

Please Vote Yes to Reduce the Waiting List for Comprehensive Residential Services for Adults with Intellectual and Developmental Disabilities in Colorado.

Name: Alan, Kathy, and Jake Tuchfeld
Littleton, CO
Zip code 80122

Picture of our family:



About my son or daughter with IDD: Jake is an active 21-year-old young man with significant cognitive and developmental delays. He is nowhere near the independence or executive functioning levels of his typical peers. He is dependent on support to most daily living skills. He is mobile, has some communication skills when he has familiar listeners, and is able to engage in some leisure activities. Jake is not able to dial a phone, call 911, bathe himself, prepare food, travel, schedule appointments, read, write, or many of the things necessary to be at an independent level where he could be alone for even a few minutes. He is under supervision 24 hours a day and 7 days a week.

Jake is not able to cross a street, unlock the front door, feed the dogs, or use the remote control for the TV without assistance. When he is at home we modify, redirect, and provide for his needs. To give you some concrete examples of how different daily life in family with an individual with ID/D can be:

*we provide full assistance with bathing (regulating water, getting in shower, staying safe in shower, soaping, scrubbing, washing hair and all body parts)

*we provide all shaving, deodorizing, grooming, and nail clipping

*all food, drinks, and toileting require assistance

Since he turned 16, we have researched and sampled Day Programs in and around the area where we live. He has participated in several experiences during his school breaks. He has truly enjoyed his experiences and learned new things through each program. It is a blessing to have the opportunity to try on programs before they become a daily necessity. However, there is a great difference in economics for families to provide this for ten weeks of summer break and then at 21 being faced with 12 months a year for an indefinite future.

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About my family: Alan and I have been married for over 22 years. Jake is my only biological son, but he has 2 older step-brothers. Jake is completing Transition from Littleton Public Schools and will be moving into Day Programs at the end of May. Over the years our journey has been tumultuous, scary, undefined, and the greatest joy ever. We have put Jake's needs to the forefront of this family. He has been able to attend quality programming from the time he could leave the house without being too medically fragile. We have traveled to conferences to learn about therapies and best practices to meet his needs. We have spent weeks in other states in order to get these services. This has been greatly out of pocket expenditures for our family and many times has needed the resources through extended family members. Our insurance bill before we left the neonatology unit several months after birth was well over 2 million dollars. To meet the needs of an individual with special needs it is often joked that you need over a million dollars. This is not funny because it is so true.

My husband and I both work. I am an elementary school teacher and he runs his own residential real estate appraisal business. We are in the sunset years of careers. Yet, when you spend your discretionary (and non-discretionary) income to meet the needs of your loved one, you worry that the sunset won't be beautiful and enjoyable. You worry that you will need to work until you drop and even then it won't be enough.

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Why we need this resource to plan for the future of our family:

As mentioned earlier my husband and I both work. This is necessary to provide for the needs of our son. With both of us at work it is imperative to have coverage of supervision for Jake. Also, as we age and close out our careers we will be retiring. Just because your parents reach the age of retirement does not mean the individual with a disability wants to retire with them. These young individuals have been raised in active communities that welcome them and they are a vibrant part of our social world. For young adults that are not able to enter the work force, they have to depend on the services and programs available to help them stay tethered to community supports, social navigation, and quality care that help them stay safe, well cared for and a vital part of their own communities.

As families age and retire several things happen:

- *you realize how much money you have not saved because there was never any left after all of the expenditures paying for care, therapy, higher levels of insurance, greater needs with services, and medical bills.

- *you realize how worn out you are from moving at the speed of light for so many years.

- *your support system ages with you

- *you don't want to leave the burden of care to siblings who are raising their own families

- *the expected level of independence does not materialize with significant disabilities

- *the cost for care never ends

- *the person with the disability needs an active, empowered, and purpose filled life with the support of others

We need to eliminate the wait list before the lives of individuals with intellectual and developmental disabilities are negatively impacted through neglect, improper levels of supervision, dangerous and exploitive situations.