



Dear Legislators,

I am the parent of an 18 y/o young man with severe, profound autism. Our hope, is that he will be able to move out of our family home into a home of his own in the next couple of years; a home where he can be safe, be happy and thrive. As government funded developmental centers have closed for cost cutting reasons it seems, I have been looking for a suitable home for my son now for several years, a home where he can hopefully live for the rest of his life. Unfortunately, those who advocated for closure of these developmental centers did not provide an answer as to where our adult DD population could live, or presumed this population would live indefinitely with the aging parents. Our worst nightmare, as parents of the developmentally disabled (DD), is that we die and there is no long term housing for our adult children in place. As you know the state and federal mandates tell us that our DD population should have the right to live in the community of their choice. Those with severe developmental disabilities can never earn a competitive income. Where can such people find housing in their community on a portion of their social security monthly income?

We have looked to day programs in different areas of the bay area for when my son is out of school. Unfortunately, as you may know, because rates for such programs are so low, they for all practical purposes exist only as a concept – a dream. Please look to San Francisco as a perfect example. There are no programs available for a person like my son.

We have had well meaning and compassionate help with an array of Regional Center case managers. Unfortunately, again as you know, their salaries are not competitive, and as a result, they can not stay in this same high pressured position for long. Currently each case worker at Golden Gate Regional Center has many more clients than the maximum of what has been the mandated upper limit. No wonder they come and go.

The severely developmentally disabled, is without question the most vulnerable sub-group of our population. They require ongoing lifetime care, and they are not able to advocate for themselves. Such basic and appropriate care and service is NOT being met as this of course requires adequate funding. Please do the right thing and our supports and services for our adult DD loved ones, and not continue to place the financial burden on parents

Sincerely,

Stephen Brotzman

To our California Lawmakers,

We are writing you to ask for your help. We are in desperate need for a funding increase for the Developmental Disability System.



WHY?

Our 30 year old son, Kevin Chu, is a very active young man on the Autism Spectrum. Despite being a client of Golden Gate Regional Center, there are many doors closed to him.

As his aging parents we have noted the following deficits in services provided for this population with Developmental Disabilities:

1. **Affordable Housing.** My husband and I are approaching our 70's. Kevin lives with us. Where will Kevin live when we are not around? He wants to move out. His fraternal twin non-disabled brother, Kyle, has moved out to his own apartment. Kevin is having a difficult time trying to understand why this has not been possible for him. Another obstacle is

Kevin's income is below the minimum income for below market rate rentals. Where do we go for help? Right now, no one is available to help us. (see #2) Do we have to wait until we are in our 80's, 90's and in a nursing home before someone can help us help Kevin?

2. **Housing Resources** to assist us in meeting his need for affordable housing. e.g. there is a 2-3 year waiting list for Brilliant Corners. It locates and provides housing opportunities for people like our son.
3. **Personal Assistant Hours** I wish funding allowed Kevin to be eligible for more hours of Personal Assistance so he could pursue his many interests and to be more active in his community. He sure has the energy for it. Unfortunately, his parents are tired old seniors.
4. **Social Workers at Regional Centers.** We need an expanded budget to accommodate MORE social workers. Why are Social Workers' caseloads at Regional Centers so much higher than their counterparts? Which translates to Kevin, *less* "quality time" for the neediest people and their families.

Due to early detection and medical vigilance, the numbers are increasing in the identification of infants, children, and people with disabilities. Services and resources must accommodate this growth.

What is available now is stretched thin. It is not working well for families who continue to struggle to provide a greater quality of life for their loved ones with disabilities.

Please help us. We ask you to support more funding in providing much needed resources and services.

Thank you for your time and attention.

Regards,

Kevin's Parents
Robin and Alycia Chu
San Francisco, CA

Dear California Legislators,



I'm Kris Moser Downing, this is a photo of my 28 year old daughter Anna, who has a very rare neurological disorder called Aicardi Syndrome. Anna, her Dad and I live in San Francisco and we depend upon GGRC for many things. Anna typically has 10-20 tonic-clonic seizures a month and is developmentally delayed. She can walk with assistance but cannot speak. Just the same, Anna is a very social young adult with a real joy for life.

GGRC supports are essential to us and to other constituents of yours. I know at least 3 other families who live within 3 blocks of my home who also rely on GGRC. I'm sure there are others. We are very concerned about GGRC's funding. We need funding increases to assure that services can continue and also to provide programs to help with needs that are not being met.

One unmet need is that there is no day program for my daughter. There are no day programs that offer one on one support. My daughter needs that support because of her high seizure rate. We are grateful for the personal assistant, Amanda, that GGRC provides in place of this program but we are worried that Amanda may not be able to continue working with Anna since her wages are low and the cost of living in S.F. is high and going up all the time.

Having a personal assistant is great but it does not provide social opportunities for Anna. I have to work hard to find social opportunities for Anna. In spite of her communication limitations, Anna is a very social person and loves being with her peers. People with severe disabilities should have a day program like their more able-bodied peers.

In addition, Anna actually has no GGRC case worker at the moment. Anna had a really great case worker who started with her when she was in preschool and stayed with her for many years but sadly she had to quit and take a job with another non-profit because her GGRC pay rate would not allow her to live in SF. Anna's most recent case worker was also helpful but he developed a medical problem. We are really sorry about this. He was very helpful. For example, at a recent IPP meeting he asked if Anna had fallen recently. We described how she had fallen at the pool where she swims and gets PT. Anna bounced herself out of the pool wheelchair and fell and hit her head so we took her to the ER. Thankfully the doctors checked her out and she was OK. I filed an accident report with the pool managers. The problem could have been avoided if the pool facility had a pool wheelchair with a functioning safety belt. I had asked pool managers to get a new wheelchair previously but they did not get one. But I noticed that shortly after Anna's IPP the pool got a new wheelchair with a good safety belt. I believe GGRC applied some pressure due to Anna's case worker reporting the incident.

Having a GGRC worker helps us deal with issues that are difficult to deal with as just one family. But now when issues arise we have no case worker and are referred to a supervisor who does not know Anna at all. GGRC should be funded properly so that the staff there can cover everyone and so that they can be properly trained.

In addition, there is a critical shortage of housing for disabled adults. There are long wait lists for these homes and many of our friends who have children with disabilities are trying to deal with this issue. Anna's Dad and I have planned for this. We own our condo so Anna will have a place to live but I'm very concerned that as her Dad and I age we eventually will not be able to care for her in the evenings, and once we have passed, we may not have enough savings to pay for caregivers who will need to fill in for us. I know from managing the care of my quadriplegic mother how quickly savings can be depleted.

When you vote on issues that affect developmentally delayed adults, please remember Anna, her Dad and me and other families with disabled children. We are your constituents. We need adequate GGRC support to care for our children. Thanks again for listening!

A handwritten signature in black ink that reads "Kristine Moser Downing". The signature is written in a cursive, flowing style.

Kristine Moser Downing

March 6, 2019

I am writing about the services my 31-year-old developmentally disabled daughter receives through Golden Gate Regional Center.

My daughter has been a client of the Regional Center since birth. She has been diagnosed with Cerebral Palsy and moderate developmental disabilities. Her challenges include speech impairment, physical limitations which include fine and gross motor skills, and an inability to handle many activities of daily living. She attends a day program at The Arc San Francisco, and lives with me.

Outside of her 5.5 hour/day program, there is not much other in the way of services or activities available to her, besides what I can come up with. The Case Management of GGRC includes a case manager who takes care of all the paperwork that goes along with her annual service plan, and meeting with us once a year to briefly review her plan. He also processes a POS for her to attend camp in the summer, under out-of-home respite funding.

Her needs are much broader, as she does not have the independent skills necessary to live in the community. She needs to have someone who spends more time with her to help her develop her skills to be more independent, to have more self-confidence in her ability to learn new skills, to address her social/emotional maturity and ability to handle the challenges she deals with in life.

The funding that provides Case Management is grossly lacking. An hour a year to meet with us, and processing paperwork, is not sufficient. And it is not really Case Management. I am my daughters real Case Manager, and I am not going to be here forever.

The funding for personal supports, for case management and help with developing places for her and others to live without their families is just non-existent. Families like myself are being strained both financially and emotionally and psychologically with the care of their adult children with developmental disabilities.

Individuals like my daughter are members of our community and deserve better. The system has not kept up with the number of individuals, or the services they require. Families are stretched beyond their ability to cope. We need an increase in the amount of funding and a guarantee that our children will not become homeless or live in inappropriate settings, and be neglected when we are not here to care for them.

Thank you,
Linda Tung
San Francisco



March 7, 2019



To whom it may concern:

Our beautiful daughter Lizzie is an outgoing and fun-loving twenty-one-year-old who enjoys toasting, going museums, watching action movies, greeting customers at Walgreens.

She also lives with significant pulmonary, orthopedic, and cognitive challenges, a function of her being born with the chromosomal anomaly Trisomy 18. She requires respiratory treatments twice a day, must be fed via gastrostomy tube, and takes medication for seizures. To say she requires a high level of care is an understatement.

Since she was born Lizzie has received a myriad of services, from California Children's Service, to Golden Gate Regional Center, to MediCal and, currently, SSI. Lizzie's mother and I have, from the beginning, coordinated all the services ourselves. !

We have also provided much of the day-to-day care for Lizzie ourselves, since the rates offered by GGRC and In Home Supportive Services are not not competitive enough in the Bay Area to attract many candidates—let alone quality candidates.

In effect, Lizzie's mother and I have not only been Lizzie's caregivers and nurses, we have been Lizzie's case managers. It hasn't been easy, but we have made it work.

But things are about to change.

When she turns twenty-two in May, Lizzie will no longer be eligible to receive services from the school district. (She currently attends the ACCESS program.) She is on the waitlist for several day programs, which currently have no room due to capacity constraints, but acceptance is by no means guaranteed. Moreover, if her medical needs get to the point where she requires a one-on-one assistant, there are currently NO programs in San Francisco that offer one-on-ones.

Lizzie's future is uncertain and we are concerned.

It doesn't have to be this way.

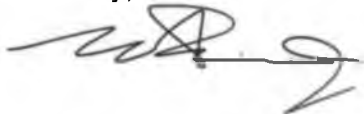
The developmental disability system in California desperately needs more money. More money for provide competitive rates in places like the Bay Area so that families can hire quality caregivers. More money so that day programs and group homes can increase capacity and offer one-on-one assistants. More money so that the regional centers are adequately staffed so that their case workers can provide families with *real* case management of services.

The California system of developmental disability services, broken and underfunded, is riding on the backs of stress-out and over-worked families like ours.

I urge you to take the first step toward fixing the system by supporting increased funding.

Thank you for your consideration.

Sincerely,

A handwritten signature in black ink, appearing to read 'W. Bivins', with a long horizontal stroke extending to the right.

William Bivins



Dear Legislators,

This is a picture of my daughter, Valerie, who passed away last year at the age of 32 from respiratory complications after contracting the flu.

Valerie, who had severe multiple disabilities, made use of a wide array of services, including IHSS, MediCal, and a long list of GGRC-funded supports.

I know it sounds awful but, in the midst of my grief, part of me is also relieved. I spent the last 10 years trying to put together a system of support for her that would outlast me. As a single parent in my late 60's, I was all too aware of how much of her life depended on me.

I began seeking below-market-rate housing for her seven years ago, and she was on at least 12 waiting lists. Nothing ever became available, as the housing situation is and has been bleak, as you certainly know. Where would she live when I was gone? Valerie loved being in the community with her friends - not in a medical facility - and state and federal mandates support her choice.

The day program that provided the one-to-one support she needed closed five years ago and, due to funding shortages, no new programs have replaced it. There are currently NO programs that accept clients needing that level of support in San Francisco, and no openings in the very few existing in surrounding counties.

The only way she was able to access an appropriate program was for me to become vendorized by the Regional Center and run the program myself. This meant I had to hire, train, and supervise staff; handle payroll and tax issues; and fill in myself when someone was sick or quit. And the turnover was high, since the salary provided is far from adequate. How could this work without me?

Transportation was also a problem. The bus company that used to bring her to and from her program went out of business because they couldn't retain drivers at the low pay rate they were able to offer. The Paratransit system we used once she was in a self-directed program was also unreliable and frustrating on a daily basis.

Finally, we have been frustrated by the diminished assistance from our Regional Center case managers, due to frequent staff turnover and huge caseloads. Case

management is a crucial service in California's confusing and fragmented service-delivery system.

The Developmental Disability system desperately needs money! We need Day Programs, Employment Programs, Housing, and fair pay for direct support staff. We need Regional Centers to be able to pay their staff well enough to keep them working and supporting our consumers.

We in California celebrate diversity, including differences in abilities, and both the state and federal governments mandate community inclusion. With Developmental Centers closing, we have no fallback. Please keep the promise.

Sincerely,

Audrey deChadenedes
San Francisco, CA 94132