DISABILITY VOICES UNITED

REALITY CHECK

Contact: Judy Mark, President, 310-621-2045
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Safety Net and Crisis Services from the Self-Advocate & Family Perspectives

Provided to the Senate Budget Subcommittee #3, Health & Human Services

March 15, 2018

Executive Summary

Many individuals with developmental disabilities experience extreme behavioral challenges that set them and their families into crisis. These extreme behaviors can put enormous burdens on families and require heightened levels of behavioral and medical support to ensure the safety and health of the individual. Some of the residents who remain in the soon-to-be-closed Developmental Centers (DCs) need this level of support, and the Department of Developmental Services (DDS) is establishing new enhanced services for them as they return to community settings.

In the 2017-2018 fiscal year, the state legislature appropriated $21.2 million to fund a “Safety Net Plan” to “broaden the continuum of service options to support individuals with the most challenging service needs.” The Safety Net Plan is not only for “DC movers.” It also targets individuals who live with their families or in the community and face similar challenges. These individuals have often found that the Regional Center offerings for support for extreme behavior are inadequate or non-existent.

Our concern is that the legislature and DDS’s Safety Net Plan have been overly focused on developing services and placements for the 534 DC movers, and not enough attention has been paid to the far greater number of adults and children in the community who have equally challenging support needs. Most of the homes, wrap-around services, and mobile crisis units are being developed in the areas where the DCs are located. Moreover, we believe that the broader voice of community families – representing consumers of all ages who have not resided in a DC – is not being heard in the development of the new supports. Our fear is that when the last DC resident has moved out, attention will turn away from this critical need to support other individuals and families in crisis.

In addition, we are concerned that the development process being implemented by DDS and the regional centers is taking too long, especially for those families who are currently facing crises. While DDS has recently established timelines, the pace to create these services is extremely slow.

Disability Voices United primary recommendations include:

1. Provide additional funding to develop more options for all adults and children facing crises, including restoring the $5.6 million in funds from the Fiscal Year 2017-2018 budget.
2. Create clear deadlines for opening of crisis homes and for statewide availability in all regional centers of the Crisis Assessment Response Teams (CAST) and ensure that there are enough providers to respond to crises within 48 hours of request.
3. Streamline the system for accessing health and safety waivers and require a response from DDS within 30 days if the individual is in crisis.
4. Ensure that all housing and services developed are available to all consumers, not just those moving out of Developmental Centers, and require information be provided to families about the availability of crisis services, including how to access crisis response teams, process for entering crisis homes, how a waitlist will be handled, and support to allow individuals to stay in their homes.

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This report and recommendations were researched and written by Ann Hien Bui (sibling, Sacramento), Diana Pastora Carson (sibling, Jamul), Connie Lapin (parent, Northridge), Judy Mark (parent, Los Angeles), and Nina Spiegelman (parent, Albany), all volunteers who serve on the board of directors of Disability Voices United, a statewide advocacy organization directed by and for individuals with developmental disabilities and their families. We advocate for: choice and control over our lives; meaningful outcomes that matter to us; and, systems that are equitable and accountable to us.

Introduction: The Whole Family in Crisis

In California, the Lanterman Act establishes a system of Regional Centers to provide services and supports for individuals with developmental disabilities. This population includes children, adolescents, adults who experience behavioral challenges of differing degrees in various settings. For a subset of these individuals, the behavioral challenges can be extreme and can involve severe aggression including physical aggression (assaults causing injuries by hitting, biting, pushing, scratching, choking), property destruction (breaking furniture, residential windows, doors, walls appliances, breaking vehicle windows and interiors) and self-injury (self-hitting, scratching, cutting, head banging, running into traffic, rectal digging and fecal smearing, suicide attempts).

These extreme behaviors can put enormous burdens on families and require heightened levels of behavioral and medical support to ensure the safety and health of the individual. Historically, California's developmental disabilities services system used the now closing Developmental Centers to address – however inadequately and inhumanely – these support needs for some individuals. Efforts are now underway to develop enhanced behavioral supports for residents of the Centers as they return to community settings.

The need for enhanced behavioral support, however, is not experienced only by individuals living in Developmental Centers. Families have been and are continuing to struggle to keep their family members living safely at home or, when that is no longer possible, to find an appropriately supported residence in their communities. But too often, there is nonexistent or inadequate support, and even heroic efforts by loving families and caring staff cannot prevent extreme behaviors from erupting, becoming dangerous and requiring crisis intervention.

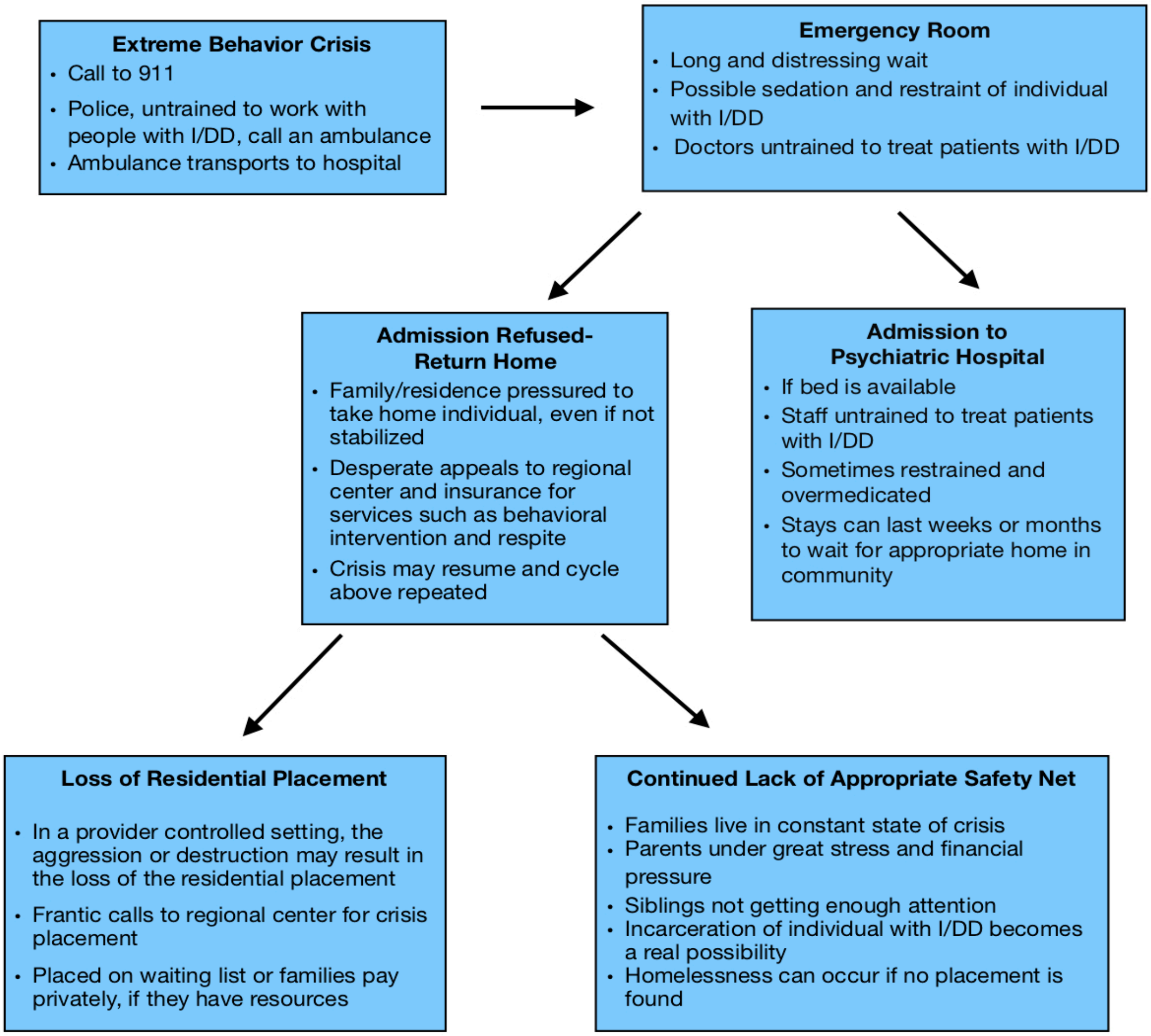
For many individuals and families, the Regional Center offerings for support for extreme behavior are often inadequate or non-existent. The majority of group homes and supported living service (SLS) agencies (as well as many adult day programs) do not serve individuals with extreme behaviors. Those services that will provide that level of support rarely have space and even, when available, may not be an appropriate fit in an individual situation. For service providers and behavioral agencies offering coverage, recruiting and retaining appropriately trained staff remain a constant challenge.

Moreover, the providers often fail to search for causes of extreme behaviors, which can range from sensory issues to a change in support staff to issues within the family to pain somewhere in the body. Because they are dealing with the crisis, families often overlook the causes of an extreme change in behavior, especially with non-verbal individuals. Underlying health issues are commonly the culprit, from a simple toothache to a cancerous tumor causing terrible pain. A thorough health assessment is rarely conducted for individuals in crisis.

In addition, families and agencies attempting to manage extreme behavior may need to pay higher wages to support workers than approved in the system. The Department of Developmental Services (DDS) establishes rates for service providers that are usually much lower than what is needed to support an individual with significant behaviors. Families sometimes seek Health and Safety Waivers from DDS in order to use higher paid staff to prevent crisis situations. Individuals in crisis who are moving from one setting to another may also need enhanced funding and higher rates for the transition period. Those requests, which need immediate attention to avert crises, instead go into a long queue in the state bureaucracy. Consequently, it becomes very difficult to recruit and retain staff and the crises for the individual gets much worse, sometimes leading to hospitalization and a much more restrictive setting.

Unfortunately, the repertoire of support options for a person in extreme crisis is similarly inadequate, often inappropriate, or ineffective. The chart below shows how many families must face an extreme behavior crisis by their family member:

Common Experience of Families of Individuals with Developmental Disabilities Facing Extreme Behavior Crisis



Extreme Behavior Crisis
- Call to 911
- Police, untrained to work with people with I/DD, call an ambulance
- Ambulance transports to hospital

Emergency Room
- Long and distressing wait
- Possible sedation and restraint of individual with I/DD
- Doctors untrained to treat patients with I/DD

Admission Refused-Return Home
- Family/residence pressured to take home individual, even if not stabilized
- Desperate appeals to regional center and insurance for services such as behavioral intervention and respite
- Crisis may resume and cycle above repeated

Admission to Psychiatric Hospital
- If bed is available
- Staff untrained to treat patients with I/DD
- Sometimes restrained and overmedicated
- Stays can last weeks or months to wait for appropriate home in community

Loss of Residential Placement
- In a provider controlled setting, the aggression or destruction may result in the loss of the residential placement
- Frantic calls to regional center for crisis placement
- Placed on waiting list or families pay privately, if they have resources

Continued Lack of Appropriate Safety Net
- Families live in constant state of crisis
- Parents under great stress and financial pressure
- Siblings not getting enough attention
- Incarceration of individual with I/DD becomes a real possibility
- Homelessness can occur if no placement is found

The previous chart is drawn from real experiences of families contending with the limitations of our DD system's capacity to help our loved ones live the life the Lanterman Act envisions. When families gather at DD events (conferences, trainings, transition fairs), inevitably there will be a subset of people desperately seeking information and help for their family members grappling with extreme behavior. And we tend to find each other as we notice our collective lack of enthusiasm for the reports of the latest exciting, innovative programs that don't serve our family members with behavioral challenges.

Danny's Story

Danny, age 22, is a client of the Regional Center of the East Bay (RCEB). He has autism and anxiety disorder and has had a period of anorexia. Between the ages of 12 to 15, and again at age 19, he was in crisis with obsessional agitation and severe aggression. A vast array of psychotropic medications were prescribed in an unsuccessful effort to calm the aggression in order to get in home help or to go anywhere outside the home. When Danny was 12, his older brother died of cancer and when he was 15, his father committed suicide. Danny's behavior became uncontrollable and extremely aggressive. A 911 call was made to the police and Danny was put on a 5150 psychiatric hold and spent 2 weeks in an adolescent psychiatric treatment facility. Then he was transferred and spent 3 months in RCEB's adolescent stabilization unit, which provided no therapeutic support, yet provided a roof over his head. Ultimately, Danny was placed in an adolescent "step-down" group home where he received therapeutic support and thrived and where a social and joyful person emerged. His aggression and anorexia abated and Danny was able to participate enthusiastically in the community.

At age 19, while living at a different, adult group home, Danny's aggression returned. There were repeated calls to the regional center's mobile crisis response unit over many months. The mobile crisis response unit sometimes helped diffuse scary situations but was mostly ineffective in preventing a descent into an agitated and aggressive state. And again, ultimately the 5150 call was made. Danny was taken to the ER and to a psychiatric hospital for week stay. Danny's mother reports that she had to beg, literally, for Danny to be admitted because of Danny's developmental disability for which the staff was untrained. Because Danny's insurance would only cover a one-week stay, she had to hunt for a new place for Danny to go, as returning to his adult group home was not possible. All crisis beds were filled, there was no adult version of a step-down home, and there were no openings at any other appropriate group homes.

Through her connections with other parents of disabled children and professionals, Danny's mom was able to find an excellent care provider who took Danny after his release from the psychiatric hospital. She and Danny's care provider have created a personalized program that works with Danny's behavioral needs. Danny is flourishing in this setting in his own community. But this care provider will not become a vendor of the regional center because the rates are too low and the bureaucracy is too high. Danny's mom must bear the enormous expense on her own. In fact, his mother has received no funding from the regional center for his personalized supported living program. For the last two years, the only service the regional center has paid for is three weeks of summer day camp, which amounts to approximately $1400 each year.

Danny's mom states that the most traumatic part of dealing with the crises is "the realization that there is no reliable safety net for severe aggression situations due in part to the DD/ mental health false choice situation. At Danny's most recent 5150, if our occupational therapist and I hadn't filibustered and begged, Danny would not have been admitted for his needed stay at the hospital and there was truly nowhere for him to go." Danny's mother's biggest fear is that "Danny will not be able to continue to live in a situation that meets his needs, allowing for growth and happiness. What he needs is not an off-the-shelf offering from the Regional Center - none of the current supported living agencies or group homes fit. Without the right support, I fear the return of the severe aggression and the possibility of prison or homelessness."

The Reality of Current Safety Net Services for Many Families

The current system of supports for regional center clients in behavioral crisis is not meeting the needs of many. Below is a list that includes the range of services that regional centers are supposed to offer these individuals and their families. We include a column with the realities of these services for families based on the stories we have collected.

Current Safety Net Services for Regional Center Clients in Behavioral Crisis	Realities of Many Families
Personal assistance	Can't find workers; untrained workers; high turnover; wage too low; difficult work
Behavior intervention	For autism, insurance must pay first; waiting lists for agencies experienced with significant behaviors
Intensive day services	Few, if any available. Many adult day programs won't accept individuals with significant behaviors or will kick them out
Respite	Has been capped at 30 hours. Even with lifted cap, hard to get more hours. Hard to find and keep workers for low wage.
Telemedicine	Not useful for individuals in crisis; specialists don't know the individual
Mobile crisis/behavioral support team	Not available when needed or not helpful. Many families have never been offered this service.
Enhanced behavioral supports home Delayed egress/secured perimeter home Community crisis home	Few beds available and even fewer close to the family home. Some regional centers hold onto empty beds in their catchment area. Staff often untrained. Individuals sometimes abused in home. Not available for children in crisis.
Stabilization, training, assistance, and reintegration (STAR) home in Northern and Southern California	Few beds available. Most families don't know about their existence.
Acute psychiatric hospital	Many individuals spend extended time in these hospitals without stabilization. Individuals often are overmedicated, restrained, or suffer from abuse. Families often have little access.

The Safety Net Is Not Just for DC Movers

To further the goal of improving the safety net, the legislature required the creation of the Developmental Services Task Force, which includes various stakeholders and has been convening for the past few years on issues related to the closing of the DCs and crisis services. As part of their work, the task force developed a set of principles and an excellent definition of the safety net:

Timely access to essential services and supports necessary for persons with developmental disabilities to maintain health and safety and to address medical, psychiatric, behavioral, residential, staffing, equipment, or other needs, when other services and supports fail, are interrupted, are not available, or additional services and supports are necessary for an urgent or medical need. May or may not require a change in placement.

Last year, the California legislature appropriated $21.2 million to fund a “Safety Net Plan” to “broaden the continuum of service options to support individuals with the most challenging service needs.” DDS designated these desperately needed new funds for specific purposes, with a primary focus on moving out the over 500 people remaining in California’s institutions called Developmental Centers (DCs).

It has been a major goal of Governor Brown and the state legislature to close the Developmental Centers for two equally compelling reasons: 1) to finally shut the remaining institutions in California and offer these individuals a better life in the community, and 2) to save California taxpayers a boatload of money. Because there are relatively few residents left living on expansive and expensive land with fixed upkeep costs, it is estimated that each Developmental Center resident costs the state over a half million dollars per year.

Note: There will be significant savings to the state because of the closures of the DCs – approximately $100 million annually, according to a recent report from the Legislative Analyst Office. But at this time it is unclear whether those savings will remain in the developmental disabilities system to pay for services in the community. We strongly support that the savings from the closures stay within our DD system to assist individuals with the most significant needs who reside in the community.

Our concern is that the legislature and DDS’s Safety Net Plan have been overly focused on developing services and placements for 534 DC movers, and not enough attention has been paid to the far greater number of individuals who reside with their families or in community settings who have equally challenging support needs. Our fear is that when the last DC resident has moved out, attention will turn away from this critical need to support other individuals and families in crisis.

Steven’s Story

Virginia Escobedo of Chula Vista, California, is raising two grandsons who both have Fragile X and autism, and one of whom also has diabetes. Ms. Escobedo’s adult daughter with a milder developmental disability lives in the home as well. Steven, 21, the older grandson, is 6’2,” is nonverbal, and becomes aggressive. He and his younger brother, Angel, also nonverbal, do not get along well and trigger one another’s behaviors. Steven lived in a level 4 group home for 4 years until, in September 2017, he ended up in the ICU for 5 days due to lack of appropriate nutrition for his diabetes. Ms. Escobedo opted not to return Steven to the group home for fear that his health and his life would be in jeopardy. Since bringing Steven home, she has received no respite services. She was told that due to Steven’s need for insulin injections, respite providers could not accept liability. Steven was also not able to go to school for 6 weeks due to the insulin injection issue and lack of coordination between the school and the medical professionals.

During this period of time, Ms. Escobedo experienced many crises in which she had to evacuate from her home to protect herself and her other family members from Steven’s aggression. She endured hours of hitting, hair pulling, pushing, and intense scratching. Her arms are still marked up from his scratching. In February, Steven was approved for insulin pills instead of injections. San Diego Regional Center offered 25 hours per month of respite which is hardly enough for Ms. Escobedo to get a true break. She will use the hours to take care of her own health appointments and to shop for her grandchildren. The respite hours granted were as a result of a home health nurse who advocated on behalf of the family, seeing how Ms. Escobedo was continuously exhausted. Ms. Escobedo’s greatest fear is that others will not be able to care for Steven adequately and that he will end up in a diabetic coma. She is also concerned that she will not be able to physically endure Steven’s aggression, or that she will become ill or die, and he will not have qualified people to take care of him.

New Crisis Services and Supports Are Being Developed Too Slowly

We are pleased that DDS has stated that the new supports being developed will be available to any consumer who is facing a behavior crisis, not just people moving out of a Developmental Center. But because people living in a DC have a current place to live with extensive supports – regardless of one's opinions of the quality of those supports – the urgency to develop these new services is felt far greater by those in crisis living with their families or in the community.

In May 2017, DDS laid out their Safety Net Plan with details on how they would spend the targeted $21 million. Very specific plans, and, recently, a timeline were provided. However, the development process, some of which is being implemented by DDS and others by regional centers, has been moving very slowly, especially for those families who are currently facing crises.

In addition, DDS is working with stakeholders and regional centers in developing the priorities for the Community Placement Plan and the Community Resource Development Plan funds. Regional centers are required to conduct outreach and engage stakeholders in the development of their plans and funding requests. The DDS process to develop guidelines is moving forward but it is likely to be a long time before new services are actually available for people in crisis. And, once again, it is imperative that the guidelines include the full input of the community, not just those related to the closing of the Developmental Centers.

We are, however, encouraged that DDS has promised that services will be developed through person-centered planning with a focus on "cultural competence, positive behavior supports, and trauma-informed care." We are concerned that there be adequate oversight to ensure these goals are met with each individual needing safety net services.

Belen's Story

Belen is 12 years old and has a diagnosis of autism. He is from Imperial County and is served by San Diego Regional Center. According to his mother, Johanna, Belen was in need of ABA therapy services (Applied Behavioral Analysis) for some time, yet their insurance took too long to approve of the therapy. Due to a behavioral emergency in which a 5150 call was made, Belen was forced to leave the family home. Belen was initially taken to a hospital in Imperial County, but it was unable to meet his needs, and no psychiatric hospital would take him. So Belen was transported to San Diego County and admitted to a hospital there for psychiatric intervention services. The mom also sought to get Belen admitted to Rady's Children's Hospital's onsite CAPS program but his insurance denied him that opportunity to receive specialty services.

Johanna reports that, in spite of her quest to find an appropriate placement for her son and the many interventions attempted (respite services, home crisis intervention services, ABA referral, placement referrals, nursing assessments, behavioral observations, therapy assessments), her son's intense needs were not being met. She asserts that there is a lack of appropriate adolescent placement homes and facilities in her community and beyond. She also states that San Diego Regional Center permits vendors of these services to choose their clients, which posed as a barrier to finding a placement for Belen.

Johanna reached out to the regional center for help on multiple occasions. They were promised help, but were ultimately told by Regional Center representatives that there was nothing they could do unless a group home or facility agreed to accept Belen. She also reached out to a State Assembly Member, and never heard back.

To date, Belen's situation has not been resolved. He was on hold for the CAPS program for 6 months without any educational rights or educational program. In January, educational rights were finally addressed. Johanna states that "the most traumatic part is being the parent and leaving my son in a hospital by himself. For Belen to be in a different environment, with a different schedule, away from family, is devastating." The mother's biggest fear is "not finding an appropriate place for Belen that includes his education and opportunities he needs to reach his potential."

The following chart covers information provided by DDS on the range of services that are being developed with the $21 million appropriation in Fiscal Year 2017-18. We then provide a list of questions and concerns from Disability Voices United and the many families with whom we work.

Type of Service	**Funding FY 2017-18**	**Status as Reported by DDS as of 2/21/18**	**Questions and Concerns from Families**
Establish 2 state-operated mobile acute crisis teams – Crisis Assessment Response Team (CAST) Only for individuals over 12 at risk of having to move from their home to a more restrictive setting *Number of people to be served: TBD*	$1.9 million from General Fund	Phasing in: Started accepting referrals as of 1/8/18 from: • North Bay RC • RC of East Bay • RC of Orange County • San Gabriel-Pomona RC	• Who is part of the CAST Team? • How many vendors are there? • What exists for children under 12? • How many referrals per month can they handle? • Are 2 crisis teams enough to handle the whole state? • When will CAST be available for all 21 regional center consumers? • Are you including families in the development of the program? • How are they making their response person-centered?
Develop intensive wrap-around services for persons with co-occurring DD and mental health needs *Number of people to be served: 20-30*	$3 million from Regional Center Purchase of Service (POS)	A meeting with ARCA and regional centers will be held to develop the scope of work *Projected service date: Summer 2018*	• How is this being monitored? • Is there a list of services that RCs have developed? • Have RCs provided a report to DDS on their wrap around services? • Are you including families in the development of these services? • Why is the number of people served so low?
Renovate two existing STAR homes on Fairview Developmental Center's Mark Lane in Costa Mesa to be five-bed state operated homes *Number of people to be served: 10*	$1.3 million from Harbor Village Account	Plans for renovation are under way and an architecture consultant will be signed to help with the design. Next steps are to secure permits *Projected service date: Fall 2018*	• Is the timeline realistic? • How long will individuals stay in these homes? • How will individuals be referred? • How will the homes abide by the new HCBS rules? • What about individuals whose families live far away? • How will the residents transition into the community as quickly as possible? • What are the qualifications of the providers? • Can individuals be evicted from these homes because of behaviors? • Are you including families in the development of the program?

Type of Service	Funding FY 2017-18	Status as Reported by DDS as of 2/21/18	Questions and Concerns from Families
Develop 2 four or five-bedroom homes this year and 1 additional home next year to relocate Sonoma STAR services and expand crisis capacity in Northern CA *Number of people to be served: 15*	$3 million from General Fund and CPP Start-Up	RC of East Bay leads housing development. Homes will be located in the North Bay Regional Center area. They have selected a HDO that has started a property search. An architect has been signed to help with design of specialized homes *Projected service date: Fall 2018*	• Is the timeline realistic? • How long will individuals stay in these homes? • How will individuals be referred? • How will the homes abide by the new HCBS rules? • What about individuals whose families live far away? • How will the residents transition into the community as quickly as possible? • What are the qualifications of the providers? • Can individuals be evicted from these homes because of behaviors? • Are you including families in the development of the program?
Develop 4 vendor-operated four-bed homes to provide step-down services for dual diagnosed individuals transitioning from IMDs or other emergency settings *Number of people to be served: 16*	$6 million from CPP Start-Up	Far Northern (1 home): RFPs have been posted Alta (1 home): Selected HDO who has initiated property search and RFP for provider was posted San Gabe/Pomona (2 homes): RFPs for HDO and providers have been posted *Projected service date: Fall/Winter 2018*	See questions above
Develop 2 vendor-operated four-bed homes this year and additional home next year to provide step down services for Porterville Secure Treatment Program Number of people to be served: 12	$3 million from CPP Start-Up	Location: Central Valley Area The HDO will be selected shortly and will initiate a property search. RFP for service provider posted and due February 23 *Projected service date: Fall/Winter 2018*	• When will this realistically open? • Will this meet the need? • What if the individual's family lives far from Central Valley? • Are you including families in the development of the program?

Type of Service	Funding FY 2017-18	Status as Reported by DDS as of 2/21/18	Reality Check
Develop intensive wrap-around services for transitioning out of Porterville Secure Treatment Program Number of people to be served: 25-35	$3 million from General Fund	DDS conducted a workgroup in August 2017 DDS is finalizing RFP to be posted Feb/Mar 2018. Contractor expected to be selected by April/May 2018 with a service start date of May *Projected service date: Spring 2018*	• When will these services realistically be available? • Are you including families in the development of the program?

Recommendations to Improve Safety Net Crisis Services to the Senate Budget Committee

Disability Voices United has laid out a set of recommendations with the ultimate goal of keeping individuals in crisis in their homes and the community. But, if that is not possible, we advocate for the development of services and supports **that can't say "no,"** meaning they cannot deny or remove the individual because of their behaviors. Our specific recommendations are:

1. Provide additional funding to develop more options for individuals facing crises, including restoring the $5.6 million in funds from the Fiscal Year 2017-2018 budget.
2. Create clear deadlines for opening of crisis homes and for statewide availability in all regional centers of the Crisis Assessment Response Teams (CAST) and ensure that there are enough providers to respond to crises within 48 hours of request.
3. Streamline the system for accessing health and safety waivers and require a response from DDS within 30 days if the individual is in crisis. There also should be an easily accessible exception policy for unique supports for individuals who are at risk of being in crisis. The issue of meeting local minimum wage requirements should be separated out from the need of a higher rate for individuals in or at risk of a crisis.
4. Ensure that all housing and services developed are available to all consumers, not just those moving out of Developmental Centers.
5. Require information be provided to families about availability of crisis services, including how to access crisis response teams, process for entering crisis homes, how a waitlist will be handled, and support to allow individuals to stay in their homes.
6. Require that additional stakeholders (non-DC consumers and families with children of all ages who have faced or are currently facing crises) are an integral part of the planning processes of developing new safety net services and programs at both the state level and at regional centers.
7. Create accountability measures and strong legislative oversight to ensure that the principles and policy recommendations laid out by the Developmental Services Task Force are enacted.
8. Create accountability measures to ensure that regional centers are offering consumers and families appropriate, comprehensive, culturally sensitive, and pre-crisis supports based on person-centered assessment and planning. Families and consumers should be surveyed to ensure these goals were met.

9. Prioritize the mitigation of abuse, neglect, restraint, and seclusion by providing funding for additional training for staff. Require that regional centers make cases of abuse transparent and inform families of each providers' records on abuse, seclusion and restraint, and special incident reports.
10. Develop a set of quality measures to assess whether individuals' crises needs have been met, they are stabilized, and there is a plan to move them back into a less restrictive setting.
11. Create more options and services for children under 12 who are in crisis, including pre-crisis planning for the families.
12. Require that Supported Living Services (SLS) are offered as an option in order to provide a more individualized level of support for people who experience regular behavior crises.
13. Require that the families are informed of the Self-Determination Program as an option.
14. Require special oversight by DDS of individuals in crisis who have no family to advocate for them and may have a non-family member or professional conservator to ensure that the least restrictive setting is arranged through a person-centered planning process.
15. Require that regional centers and providers explore causes of behavior, such as health crises, transitions, inappropriate placement, overmedication, and abuse.
16. Require DDS and regional centers provide data on:
    - The number of families/caregivers who have alerted regional center staff their family member is in a crisis.
    - The services provided to those individuals and their 1, 2 and 3-year outcomes for the individuals, ie, how long they lived in a more restrictive setting or hospital, how quickly were they moved home or into a community setting with supports
    - Whether the individual in crisis was provided a person-centered planning process to assist them in managing the crisis
    - The number of individuals in crisis who have been provided 24/7 supported living services
17. Require regional centers to assess the stress and hardship that a behavior crisis places on parents, family members, and other caregivers.
    - Ensure that families are aware of supports to relieve family stress provided by regional centers such as behavior respite, out of home respite, and parent training, among others.
    - Ensure that families are aware of supports to relieve family stress provided by Medi-Cal, private insurance, and other generic resources, such as family counseling, stress management, sibling care, and maximizing IHSS hours under protective supervision, among others.

Jake's Story

Jake is 12 years old and has a dual diagnosis of autism and severe mental illness. He is a client of San Andreas Regional Center. Between the ages of 8 and 11, Jake experienced behavioral crises that required specialized support outside of the family home. His behaviors were so unique and intense, however, that no in-state placements would accept him (except UCLA's psychiatric hospital, which ended up expelling him even though they were unable to stabilize him). As a result, Jake was transferred between various psychiatric hospitals and residential treatment centers in the West, East Coast and Midwest. Every intervention known to medical and behavioral science was attempted, including psychotropic medications, behavioral interventions, alternative therapies, and cutting-edge medical treatments. During these years of overwhelming effort on behalf of their son, Jake's parents resorted to a "joint custody like" arrangement whereby every other week, one of them would fly across the country to visit him, while the other would stay home to care for their other child. Two weeks later, they would trade roles. Since this arrangement made full-time work impossible, Jake's parents had to take two-year leaves of absence from their jobs.

It wasn't until they created their own specialized program for him on their own property that Jake was finally able to live again in California. For the past year and a half, he has been supported by a person-centered program in a home where he is the sole resident, and where he receives around-the-clock support from staff specially trained to care for him. Although he still has autism and mental illness, he is in a stable environment that he can call home, sees his family often, and receives personalized care. Jake's mother reports that the most traumatic parts of this experience were "fighting one battle after another with a series of hospitals, agencies and institutions that initially claimed to be client-centered, but then gave us one rationalization after another for making Jake someone else's problem," and "trying to troubleshoot constant crises - such as abuse, hunger strikes, and threats of immediate discharge - from thousands of miles away."

She also reports that finding an appropriate placement in California was hopeless. "We tried for years to attain a shred of stability and normalcy for our family by getting an in-state residential treatment center or specialized group home to accept him. But no one would touch him. Our stress, fear, and anxiety were so high that we were amazed – both at the time and in retrospect – that we both have nervous breakdowns. We constantly felt guilty of neglecting our other child in our efforts to keep Jake alive." Jake's mother states that unless there is some new medical breakthrough that enables his condition to improve, Jake may never be able to access the community, although his parents will continue to try everything in the hopes of one day achieving that goal. "Our priority is to keep Jake alive, safe, in California, and as content as he can be in the home we have created for him. At the very least, we want him to always know that he has a family that loves him."

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For more information on Disability Voices United, go to:
www.disabilityvoicesunited.org
530-JOIN-DVU