the community can be quite difficult. Most individuals have probably encountered multiple barriers, including accessibility problems, wellness professionals who lack training or have misinformed attitudes about people with disabilities, emphasis on segregated activities for people with disabilities, high costs, transportation issues, and lack of adequate supports. There are multiple sources of these barriers. Some of these barriers come from the programs themselves. Quality, inclusive wellness activities that welcome people with intellectual and developmental disabilities are difficult to find in many communities. Wellness and recreation providers may have a number of fears; they may be concerned about liability, worried about individuals with disabilities participating

and having bad experiences, or reticent to open the door to accommodations they fear will be expensive or beyond their expertise.

Coming up against barriers to wellness participation in the community can be frustrating, but know that you can advocate for inclusion. Here are some tips to get you started:

- 1) **Know the law.** The Americans with Disabilities Act guarantees you the right to participate, the right to participate in the most integrated setting, the right to reasonable accommodations, the right to use adaptive equipment, and the right to not be discriminated against due to safety concerns without an assessment.
- 2) **Advocate for change.** Assert yourself, ask for what you want, and follow up to make sure change happens.
- 3) **Be positive.** Although *sometimes* it is true that wellness program staff want to limit participation by people with disabilities because they are fearful or have negative attitudes about people with disabilities, in many cases they may just lack experience or information. Be willing to provide that experience and information! Even if a program is not initially ideal, being there and participating can be a first step in changing attitudes and opening the door for further participation and accommodation.
- 4) **Be prepared with resources.** There are a number of resources on wellness participation for people with disabilities, including the American Association on Health and Disability (<http://www.aahd.us/resource-center>) and the National Center on Health, Physical Activity and Disability (NCHPAD) (<http://www.nchpad.org>).

### **Advocating for Increased Supports**

People with disabilities also frequently encounter difficulty using existing programs and activities because of barriers from support services. These barriers are generally unintended, but can still hinder participation in wellness,

especially inclusive wellness programs in the community. Service or support providers may be limited by resources, including staffing resources. Limited resources may limit transportation or individualized supports provided to clients with disabilities who want to participate in wellness in the community when other individuals want to stay home or do non-wellness activities. Service providers may feel limited by rules governing benefit programs and the types of supports that are eligible for reimbursement.

Therefore, individuals with disabilities and their families may also find themselves advocating for supports from service providers to access inclusive wellness programs in the community. These are some tips for increasing supports:

- 1) **Keep wellness in mind when seeking out supports.** Choose service providers who are enthused about wellness and interested in providing supports related to wellness.
- 2) **Incorporate wellness in planning.** If wellness is important to you, make sure to include this in goals set during person-centered planning and individual support plan meetings. Advocate for inclusive wellness as an important aspect of participation in the community.
- 3) **Ask service provider organizations to make changes.** There may be small, doable policy changes that organizations can put in place to support wellness. For example, ask whether performance of support staff is evaluated in part on whether they support health and wellness goals of individuals for which they provide services. If not, ask whether they would make that change.

### **Creative Options for Wellness Participation**

Be creative! While seeking out quality, inclusive programs and positive supports for participation, also remember that wellness should not be found only as part of a “program.” Inclusive wellness

opportunities can emerge from other aspects of life, and maintaining health is easier when it is integrated into your lifestyle. I have a sister who has a developmental disability, and wellness has always been an important part of her life. Despite a number of different employment positions throughout her adult years, she has maintained part-time work or volunteer opportunities at

*Identify quality, advocate for inclusion, plan for supports, and work to incorporate wellness into your lifestyle.*

her local YMCA. These jobs have been an important way for her to work in the community, but they have also provided wellness opportunities. She can go to work early or stay late and walk on the track or take in a Zumba class. As an employee, using the facilities is free. She has developed friendships with other employees and “regulars” at the Y, so even if she chooses to walk on the track alone, she sees people she knows, making workouts social opportunities.

Identify quality, advocate for inclusion, plan for supports, and work to incorporate wellness into your lifestyle. Have fun and be well!

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## ***In This Issue...***

- **Advocating for Quality, Inclusive Wellness Opportunities in Our Communities**
- **From Wellness to Flourishing for People with Intellectual and Developmental Disabilities**
- **SELECT a Lifetime of Physical Activity**
- **Workplace Wellness Programs and People with Disabilities: A Summary of Current Laws**
- **The Flourishing Through Leisure Model**
- **Flourishing and Spirituality: Healing and Wholeness Without Perfection**
- **Friendship Matters! Improving Health and Well-Being by Supporting Relationships**
- **Including Wellness in Individual Service Plans**
- **The Role of Direct Support Professionals in Promoting Health and Wellness**
- **Preventing Polypharmacy in Individuals with Intellectual Disabilities**
- **Aging and End of Life**
- **Profiles from Kentucky, Montana, Minnesota**
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## **Impact**

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