

Other Views

2018: Hope for parents of disabled children



Your Turn

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Guest columnist

His words still haunt me. Although it's been several weeks, I can't get them out of my head. Nor, frankly, do I want to.

It was at a meeting to discuss disability issues. Most of the people around the table were parents of adult children with special needs. One by one, each person shared a few minutes of her or his story – why they were there, who their children are, what needs to be done.

In telling his story, one father explained what he termed “the hard truth” – that “unlike most parents, we hope our children die before us.”

So powerful. So revealing. His words were as poignant and painful, as they were honest and beautiful, and they spoke to the very real fear – acknowledged by most of the people at the meeting – that their beloved children will someday be left all alone. No family. No home. No one to care for them. No one to

love them.

In fact, it is that fear that drives thousands of parents throughout our state to be parent-advocates, constantly attending such meetings and consistently pushing for better policies and support from government. It is the reason that there is a sense of urgency in almost everything they say and everything they do. And it is why they often think about mortality – theirs and their child's – and have otherwise unthinkable thoughts.

I've known such parents for a long time. I've worked with them. I've advocated with them. And yes, I was raised by a mother who cared for my special-needs sister until their near-simultaneous deaths.

Simply stated, these parents are extraordinary people living extraordinary lives. In service to their child, they become experts in everything from health-care to finance to government. In service to their families, they become expert in balancing an array of jobs and responsibilities and personal relationships. Their love for their children is deep and unconditional. And their lives – literally – are built around and shaped by their children – 24/7, 365

days per year.

And as we turn the page onto a new year, I know many of these families are looking forward with a glimmer of hope – hope that the next year will bring answers to their questions and concerns, hope that their children will get the support they need and deserve.

Fortunately, at least here in New Jersey, there is reason for optimism. Trenton seems poised for a paradigm shift in the way it manages disability issues. State Senate President Steve Sweeney, whose daughter was born with Down syndrome, has been a champion in this space. Many other legislators, including several from our Bergen delegation, have been passionate advocates themselves. And very soon we will have a governor, Phil Murphy, who has demonstrated a genuine commitment to people with disabilities and their families and has expressed his determination to give them a seat at the policy-making table as a starting point.

Moreover, New Jersey is home to an increasingly robust and effective network of non-profit organizations, providing critical services and supports. They come in all shapes and sizes, but

are largely staffed by dedicated professionals who come to work each day with an unrelenting sense of purpose.

My hope, therefore, is that 2018 will be a real game-changer for these parents and their children. A more user-friendly government that is easier to navigate for disability programs and services. Better housing opportunities that allow for more independent living as well as safer group home options. The resources needed to hire and retain the very best direct support professionals to assist and protect their children.

And as such, my hope is that – by working together – we will begin to mitigate “the hard truth” and change the narrative for these families by creating a community of care throughout our entire state.

After all, no parent should want to outlive their children.

Paul Aronsohn, a former mayor of Ridgewood, is a founding member of the Ridgewood Community Access Network, a local disability organization. He is also a Board Member of Heightened Independence & Progress (Hackensack) and the Adler Aphasia Center (Maywood).