

--Power Outage – 755 in Forsyth County Still Waiting* --

Downed power lines, flooded basement or failing infrastructure hit your neighborhood? How about gridlock (the human kind) or blinding blizzards (the political kind)? The North Carolina Legislature continues to “kick the can down the road,” ignoring 755 of our Forsyth County neighbors without power.*

**Power – The ability to act or produce an effect; Capacity for being acted upon or undergoing an effect; Legal or official authority; Mental or moral efficacy...*

The NC Legislature has failed – by any definition of power – to address the 12,000 North Carolinians with Intellectual and Developmental Disabilities (I/DD) who wait year after year for financial relief from “The Registry of Unmet Needs.” Here is what an oversaturated legislator needs to hear:

DHHS staff report “The numbers are soaring as some with I/DD find their life expectancy doubling and the dramatic rise of autism spectrum disorders challenging more families’ every day.”

“My son and most of his peers have been on the wait list for 13 years; I have skills to share and would like to work, but cannot take a job because of his needs for care.” *Forsyth County Parent*

“My son was 62 when I learned of the “waiver.” I didn’t know how to register and now feel it is too late. I don’t know who will take over when I pass.” *A Neighbor.*

“These families are desperate, but are caught in the vortex of political gaming and short sighted economics.” *A Winston Salem managed care provider.*

The Medicaid (Innovations) Waiver (1915c) is the legislatively capped and federally accessible funding source for this relief, based on a medical diagnosis and significant intellectual or developmental disability. For people with I/DD, which may include Down syndrome, Cerebral Palsy, and Autism, such things as home and community supports define the vital, life-sustaining services and for many, increased independence toward productive citizenship.

Local advocates go further. “It is a linear (birth to death) lifeline; a community access point to relationships and dignity. A single Bill or speech in Raleigh doesn’t cut it.”

The math for Forsyth County is very discouraging. The power outage arrives like a lightning bolt locally, where 755 I/DD families sit waiting on the “Registry.”* New waivers happen only when a recipient leaves the state or dies or the General Assembly appropriates new dollars. 12,000 residents of NC presently receive the waiver thanks to a continuing legislative appropriation, at an average cost of near \$50,000.

DHHS estimates, along with the 12,000 served by the waiver and 12,000 waiting on the Registry, there may be another 10,000 children and adults with I/DD eligible and unregistered across the state. Where is our legislative leadership in all of this?"

In 2014 the state budget "required" a plan be developed to create 3,000 new support waivers over three years.....

In 2017 the Governor budgeted for 1000 new waivers and an additional 1000 for less acute individuals..... 250 slots were awarded by the General Assembly.

In 2018 500 slots were awarded by the General Assembly.

In 2019 Rep. Lambeth helped co-sponsor a Bill (HB728) to fund 500 new slots....

In 2019 the General Assembly budgeted for 1000 – now stuck in political stalemate...

In 2019 Sen. Krawiec said, "Until all on the I/DD waitlist are taken care of, we should not even consider funding health care for able-bodied adults"

Surely that was thunder!

In Forsyth County no new waivers have been awarded in four years, and none are projected in the near future under a state-wide algorithm committed to addressing underserved counties.

When a recipient in Forsyth dies, the state algebra sends the waiver, via Cardinal Innovations, to Rockingham or other lesser served county in the Cardinal catchment area. (When you hear the bell, a Rockingham Angel gets its wings?) In Forsyth County, without legislative action, a newly diagnosed, eligible child and their family will have a 25 year wait for this service.

To be fair, it's not easy; it's expensive. 755 waiver slots for Forsyth County would cost North Carolina's taxpayers \$35 million. But, it's a start, building on the already existing half billion dollar line item and only a few sandbags shy of the \$800 million in the state's 2019 surplus. That the issue (waiver service options and potential funding streams) is scarcely being studied while so many wait and such productivity is lost, is the shame.

It's estimated that nearly 200 people in Forsyth County have already waited over ten years. The costs of affordable caregiving and the loss of working family contributions to North Carolina's tax base mitigate the discussion. The rising numbers of adults with disabilities outliving their parents who seek creative housing, work, medical care and transportation only adds to the dilemma. It is why the Waiver was created.

A storm is on the horizon. Desperate neighbors are already without power as the legislature plays kick the can.

Families on the Registry who are interested in learning more and engaging in the discussion may contact: Dr. Bill Donohue, bdonohue@triad.rr.com