

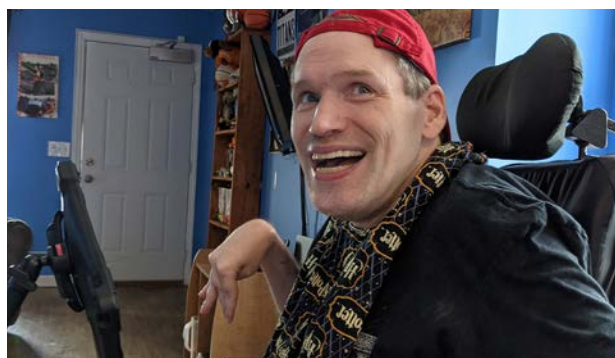
## Recognizing and Remediating Common Forms of Over-Support

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By Carli Friedman, Director of Research, CQL

The human services field, especially for people with intellectual and developmental disabilities (IDD), has traditionally operated under a custodial model of care, where the focus is on safety, supervision, and minimizing risk, rather than support. Unfortunately, this custodial culture often continues today. As a result, many people with disabilities are denied choices and opportunities and are over-supported.

To avoid over-supporting people, it is important to be able to recognize what over-support looks like. It is also important to know how to remedy over-support or even how to avoid it altogether! In this Capstone, CQL | The Council on Quality and Leadership staff share what they've observed about over-support in human services. Then, Susan Arwood, Executive Director of Core Services of Northeast Tennessee, shares how her organization moved away from a restrictive service model to a person-centered service model.



### Over-Support: Perspectives from CQL Staff

I asked CQL staff to share examples of over-support they commonly see as well as what best practices should be implemented instead. While they offer specific stories of over-support that they have observed, these can be applied more universally to other aspects of people's lives. Here's what they had to say.<sup>1</sup>

#### Kendra Julius, CQL Quality Enhancement Specialist

##### **Example of over-support:**

"The most frequent situations of over-support I see are due to an organization's assessments (safety, medication, etc.) functioning as a gatekeeper, rather than a tool to provide real support. For example, recently I conducted a Personal Outcome Measures® interview with a 17-year-old young man named Ari who never had the opportunity to ride his bike or go for a walk on his own. His host family and his support coordinator just simply hadn't thought about what would be typical for a teenager his age and had not tried to determine what supports he might need to be able to do these things more independently. The risk assessment simply stated, 'Ari always has an adult with him during walks/bike rides' rather than delving deeper into what Ari knew about pedestrian safety (he knew a lot from talking with him!) and if there were other natural or environmental supports that would keep him safe (there are)."

##### **What could have been done instead:**

"The support coordinator and host family could have assessed the need for supports to promote independence, rather than simply stating what they were doing to keep Ari safe. They could have asked Ari questions to determine what he knew. It also would have been helpful to think outside of support as being just line of sight supervision."

## Jen Papouchis, CQL Support Systems Specialist

### Example of over-support:

“Jeanette is a young woman I used to help support who likes to stay busy. If she wasn’t working on a craft of some kind or talking on the phone with her boyfriend she could often be found wandering in the kitchen to snack. Jeanette’s guardians became concerned that she was gaining weight and, due to a family history of diabetes, they wanted her put on a restrictive diet. The decision was made (without Jeanette) to restrict Jeanette’s diet and block her access to the shared kitchen between scheduled mealtimes.”

### What could have been done instead:

“Someone could have explained to Jeanette the difference between junk food and healthy snacks. Because of Jeanette’s need to be kept busy I believe she would have enjoyed helping to create a shopping list and shopping for healthy foods. By explaining to Jeanette ‘the why,’ she could have learned how to make the decision for herself.”

## Leanne Mull, CQL Quality Enhancement Specialist

### Example of over-support:

“Lucas lived with his grandmother and his mother. Lucas took care of everything in the home; he did all of the grocery shopping, he cleaned the house, he took public transportation, and worked in the community. When Lucas’ grandmother died after a short illness, his aunt placed his mom in long-term care and Lucas into a 24-hour group home. At his group home Lucas was not allowed to shop, cook, or clean. He was also not allowed to leave the home without staff, which limited visits with his mom who lived nearby. Since the community job he had required hours that did not work with residential services, he entered sheltered work, where he has remained for about 15 years. When a supported living opportunity came up, staff said he was not ready. Today, Lucas is still receiving 24-hour supports and he’s lost many of his previous skills due to over-support.”

### What could have been done instead:

“Rather than entering a group home, Lucas’ independent service coordinator could have explored intermittent services, either in the home he lived in with his family or in an apartment. He would have maintained his independence while receiving support with what he needed after he had a reasonable and accurate assessment of his skills.”

## Crystal Hicks, CQL Quality Enhancement Specialist

### Example of over-support:

“A situation I see too often is 24-hour support provided to people when they sleep all night. These supports are provided because of the possibility of what might happen rather than what has happened to the person. Documentation from the direct support professional indicates either sleeping all night, or getting up and using the restroom, or maybe getting water and going back to bed. There is no need for direct support professionals to be present, instead the overnight staff support creates an environment of over-support for the person.”

### What could have been done instead:

“One possible strategy to decrease over-support is utilizing enabling technology and providing remote support opportunities for people to feel safe. Remote support can include items like off-the-shelf technology or customized person-centered plans put together by technology vendors. These plans should ensure the person is comfortable utilizing this technology. Strategies for everyone to understand and use these technologies should also be developed.”

## Katherine Dunbar, CQL Vice President of Accreditation

### Example of over-support:

“Ryan moved from his family home to an HCBS setting. At his family home, Ryan managed his diabetes and could calculate his insulin dose in his head and would confirm it using an app on his phone. While living with his parents, Ryan would go out in his community by himself and would also stay home alone. However, once in formal services, the state determined that Ryan needed line of sight supervision (due to seizures) and a registered nurse had to take over his insulin. Ryan had less freedom and control over his life in a residential setting than he did living with his parents.”

### What could have been done instead:

“The agency was supporting Ryan to advocate for himself; it was an issue of risk awareness versus risk aversion on the part of the state. The independent support coordinator could have advocated for Ryan to have far fewer restrictions. The risk assessment could have been presented in a way that focused on strengths.”

## Epp O'Neill, CQL Quality Enhancement Specialist

### Example of over-support:

“A very simple example I saw recently was staff not asking Destiny what she wanted for lunch; they just made the lunch for Destiny, had her sit at the table, and then put it in front of her. Not once was Destiny given the option of doing any of these steps on her own or with some assistance. Destiny definitely could have done most of these things all by herself.”

### What could have been done instead:

“Destiny could have been asked what she wanted for lunch, even if it was out of 2-3 choices available. She could have been asked to get the food out and asked if she needed help with getting it ready. The lunch did not consist of anything that required the use of a stove. Then Destiny could have been encouraged to put her dishes in the sink or dishwasher. It really is so unfair to people for them to not have this control of their life.”

## Kristen Heichel, CQL Quality Enhancement Specialist

### Example of over-support:

“I’ve seen so many instances of over-support but one that stands out because it happens so frequently is people being unable to stay ‘home alone’ or be in the community by themselves.”

### What could have been done instead:

“Ideally, people would be provided with more education and experience around the skills needed to be safe and successful in these areas. For example, many times people are not allowed to be alone because they can’t repeat their address and phone number. But not ‘knowing’ your phone number and address can be easily remedied with putting it into a cell phone, carrying it in a wallet, etc.”

## Anne Buechner, CQL Quality Enhancement Specialist

### Example of over-support:

“Because of perceived regulations and legacy practices, many people receiving supports continue to be on a regularly scheduled ‘bed check.’ Most times, this practice is not viewed as a potential infringement on people’s rights; therefore, the activity is not fully reviewed for adequate due process. Or even if adequate and robust due process has been applied for one person – for example, safety or health reason – these bed checks are ‘blanket’ practices and have the potential to infringe on others’ privacy. Additionally, even if by chance

some form of due process has been sought, organizations often do not fully explore all creative solutions to minimize this invasion of privacy to prove least restrictive measure.”

**What could have been done instead:**

“Instead, adequate due process could have been conducted to rule out this restriction and any and all lesser restrictive interventions should be pursued. What I often see though is the organization does not challenge legacy practices, nor does it adequately seek to mitigate what might be perceived regulations. Challenging of the actual and/or perceived rule or statute, or the perceived funder criteria, is limited or non-existent.”

## Moving Away from a ‘One-Size Fits All’ Model

By Susan Arwood, Executive Director, Core Services of Northeast Tennessee

In 2017 Tennessee celebrated the dismissal of all federal lawsuits ending a quarter of a century of litigation and court oversight of intellectual disabilities services in the state. The 25-year journey was a transformation from institutional care to community services. Despite all the positive changes, what emerged might be described as a culture of heavy staffing and risk aversion. Through an Enabling Technology “test project” Tennessee leaders hoped to put a toe in the water and feel a way out of the trend of heavy staffing and a ‘one size fits all’ service model.

Core Services jumped on the Enabling Technology test project opportunity seeing the potential to break away from a restrictive service model (one-size fits all) to a person-centered service model where the level of support is designed around the desires and needs of the person. The agency recognized that when a person desires more independence, no amount of paid supports, no matter how excellent those supports might be, can provide people with their preferred life.

## Addressing Over-Supports Through Technology

To get started the people who were most vocal about wanting independence were identified. Next came a process of identifying outcomes — what was missing from the person’s idea of a preferred life? Can technology achieve a dream that traditional services could not? Evident early on was the fact that the traditional service model was a poor match with desired lifestyle.

Fast forward four years and 47% of people supported by Core Services now use technology for increased independence. 22% have significantly reduced DSP support, such as living independently or have no third shift staff. The improved quality of life is evident to even the most casual observer. Recent agency Personal Outcome Measures® (POM) data revealed that people supported with technology resulting in reduced paid supports were 50% more likely to have outcomes present in their life. They were also 19% more likely to have supports in place to achieve those outcomes.

Lessons learned along the way include that you do not need a state initiative to get started. There are countless opportunities to use technology so people can control aspects of their lives. The idea of being able to spend time alone at home is a foreign concept to most, but a desired goal. Technology reduces the cost of services and pays for itself. People are far more capable than others give them credit for, they want this opportunity and are overwhelmingly excited about it. Any change of this magnitude will face opposition and the best way through it is education and open communication – with everyone.

# Maintaining Balance Between Your Supports

By Carli Friedman, Director of Research, CQL

The best support balances the duty to care with dignity of risk. This doesn't mean putting people in unsafe situations, but instead supporting people to understand risks and facilitating informed choice. Self-determination and dignity of risk are not only crucial for person-centered services and supports, they are also essential for quality of life.

<sup>1</sup> Pseudonyms are used in the examples from CQL staff.