

WHEN IT COMES TO RIGHTS IN SOMEONE'S HOME, ASK "HOW" ... NOT "IF"

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For many years, we have said and heard, "People with intellectual and developmental disabilities (IDD) have the same rights and responsibilities as everyone else." There are many efforts across the world that are pushing organizations that support people to take real action to make sure this is the reality. There are advocacy groups. There are new rules. There are state initiatives. There are federal directives. And above all, it's the right thing to do!

When we try to put our beliefs into action about exercising rights, we run into barriers. These barriers may be real or not; but they often keep us from doing the right thing. People with disabilities want to live their lives as every other person does.

The truth is that supporters of people with IDD must stop making excuses and ensure that they are supporting people to live a life that is just like someone who does not receive services. We need to stop asking "if" and start asking "how?" In this Capstone we will look at two important rights, specifically because of their prominence in changes to the HCBS Settings Rule - the right to have visitors and the right to have keys.



WELCOMING VISITORS

As support providers, we challenge ourselves to balance our role of empowering people to live the life they choose with our responsibility to ensure health and safety. When we think about supporting people to have friends and family visit them at home, we can be influenced by the obstacles. Some of the obstacles may be real, while others may be our own perceptions, fears, or misconceptions. When it comes to relationships, no one wants to see anyone be hurt physically or emotionally; but we also know that regardless of potential "risks," people both with and without disabilities want to form connections with others.

Many organizations are struggling with the idea of abandoning long-standing systems and practices that keep people safe. Sometimes we have to start with figuring out what concerns we have, before we can design personalized supports to be sure that people invite visitors to their homes in a way that works for them.

Fear In A Bucket

'Fear in A Bucket' is an activity you can use to identify and address fears. The activity takes about 15 minutes for a group of 10 people. It allows each person to anonymously share fears they have about supporting a person to have visitors at any time.

1. The facilitator (who could be the person supported) begins by explaining that it is natural to be anxious about a different experience (having visitors) and that a good way to manage these concerns or worries is to acknowledge the fear so that it can lead to ways to reduce the fear. Sometimes just sharing a fear reduces its intensity.
2. Each person is given paper and asked to complete this sentence: The worst thing that could happen if ____ had visitors at any time would be_____.
3. The person puts their "fear" in the bucket.
4. The facilitator mixes the fears up and hands them out to different people.
5. The facilitator explains the next step. The person will read what is written and react. No one is to comment on what is read or said.
6. Go around the group one-by-one, reading what someone else wrote on their paper and describing their understanding of the fear.
7. Continue with each person reading and reacting to what is written.
8. When all the fears have been read, discuss what people felt and noticed.
9. The facilitator thanks the group for their honesty and discussion.



This activity is useful as it opens up a lot of emotions and leads to an honest conversation. It also gives the group a direction of next steps to address real concerns.

Coupling this activity with what we know about a person will help us to develop personalized supports and guide us in taking what people [and The Centers for Medicare and Medicaid Services (CMS)] are telling us is important - for people with disabilities to have lives like people without disabilities. The HCBS Settings Rule gives some authority to what people have been telling us for a long time. It also gives supporters an opportunity to explore the best ways to 'make it happen,' person-by-person.

And, we must always remember that it's the person who should be making decisions about visitors. Family members, friends, staff, and other professionals may also be involved. If it's not the person's choice, it is likely a rights limitation! A person's rights extend beyond just who visits their home, to who has the control over access to their home.

THE PERSON WITH THE MOST KEYS HAS THE MOST POWER

We don't always think about how important having a key is until we don't have a key ... then it's much clearer! Walk up to your front door and wait for someone to let you in and you might realize how important it is. "I enjoy having the right to come and go as I please. No one knows my code except for me. If anyone wants to come in they have to knock," states Brian, Secretary of 'Advocates Working For Life Board of Directors' at Life's WORC.

At Life's WORC on Long Island in New York, they started a "Key Initiative" in 2018. Through this initiative, "everyone supported had a key to their own home, and staff were trained to ensure supports were in place to use their key," shares Mary Ann Greco, Senior Director of Person Centered Supports at Life's WORC. They recognized that just giving someone a key didn't change anything, if there weren't supports in place for the person to use the key. For some people, they took their responsibility seriously, carrying their key and using it when they were coming or going.

For others, after years of being "let into" their home, supports were designed to help them navigate this change. There are many ways to support people in not only obtaining their keys, but especially using them. Through CQL's experiences in accreditation, training, and certification, we have witnessed many different approaches that organizations have implemented:

- When a person did not have experience with the use of key, she didn't see the key as important. The agency designed a program to help her learn the value of the key. Every day when she left her home, the staff would ask her to check for her key. She would get the key out and lock the door. When she came back home, the staff would wait, and remind her if needed, to get her key and unlock the door. Over time, the person learned the key had value and she used the key regularly.
- One woman with a physical disability used an app on her phone and other Smart Technology to open her door. She didn't have the dexterity to use a typical key so she and her staff researched various technology options that are available, and came up with the solution.
- At Life's WORC, one man was supported hand-over-hand, to open the door to his home.
- Some people have chosen to use keypads, swipe cards, or fobs rather than a traditional key. There are numerous types of keyless entry systems on the market.

In Life's WORC efforts to promote privacy, they ask people about their preferences and listen to people. Jason, a person receiving services through Life's WORC said, "I found my voice and feel respected. I feel happy too about having my own house key."

Life's WORC has continued to work to promote privacy through the use of keys. They have improved access to areas traditionally locked by offering a variety of options. Many people have a way to secure their personal bedroom with a key or keypad. Some people chose to have a secure closet or space in their bedroom. Others who are responsible for their own medications, have a lock box (key or combination) or a safe in their bedroom.



One of the many lessons learned is that it's important to ask the right questions - What do you want? What are you doing or what do you want to do to keep your things secure? Sometimes, that requires helping people explore different options like different entry systems (keyed or keyless) or securing different spaces (bedrooms, closets, safes). "Having a key to my home makes me feel important," says Phillip, a man who is supported by Life's WORC.

Remember, it's time to ask "how" and take action!