KEPRO
INTELLIGENT VALUE

HCQU CARES

Spring 2018 Edition

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Introduction

By Carrie Perrell, Clinical Educator

The need to belong is a powerful and important need all people share. Psychologist Abraham Maslow believed it to be so important that he listed it at the third level of his "Hierarchy of Needs" (Maslow, 1943), preceded only by physical needs and the need for safety. One way to satisfy this need to belong is through community participation. Being an active member of one's community and fostering relationships with others is a part of living an *Everyday Life*.

Because the need to belong is vital to every person's wellbeing, Pennsylvania's Office of Developmental Programs (ODP) implemented its ***Community Participation Support Initiative*** to support individuals with intellectual and developmental disabilities (I/DD) to become active members of the communities in which they live. As part of this initiative, individuals with I/DD who attend a service location three or more days per week will spend 25 percent of that time in the community (PA DHS, 2017). Service providers must fully implement this requirement by September 2018.

This edition of *HCQU Cares* offers information and tools to assist caregivers to enable and encourage individuals with I/DD to become more active in and interconnected with their communities – to feel they *belong*.

References:

ASCD. (September, 2010). Well-Balanced Teacher. Retrieved from http://www.ascd.org/publications/books/111004/chapters/Belonging@-Becoming-an-Important-Part-of-a-Community.aspx

Simply Psychology (2017). Maslow's Hierarchy of Needs. Retrieved from http://www.ascd.org/publications/books/111004/chapters/Belonging@-Becoming-an-Important-Part-of-a-Community.aspx

Pennsylvania Department of Human Services (2017, March 2). Community Participation Supports. Retrieved from: http://dhs.pa.gov/cs/groups/webcontent/documents/document/c_259195.pdf

Helping Individuals with Intellectual and Developmental Disabilities (I/DD)
FIND MEANING AND JOY IN
COMMUNITY PARTICIPATION

"Being involved in community life creates opportunities for new experiences and interests, the potential to develop friendships, and the ability to make a contribution to the community. An independent life, where people with and without disabilities are connected, enriches all of our lives."

Everyday Lives: Values in Action, 2016

By Erin Sass, Clinical Educator

Community participation is a part of an "everyday life" – a life in which a person can experience meaning and joy. People often find meaning and joy when they feel they belong and are connected with others. Supporting people with I/DD to live an "everyday life" enables them to experience the meaning and joy that every person desires, including active participation with others in the communities to which they belong.

Beginning in September 2018, prevocational, day habilitation, and adult (and older adult) training facilities must offer community activities during no less than 25 percent of the person's time spent in that program. According to the ODP, the purpose of community participation is to broaden the variety of opportunities for life-long learning experiences available to individuals receiving I/DD services. It is intended to increase the potential for employment, sustainable and valued relationships, independence, and meaningful inclusion in the community (Community Participation Supports, 2017).

To be meaningful, community participation might require special planning and coordination, taking into account the person's specific needs, wants, and abilities. A person who feels anxious or scared around groups of strangers probably will not obtain joy and meaning by going to concerts or amusement parks. Visiting local gardens or visiting with people in a nursing home may be better activities for that person.

Employment can be another form of meaningful participation in one's community. A job in the community provides income, offers opportunities to build skills and meet people, and increases a person's sense of pride and self-confidence. In return, employment enables a person to contribute back to the community through production of goods or services and payment of income taxes.

The following questions can help caregivers identify and plan community participation activities that are relevant to a person's individual preferences and experiences – activities that are meaningful to that person.

Personal Interests

- In what topics or activities does this person express interest? What are this person's dreams? (They do not have to be realistic or practical.)

Personal Preferences

- With what type of people does this person like to spend time? Where does the person enjoy going?

Skills and Strengths

- What does the person enjoy doing? At what does the person excel? What skills would the person like to obtain or improve? What does he or she hope to achieve?

Communication Skills and Language Preferences

- How does this person prefer and feel most comfortable communicating – using words, signs and gestures, a computer, or pictures? How will his or her communication needs and preferences be met?

Need for Choice and Freedom, in all Aspects

- Does the person feel that his or her choices and rights are honored and valued? Does the person have confidence and trust that the caregiver respects the person's right to manage his or her own life?

Self-Direction

- Does the person have adequate information, assistance (as needed), and opportunities to make choices?

Employment

- Does the person want to be employed in the community? What type of jobs are suitable to his or her interests, skills, and abilities?

Health, Wellness, and Safety

- Does the person have the tools and supports necessary for health and safety, including information about nutrition, exercise, boundaries, and self-protection? Is that information presented in a manner he or she can understand?

Complex Needs

- What types of sensory input needs does the person have, i.e., a quiet, dimly-lit environment or a setting in which the person can be mobile? Do such needs change regularly? Does this person have any complex needs, physical or behavioral, that might interfere with his or her ability to participate in a community activity?

Support

- How will the person's needs be supported in the community? How will this person's needs and wants be respected, valued, and honored?

Support for Caregivers/Family Members

- What support do caregivers and family members need as they encourage and assist people with I/DD to fulfill an "everyday life" – resources, trainings, tools, etc.?

It is important for caregivers to take time with each individual – really get to know the person and his or her specific needs, interests, desires, hopes and dreams – and then provide effective support that helps each of them find meaning and joy in their community and benefit from living an "everyday life".

References:
Everyday Lives: Values in Action, 2016, Pennsylvania Department of Human Services, Office of Developmental Programs
Community Participation Supports, Provider Meeting, April 2017

Supporting People Who Feel
Anxious in the Community

By Elizabeth Hobbs, Clinical Educator

Have you ever experienced the feeling of butterflies in your stomach before a test? This was likely due to anxiety. Anxiety is a normal part of the human experience; it can help a person to prepare for what is to come, or to become more cautious (Medline Plus, n.d.). For some people, however, the feeling can get so intense that it disrupts their ability to function in their daily lives (APA, 2017).

An increase in anxiety symptoms when a person is in the community does not mean the person does not want or is not able to participate in the community. With effective support, the person can improve his or her experience during community activities. Techniques are available to assist caregivers to support people who have this type of anxiety.

Preparation

Regardless of one's needs, it is helpful to be proactive and prepare for going into the community. When going on a "trip", most people prefer having a plan – a "roadmap" – that tells them when they will be leaving, where they will be going, what they will be doing, and when they will return home. Caregivers are often responsible for planning the what, when, where, and how for the time an individual with I/DD spends in the community.

Strategies to support an individual with anxiety prior to going into the community

- Share the "roadmap" with the individual, explaining what will happen, where it will happen, how it will happen, who will be there, how long it is expected to take, and at what time he or she can expect to return home. It might be helpful to assure the person that the exact time of returning home might change, but he or she will return home.
- After explaining each step of the plan, allow the individual approximately 20 seconds to process what was said and how he or she feels about it; resist the urge to fill the silence. Afterward, use questions that require more than a "yes/no" response to determine if the individual understands the information that was shared.
- Use pictures to create a schedule to help the person visualize the order in which each step of the "roadmap" will occur and at which step other people might participate. Consider using a portable version, such as one on a mobile device or a collection of printed pictures.
- Use a rehearsal guide, or similar tool*, to guide the person through what can be expected in the specific situation. The rehearsal guide format, developed by the KEPRO HCQU, uses realistic pictures; concrete ideas; clear, brief instructions; helpful suggestions for caregivers to follow to make the experience meaningful for the person and increase the likelihood of a successful outcome. Rehearsal guides offered by the KEPRO HCQU focus on situations related to medical needs, such as doctor appointments, hospitalizations, and medical procedures. They help the individual become familiar with the situation by learning what to expect at each step. A rehearsal guide can be used to prepare for and during the situation to assist the individual to complete each step successfully. Rehearsal guides are available for viewing and downloading in the "HCQU Informational Resources" drop-down list on the "Other Resources" page of the KEPRO HCQU website (https://hcqu.kepro.com/content/pages/otherresource.aspx).

*A similar tool is a Social Story™, which consists of a series of pictures or a brief written story that tells a person what he or she can expect in a certain situation and, in return, what is expected of him or her. A Social Story™ describes a situation, skill, or concept in terms of relevant social cues, perspectives, and common responses in a specifically defined style and format (Carol Gray Center, n.d.).

Ultimately, knowing the people you support is important when preparing for participation in the community. This includes understanding their specific signs and symptoms of anxiety and what triggers them. Knowing what triggers anxiety in an individual enables caregivers to minimize exposure to those triggers, to the extent possible. For example, if a person's anxiety is triggered by crowds, caregivers could be selective about the times when they take the individual shopping. Knowing a person's preferences and coping strategies is important, as well. Some people may have been taught personalized techniques by a therapist to help manage anxiety. Understanding those techniques and being prepared to assist individuals to use them in the community helps caregivers provide more effective support. For example, if a person utilizes specific music to relieve anxiety, a caregiver can ensure availability of a device on which the person may listen to that music when feeling anxious.

In the Community

Even when prepared, people still might experience anxiety in the community. Below are some strategies that can be effective when that happens. These strategies can be used separately or in combination.

Strategies to support an individual with anxiety while in the community

- Gently remind the person to use techniques that they have learned. It may be helpful to practice these techniques with the person. For example, if the person has learned to calm down by counting with his or her eyes closed, do this with the person.
- Suggest the person take a break or step away from the activity. As soon as the person shows signs of becoming anxious, suggest that he or she take a break or step away for a few minutes. Use a supportive tone; plan ahead to ensure there is adequate caregiver coverage and a quiet place the person may go.
- Slowly count to 10 with the person (ADAA, n.d.). This directs the person's focus onto something else for a few moments and allows time to regulate the symptoms. Some people may need to repeat or extend this (ADAA, n.d.).
- Encourage the use of deep breathing – inhaling and exhaling slowly (ADAA, n.d.). Ideally, inhalation is done through the nose and exhalation through the mouth; however, anything the person can do to breathe more deeply is helpful.
- Suggest the person practice visualization (WebMD, 2016) by imagining, with eyes closed, a place where he or she would feel relaxed and safe. As the person does so, mention sensations of this imagined place that might be soothing, such as the smell of the air or the sounds one might hear there.
- Encourage the person to talk when feeling overwhelmed (ADAA, n.d.). Listen to what the person says and acknowledge his or her feelings. Ask the person what might help relieve those feelings. If the person offers suggestions, do what can be done at that moment.

For further information, consider exploring the HCQU's *Generalized Anxiety Disorder* training, which is available online at https://hcqu.kepro.com/content/pages/online_training_registration.aspx.

References:

Anxiety and Depression Association of America (ADAA). (n.d.). Tips to manage anxiety and stress. Retrieved February 2018 from https://adaa.org/tips-manage-anxiety-and-stress

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American Psychiatric Association (APA). Help with Anxiety Disorders. (January 2017). Retrieved February 2018 from https://www.psychiatry.org/patients-families/anxiety-disorders/what-are-anxiety-disorders

WebMD. Preventing Anxiety. (April 2016). Retrieved February 2018 from https://www.webmd.com/anxiety-panic/preventing-anxiety

Recognizing Illness

By Pam Lodge, Clinical Educator

Illness can happen to anyone, at any time, for any reason. Supporting an individual to experience an "everyday life" includes recognizing signs that indicate the person might be ill and knowing what to do. Consider a scenario about three housemates and their monthly night at the movies:

> *Once a month Christopher, his housemates (Matt and Bob), and two caregivers planned a movie for their Friday night outing. Most movie nights were successful and enjoyed by all who participated, including the caregivers. One Friday, the group planned to see a movie they all wanted to see. The movie started and everyone seemed interested. One caregiver noticed Christopher holding his stomach and rocking back and forth in his seat, but he thought the behavior was Christopher's way of expressing excitement about the movie and did not question it. However, when Christopher began making a grumbling noise and rocking continuously, Bob shouted for Christopher to be quiet and stop moving. At that point, the caregiver asked Christopher if something was wrong, and Christopher said he needed to go the restroom. In the restroom, Christopher complained of severe stomach pain and then vomited on the floor. Christopher became very upset and said he was "fine"; he really wanted to see the movie and didn't want everyone to be angry at him for being sick and having to leave. The caregiver explained to Christopher that no one would be angry or upset with him. He notified the supervisor and arranged to take Christopher home, while Matt, Bob, and the other caregiver stayed to finish the movie. The next day, Christopher was diagnosed with the flu. When he felt better, Christopher and his caregiver went back to see the movie.*

Individuals with I/DD might not express symptoms of illness in the way one might expect, whether due to challenges with verbal communication or with not knowing how to describe what they feel. Caregivers who are not familiar with alternative methods individuals use to express symptoms of illness might misunderstand the individual's behavior as indicating the individual does not want to participate in the activity or desires attention.

Signs and Symptoms of Illness

- Holding head, stomach, or other body part
- Restlessness, rocking
- Refusing to perform tasks, such as getting in or out of a vehicle, eating, etc.
- Vomiting
- Diarrhea
- Holding chest and sitting down suddenly
- Changes to appearance of skin, such as flushed or pale cheeks
- Removing or adding clothing or blankets
- Skin feels hot or cold to the touch
- Extreme behavior, such as throwing objects, verbal abuse, slamming doors
- Crying without identified cause
- Withdrawal, such as not engaging in conversation or avoiding usual activities
- Sudden and/or frequent need to use the restroom
- Low energy, difficulty staying awake
- Unusual sweating
- Non-typical sounds, such as humming, moaning

To minimize the impact of sudden illness when individuals are participating in a community activity, caregivers might consider the following suggestions.

- **Plan ahead –** Have a plan in place and prepare for "What if" scenarios. Ensure the proper number of caregivers are present to permit one caregiver to take an individual home (or to a healthcare facility) while the other individuals and caregivers continue the activity.
- **Listen and observe –** Listen to what individuals communicate, and observe individuals for signs of illness throughout the activity; avoid focusing on the activity to the extent that signs of illness are overlooked.
- **Know the environment –** When planning an activity in the community, become familiar with the setting in which it will occur; be prepared for illness and emergency situations by learning the location of public restrooms, local medical facilities, and transportation routes; the availability of cell phone signals; etc.
- **Be creative –** Have an alternative plan for the group in case the original plan must be canceled because of illness, injury, or other occurrence.
- **Prepare to support other individuals –** Consider how individuals might feel and react if one of them gets ill and plans are changed. Be prepared to explain the situation in a way that helps them understand what happened and prevents negative feelings toward the individual who is ill. Reassure them that the person will feel better and that everything is OK.

Reference:

Beck, K. (n.d.). Community Inclusion. Retrieved June 8, 2017, from http://www.dhs.state.il.us/OneNetLibrary/27896/documents/By_Division/Division%20of%20DD/ResidentialDirectorCore/Module5RDCCommunityInclusion.pdf

Community Participation Supports

By Margie Grieser and Rebecca Trigger, Clinical Educators

Many resources are available to support provider agencies, individuals, and family members with regard to increasing community participation, several of which are listed below.

Community Participation Supports for Direct Support Professionals

"This training series is a high-level introduction to Community Participation Supports for Direct Support Professionals. This training is an ODP Required Training for Direct Support Professionals who provide Community Participation Supports. The training is also available to Individuals and Families. Professional Development training credit is available to Supports Coordinators and all other professionals."

Webcast Topics: *(Webcasts must be viewed in order.)*

- Webcast #1 – The "Why" – Everyday Lives
- Webcast #2 – What are Community Participation Supports
- Webcast #3 – Where Community Participation Supports are Provided
- Webcast #4 – Inclusion/Integration
- Webcast #5 – Person Centered Planning
- Webcast #6 – Introduction to Community Mapping
- Webcast #7 – Building Relationships That Sustain a Community Life

Course requirements consists of five steps. All steps must be completed in order to receive a Certificate of Achievement.

1. Complete the Pre-Test.
2. View all seven webcasts.
3. Complete the training confirmation.
4. Complete the post-test and obtain a score of 80 percent or higher.
5. Open and print a Certificate of Achievement. It is important for you to open and print a Certificate of Achievement for your work to be accurately reflected.

This training series is available on *MyODP* at https://www.myodp.org/course/view.php?id=993.

CareLink – Supported Employment Education Programs

CareLink is located in eastern Pennsylvania, but this site can prompt ideas for opportunities that may exist in other local areas. According to the website, CareLink was founded "to provide people with mental illness a progressive alternative to the revolving door of hospital care. Caring support, housing, assistance with jobs, and practical help in the community resulted in more dignity, stability, and hope." Enter "Supported Employment Education Programs" into the website's search box to find information about this particular topic. The program's website can be accessed at http://www.carelinkservices.org/index.php/about-carelink/.

Allegheny County Family Resource Guide

This guide is a compilation of services, systems and resources that includes information and resources to consider when planning for transition. The resource guide is available at http://www.familyresourceguide.org/trans-to-adulthood/vocational-job-training.aspx.

Private Industry Council (PIC)

According to the website, "The Private Industry Council of Westmoreland/Fayette, Inc. (PIC), is a 501(c)(3) nonprofit organization that operates employment, education, and training programs in southwestern Pennsylvania. PIC assists youth, adults, dislocated workers, and the economically disadvantaged in reaching their educational goals, supporting their family growth, and obtaining training and employment." The PIC's website can be accessed at http://privateindustrycouncil.com/.

AARP Online CAREversations Workshop

This workshop is a free, 58-minute webcast described "as a live interactive event" where an AARP expert "discusses the many roles of caregivers and how to talk about important issues with family members and others." To read a summary about the event, and to register, go to https://event.on24.com/eventRegistration/EventLobbyServlet?target=reg20.jsp&CMP=RDRCT-CSN-OTHER-WORKSHOPS-073117&eventid=1407086&sessionid=1&key=E32AEF7E3C522E2A8D61AF600D179C3B&regTag=148424&sourcepage=register.

Charting the Life Course Resources – LifeCourse Toolkit

This toolkit provides "LifeCourse tools for individuals, families, and professionals". The site lists "tools for having conversations with individuals and families about a vision for a good life and how to achieve it." Included are "corresponding handouts... intended to be used to supplement, further understand, and generate ideas when using the tools."

One resource titled, "Charting the Life Course – Experiences and Questions Booklet – A Guide for Individuals, Families and Professionals" may be particularly useful. It is described as a booklet that, "...helps individuals and families know the questions to ask and things to think about throughout the life course, in order to have the experiences that help lead to the good life that they envision." It uses the following six categories to address the life domains: daily living, community living, safety and security, healthy living, social and spirituality, and citizenship and advocacy. The domains are further categorized by life stages that offer questions to provoke desires and ways to formulate a plan. LifeCourse tools are available at http://www.lifecoursetools.com/planning/.

Transitional Paths to Independent Living (TRPIL)

TRPIL headquarters is in Washington County, and there is a branch office in Monroeville. It is described as "a membership based center for independent living operated by the local community of people with disabilities" whose "programs include peer support, home care and nursing home transition, youth programs, advocacy, and information on equal access, assistive technology, education, employment, housing, and transportation." Many programs and services are offered, including skills training and person-centered counseling. Links are provided to other resources and programs such as Faith in Action, which "links seniors and people with disabilities with community activities, social services, and health care...making it possible for them to live independently in their own homes, enjoy effective, loving relationships with their families, and experience an improved quality of life." To view additional programs and other quick links, go to https://www.trpil.com/main/programs.

Autism Connection of Pennsylvania

Autism Connection offers a vast network of autism support groups across Pennsylvania. For instance, an adult outings group, an adult social group, and an advocacy group are listed under Allegheny County, and a young adult social and support group and a special needs advocacy group are listed under Cambria County. To see the full listing, go to https://autismofpa.org/support-groups/.

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