Long-Term Care Workforce Commission Meeting 10/24/19
Consumer Voice: Kim Humphrey

My name is Kim Humphrey. I'm from Auburn. I have a Master's in Public Health. My son, Daniel, has severe autism and bi-polar characteristics and lives in a two-person group home. I founded Community Connect Maine in 2015, and it has since grown into a network of over 4,000 people, with a mission to connect families, caregivers and communities to improve the standard of care for the Developmental Disability community and related conditions. It goes without saying that "families" includes individuals with disabilities. As much as possible, it is the individuals who express the supports they want and need. In addition, I have two 91-year-old parents: My father is the sole caregiver for my mother, who is in her sixth year of dementia, and I travel to spend a week with them every 4 to 6 weeks.

During one of the earlier Long-Term Care Workforce Commission (LTCC) meetings, I heard someone express what an eye-opening experience it was to learn how incredibly challenging it is to navigate the long-term care experience for an aging parent. I had the same eye-opening experience almost 30 years ago when my son was diagnosed. These challenges have carried on for the nearly three decades since, but now I am also helping my parents.

How are long-term care workforce solutions relevant to climate change solutions?

A few months ago, I saw a headline in the Bangor Daily News stating that the Intellectual and Developmental Disability (I/DD) Community was left out of the long-term care discussion. There were only two reader comments about the article, one of which asked, "What about climate change?" At first, I rolled my eyes, that even this commenter didn't care about people with disabilities. Then it occurred to me that the answer for solving the LTC workforce issues is the same as it is for protecting the earth from climate change: If we raised our level of concern about our fellow human beings, we would meet the daily support needs of both the I/DD and aging population, and we wouldn't destroy the planet that is essential to the survival of all of us. It's simply a matter of caring enough to do something about it.

Let's eliminate stigma in Maine

Stigma is ubiquitous. Let's create a new culture where Maine leads the nation in putting the people first, by changing the stigma around I/DD and aging. The I/DD population has been kept invisible for centuries. Less than 50 years ago, people with disabilities were not legally entitled to a free appropriate public education, and Pineland, the Institution for Developmentally Disabled in Maine, was only closed in 1996.

A few years ago, I stopped coloring my hair. Shortly after, for the first time two people asked me if I was a grandmother. I was offended that these people thought I looked my age. Our culture trains us to want to look, feel and act young and "perfect." Getting old or being disabled are unacceptable. Stigma is strong and often unconscious. Let's change that in Maine. Jobs for the aging population and the I/DD community are lowerpaid and unpopular, because we do not value them. My 91-year-old Dad recently finished 50 online credit hours to renew his medical license for two more years. He told me how frustrating it is that he is no longer taken seriously because of his age.

Should I work?

When I was in my 20s, I had a faculty appointment at the University of Massachusetts Medical School as a Research Associate. I worked on an epidemiological studies team managing data and enjoyed my chosen profession in public health. It has proved useful in understanding systemic perspectives.

When my daughter was two and my son was a baby, I moved to Maine. It soon became apparent that the best use of my time was not pursuing a career but caring for my son. I didn't resume work for the next 20 years, when my son moved into a group home. Instead, I pursued an exhausting marathon of a journey as an advocate for my son, navigating the most difficult bureaucracy I ever could have imagined. As a result of my son's painstaking hard work, my efforts, luck, and the teaching and care given to him by hundreds of people, my son has developed good skills. It's hard to imagine how this could have been done simultaneously with a full career, or if I were in a position where I had no choice but to work. What happens to children like my son whose parents don't have the luxury of advocating for them fulltime? The system makes it impossible for them to achieve what my son has achieved.

Who is Daniel? There are many like him.

Historically, we learned that there is a large discrepancy between who Daniel is as a person, based on whether or not he has the appropriate daily supports. When his program is in place, he is able to participate in his community, such as serving his 12 Meals on Wheels clients and his taking excess food from Bates College to a nearby soup kitchen. With prompting he can do daily chores, such as his laundry. But if there are gaps in staffing, inconsistent staffing, untrained staff or staff tension, his skills deteriorate rapidly: He stops doing what he has learned to do over many years of careful therapy, like eating with utensils, wearing clothes, and using the toilet. He starts communicating his frustration with aggression, such as pinching, pulling hair, and biting. The difference is civilized versus uncivilized behavior. The aggression also occurs if he has undetected pain. His life hangs by a thread.

The story matters because people's lives matter

Policymakers, such as each and every one on this committee, potentially have power over my son's wellbeing and that of thousands of others. While I have training in biostatistics and enjoy data, if we were to talk only about waiting lists and numbers, we would miss the most relevant part of this discussion – the people. Waiting lists, inconsistent care and system gaps create human suffering, duress, and wasted days and wasted potential that they will never get back. Let's fight for these citizens.

The career launcher—Reframing direct care work

My son needed substantial in-home supports by age seven that could not be accessed through Medicaid. For two years I hired and trained staff as a non-professional, based on observing his therapies. I did so much hiring, I began to predict who would do well with my son. An important factor for their success was if the direct care workers had a career objective that aligned with the work they would be doing with my son. There are many careers that align with direct care work—rehab, occupational therapy, speech and language therapy, social work, psychology, medicine, education, special education and recreational therapy. It also aligns with all kinds of specialty care—neurology, psychiatry, behavior management, case management, clinical psychology, child psychology, geriatrics. There were a number of people who did well with my son who went on to have terrific careers. I came to think of my son as a career launcher. Direct care work provides an invaluable learning experience for a whole array of people-oriented professions, but we need to value it as such.

Maybe pooled funding streams could help

My son went out of state to a residential school that specializes in autism when he was 11 years old. He was not making progress in Maine, because the necessary in-home support staff were too inconsistent to meet his needs. That was almost 20 years ago, and the direct care worker problem is still an issue today. We wanted to bring my son home when he was 12. An agency even demonstrated that they could set up a program for him that was cheaper than his out-of-state program. He qualified for the Home and Community Based Service waiver that was necessary to implement the plan, but there were insufficient funds. Instead he spent eight years on a waiting list, living out of state with greater separation from his family and at a higher cost to the state. The funding for his education came from the DOE. Maybe pooled funding streams could have helped. Finally, when he was 20, he received the waiver and came back to Maine to live in a group home.

Behavioral issues and undetected pain

My son's life and all of the lives he touched would have been less traumatic if healthcare workers and schools were trained to rule out pain before addressing challenging behaviors. I would assume this is also true for elders who have lost their ability to communicate. There was a 6-month period while my son was in school where the school called weekly meetings to deal with his escalating behaviors. The team became larger and larger as the level of expertise required increased. Finally, an out-of-state neurologist asked, "Has he seen a dentist?" It turned out he had 6 cavities and needed a tooth capped. He was lashing out because he was physically suffering.

When he was 18, he was hospitalized for 2½ months in a psychiatric hospital that would not do a comprehensive evaluation. (Four other hospitals already had refused to take him). Because the family, not the hospital, had to arrange the appointments with specialist, the appointments were not treated like emergencies. In the psychiatric hospital, he learned new aggressive behaviors, like head butting, while he waited to see specialists outside the hospital. These appointments were critical to figure out if something might be medically wrong. Fortunately, my ex-husband was a physician and figured out which appointments were necessary. We kept the primary care provider informed, but she was passive. It turned out that when he was treated for chronic esophagitis and obtained a partial root canal, his behavior improved and he was released.

The quality of direct care worker's job suffers along with those they serve when the system of care provides no avenue to properly diagnose the root of behavior issues. This could be fixed.

The cost of waiting for supports for basic needs

When my son was diagnosed, we were told that early intervention is the best path toward a good prognosis. It is a special form of torture to immediately be put on a waiting list for the services necessary to work toward that positive outcome. There were costly delays throughout the decades, when new aggressive behaviors were added to his repertoire while other higher quality opportunities were lost.

For example, when my son was eight, he was recommended for an augmented communication device. For over a year, the school fought the recommendation but then, came through with an amazing keyboard communication program that worked with a computer. Unfortunately, the school computer was too slow for the program to be effective, and it was not a priority of the school to fix it. Year after year, we advocated for an augmented communication device that would work for my son. This didn't happen until he turned 20. With the new device, he was entitled to 10 language therapy appointments to train him and his staff on how to use it, but he was never able to access those appointments over the next 10 years. The speech therapist would show up once or twice then mysteriously stop showing up. After a series of case managers came and left my son's team, the most recent one that we consulted said, there was a funding issue that had been holding up my son's speech and language therapy. No one had informed us before. By the time we found out, the device was obsolete.

Miraculously, my son now has a great speech therapist an hour away who wants to see him every week. But his group home is so short-staffed they cannot take him out of the house more than every other week. In this case, each time the system of care provided an opportunity to my son, a systemic inefficiency or shortfall snatched it away.

Let Maine lead the world

Let's fight for all citizens of Maine. Let's include the I/DD and aging populations with LTC needs. Let's include the DCWs who provide support for them. Make it a priority. Provide the daily supports they need without delay. It is training wheels for saving the planet from climate change.

Quiz

The long-term care services, hampered by a severe workforce shortages, are going up in flames. Imagine that you are serving on the Long-Term Care Workforce Commission and you see that your house is burning down. What do you do?

A) You recommend that the committee build a better prevention system and a new state-of-the-art fire department.
B) You put out the fire.
C) You recommend better fire prevention *and* putting out the fire.

Overarching Considerations for the LTCC:

1) **Change the culture. Make caring about people the priority:** Make it a priority that all Mainers have access to the services that will meet their daily needs. The direct care work for these populations will earn the respect they deserve, and the rates will reflect the dignity given to the work.
    a) **Prioritize the elimination of stigma in Maine.**
    b) **Keep the focus on the lives of people by:**
        i) ***Avoiding siloed areas of service needs:*** Have departments work together on the system of care—DOE, DHHS, DOL. Use care coordination and good case management. Consider options for pooled funding streams
        ii) ***Respecting feedback as an opportunity to achieve the most responsive, high-quality system of care.*** Provide transparency and an open, authentic channel for ongoing feedback from the public regarding each long-term care service system. Collaborate across groups of stakeholders. Remember that people who are experiencing the system for the first time find it eye-opening; this highlights a need for continual responsiveness to their needs.
        iii) ***Fully funding basic support needs of the long-term care populations in a way that is dynamic with the economy.***
2) **Recognize that long-term care for disabilities can be for a lifetime.** Whether our state gets it right or not can affect people for decades.

Response to Directives:

1) **Current and Future State**
    a) Include data on unfilled and overtime hours of section 21 and 29.
    b) Show data on numbers of people with disabilities within the aging population.
        i) Show the three-decade trend of the DCW need for people with disabilities.
        ii) Compare data regarding access to services for people with behavioral challenges to those without.
    c) Five studies could be done on the current state that would show if a different way of providing funding would be more cost effective and of higher quality. Paying more dignified rates may be cheaper for Maine and healthy for Maine citizens. Remember, the DCW problem has existed for at least 20 years. Maybe something drastically different needs to happen. The five studies are:
        i) Investigate whether the money direct care workers collect in general assistance would be better spent on a more dignified rate of pay. It may actually be cheaper to pay workers a decent wage, so that they no longer qualify for public assistance.
        ii) Study the financial impact of families participating less or not at all in the workforce because they are navigating the challenging system of care for a family member(s) and/or providing care themselves.

        - **iii)** Evaluate the cost to MaineCare for funds spent on pharmacology related to behavioral issues. These costs could be much reduced by providing consistent, high-quality services without waiting lists, in addition to being a more humane solution.
        - **iv)** Compare the cost of paying DCWs a competitive wage to the cost to providers of rapid turn-over and the behavioral/quality-of-life costs to those served.
        - **v)** Analyze the cost of ER visits, hospitalizations, incarcerations, crisis services and homelessness as a result of people in the LTC population not being able to access the support they need within the current system, resulting in escalating behavioral issues.

2) <u>Campaign for recruitment of DCW</u>

- **a)** Focus on direct care work as a career launcher and highlight all of the career tracks it can open up: psychology, psychiatry, medicine, nursing, occupational therapy, physical therapy, speech and language therapy, technology, special education, education, neurology, rehabilitation, case management, care coordination/patient navigation, recreational therapy, behavior management, social work.
- **b)** Focus on direct care work as integral to providing quality of life for many members of the aging and disability community.
- **c)** Make campaigns that are tailored to every level of education in the state—such as high school guidance counseling, college career development, graduate student internships.

3) Career Ladders

- **a)** Provide differential training, rates and job status for direct care workers that accurately reflect the level of difficulty they face providing care, such as clients with challenging behaviors, and/or those who require integrating multiple interventions.
- **b)** Create internships for direct care work that are aligned with colleges and graduate school classes for a wide variety of related fields. Do this within the state and nationally.

4) Education of workers

- **a)** Emphasize that the work they do affects the quality of life for those they are supporting.
- **b)** Educate workers to contact medical providers to explore whether undetected pain is the reason for behavioral issues in the people they support.
- **c)** Use both universal core training and differential training to make jobs more portable but also able to meet unique needs.
- **d)** Increase options for course credit for DCW.
- **e)** Offer more hybrid courses: in-person and online. Could this be done nationally to share this need and task across the country?
- **f)** Have a specialized DCW track that has training in Applied Behavioral Analysis. It is an affective, evidence-based support for many people with challenging

behavior and for those who would benefit from acquiring new skills that lead to greater independence.

5) **Barriers to Hiring and Methods to Overcome**
    - **a)** Provide differential pay for individuals with more challenging behavior and/or harder work.
    - **b)** Decrease the demand for DCWs by providing support to families where the person wishes to stay at home; that support may include providing respite for these families.
    - **c)** Fully fund the workers in a way the fully supports those being served. Prioritize the goal of everyone getting what they need. Pass LD 399 and all bills that competitively fund the workforce.
    - **d)** Create a system of care that provides immediate access to a higher level of expertise when behavioral challenges arise. Make sure applicants know this is available.

6) **Improve Quality of Job**
    - **a)** Long-term goal: Improve the system of care (quality of life) across the lifespan for people with I/DD and for the aging population. The quality of the direct care worker job will improve as a secondary consequence.
        - **i)** Do this by providing consistent and appropriate supports across the lifespan. It will decrease challenging behaviors and increase functional skills and independence.
        - **ii)** Eliminate waitlists which can lead to a lifetime need for higher levels of support.
        - **iii)** Support the self-advocacy movement and equally respect the advocacy of guardians who represent the voice of people who are unable to be self-advocates. **All people at all skill levels deserve dignity.**
        - **iv)** Train healthcare professionals more comprehensively on the aging and disability populations.
        - **v)** Greatly improve the current transportation system so that accessing the community is not a frustrating experience.
        - **vi)** Make Maine a state that is most accessible to people with disabilities.
        - **vii)** Make speech, OT, PT, counseling, behavior management, Applied Behavioral Analysis support available to those who want it and would benefit from it. Base the level of service offered on what they actually need.
        - **viii)** Minimize challenging behaviors: Create a system of care that allows access to improving the quality of behavioral intervention support. Include access to functional assessments when needed and expert oversight to help people recover from difficult periods.
    - **b)** Teach DCWs to seek medical help to discover if undetected pain is the root of a client’s difficult behavior
    - **c)** Allow more flexible hours of DCW to support students and single parents

7) **Opportunity for shared staffing**
    - **a)** Interns can be extra workers