

Successful Community Living for People with Developmental Disabilities

UCSF Osher Mini Medical School for the Public

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Disclosures: I have no financial relationships with commercial interests.

Introduction

[slide: opportunity, stability, care, respect] I'm the Mom of an Autistic teen. Of course I want what's best for him. I want him to have opportunity, stability, care, and respect.

After trying to learn everything I could, I realized that *wanting* what's best, and knowing how to *achieve* it, are two different things.

Fortunately, we live in California. The Lanterman Act was developed by-and-for parents. It was signed into law by Ronald Regan in the 1970's.

A generation of parents and visionary lawmakers had the wisdom to see a future where people with developmental disabilities could have the same opportunities as everyone else, not separated or segregated; fully included.

Since that law has passed, our population has doubled, yet the vast majority of people with developmental disabilities remain in the community, where they live, work, laugh, and cry, like everybody else. The Lanterman Act has been immensely successful on so many levels.

[slide: Inclusion] I'm also a family physician specializing in the primary care of adults with developmental disabilities. This gives me the privilege of learning directly from people with disabilities, what's best for them. And to witness first-hand, how the Lanterman Act has been an advocate for them, by protecting their rights to receive care as fully-included citizens.

Before the Lanterman Act, families had to wait for placement in institutional centers. And while they waited, they didn't have alternatives in their local communities. If they wanted an education for their children, THEY had to create one.

Other states are still years behind. They rely on outdated institutional models of care, and lack community-based resources. Waiting lists for getting any services is still the norm. Parents are desperate!

In California, the Lanterman Act mandates a system of regional centers. Regional centers are required to respond to the needs of local people and to keep families and communities together. They strive to maximize the potential of people with developmental disabilities of all ages. We are far better off than in other parts of the country.

Let's hear from Carol, a parent leader who has been around since the beginning of the regional center system. [clip-Lanterman parent, Carol]

[slide] The Lanterman Act articulates a set of values that guide my personal life as a parent, and as a professional:

The State of California accepts a responsibility for [people] with developmental disabilities and an obligation to them which it must discharge...

The complexities of providing services and supports... requires the coordination of ... many state departments and community agencies to ensure that no gaps occur... A consumer...shall have a leadership role in service design.

An array of services...should be established which is sufficiently complete to meet the needs and choices of each person... regardless of age or degree of disability..., and to support... integration into the mainstream life of the community. ...[S]ervices...should be available throughout the state to prevent ...dislocation...from...home communities.

Services should...enable [people] to approximate the pattern of everyday living available to people without disabilities.... Consumers...should be empowered to make choices in all life areas. These include promoting opportunities...to be integrated into the mainstream of life in their home communities, including supported living and other appropriate community living arrangements...[C]onsumers...should participate in decisions affecting their own lives, including... where and with whom they live, their relationships with people in their community, the way in which they spend their time...[and pursue] their own personal future...

The contributions made by parents and family members in support of their children and relatives...are important and those relationships should also be respected and fostered...

[slide] **Comparative History**

The values and attitudes that people can have, either support or create barriers for people with disabilities.

Do any of the following attitudes sound familiar to you?

We don't want your kids as neighbors:

- His behavior is disruptive.
- Our playgrounds and sidewalks and buses, and schools aren't accessible.
- She'll be isolated.
- He won't have friends.
- They won't have work or meaningful activity.
- She might wander, or make noise, or damage property.
- They might be a danger to themselves or others.
- We won't rent to your family.

Shouldn't you send them...somewhere....special?

[clip-Carol talking about attitudes]

The Lanterman Act combats those attitudes. It respects the sanctity of all lives; freedom; a commitment to our fellow citizens. It assumes that with support and opportunity, all people can make their lives a blessing.

After providing years of intensive care, as a parent, it's hard to gradually let go. But my child had his own ideas; and he is learning to express them. With good public policy, people with disabilities don't have to trade liberty for care.

[clip-Elizabeth on attitudes]

Before the 1980's, most people would have assumed that my son should be "placed" for his own benefit. The institution may have been called a school or a community, and it might have had a pool and beautiful grounds. Non-disabled staff might have lived there too. But it would have had the hallmarks of an institution: meals, and activities chosen FOR clients BY staff. There would be a lack of privacy and walls, locks and gates to restrict access. All the choices my son would be presented would be part of a program model. Opportunities for personal growth would be limited by those choices and social interactions. Access to the outside community would be a field trip. A job would be a vocational program, likely with pay below the minimum wage. Separate isn't equal.

How would my son react to this placement? Would he feel accepted, loved, cared for? Would he feel challenged, excited, and motivated to work, learn and experience new things?

Congregating people with disabilities together will always limit personal growth and fulfillment, no matter what the level of disability. Grouping people together imposes efficiencies that overshadow the needs of individuals. It just isn't logistically possible to preserve choice and freedom, when we group people together. For example if one person has difficulty controlling their diet, and needs the refrigerator locked, nobody is getting their own snack. If one person wants to go to the movies and another doesn't, one of them isn't going to go where they want. That's not fair. Congregate care forces good workers to make bad decisions. It is impossible not to. Individual support, in community settings, is the only way people can achieve their full potential. These problems start when you group as few as five people.

[slide] **Research on Dispersed Housing**

Additionally, objective research on housing and service models has consistently shown that congregating and clustering people with disabilities leads to worse outcomes on a full range of quality measures.

Models that have been studied can be grouped into three types:

Dispersed housing, which is family-size homes in neighborhoods.

Clustered housing, which is individual homes for people with disabilities which are clustered together to share services or staff.

And Congregate care, which is any housing with 5 or more disabled people living together on the same property.

Both experience and the consensus of experts is clear: dispersed housing models out-perform clustered and congregate care. And that should make sense to anyone who has needed things that don't fit into standard benefits and programs that are offered.^{1, 2, 3}

Federal and State policy is solidly against spending public money to build new congregate and clustered care projects. It is closing down the ones that currently exist. This is good public policy, based on solid services research. We should support it. And those who want to develop new congregate and clustered models should be prepared to fund them for the long-term without public support. Over time, segregation makes it harder to sustain funding. That means they become unstable and quality goes down.

Inclusion builds public support. When we get to know and understand people, we care about them more. We vote for better policies. This strengthens the sustainability of good service models that benefit both individuals and society.

[slide] Summer Camp

Institutional models are being called things like “intentional communities,” “farmsteads,” or “work/play environments.” Some people compare these new projects to summer camp. I like camp. I enjoy the activities and camaraderie. But, what would life be like for me if my parents sent me to camp and never picked me up?

Going to camp is enriching. Living there indefinitely is not. Even people with significant intellectual disabilities benefit from broader experience.

Other people compare clustered and congregate care models to assisted living or retirement communities for elders. But when elders choose these communities, they bring with them a lifetime of experiences and relationships. They privately fund them with their life savings. And they typically only live there a few years. This is very different than being isolated your whole life with a limited group of people whose social connections, experiences, and resources are also very limited.

Some people confuse congregate and clustered models with Village communities such as L'Arche. In Village communities, disabled people and non-disabled people share their lives—for free. It isn't a service model. No staff is paid to provide care. This model can't be broadly replicated.

There have been many attempts to develop better congregate care, some of it well-funded, all of it well-intended. Even if they look good at first, the models don't stand the test of time.

[slide] Housing

¹ Mansell, J., Beadle-Brown, J. Dispersed or clustered housing for adults with intellectual disability: A systematic review. *J of Intel Dev Dis.* 2009;34(4):313-323.

² Mansell, J. et. al. Deinstitutionalization and community living: position statement of the comparative policy and practice special interest research group of the international association for the scientific study of intellectual disabilities. *J of Intel Dis Res.* 2010;54(2):104-112.

³ Kozma, A, et al. Outcomes in different residential settings for people with intellectual disability: a systematic review. *Am J of Intel and Dev Dis.* 2009;114(3):193-222.

People with disabilities should have the same opportunity to choose where to live. Many people want to live with family. But housing is a complex dynamic of availability; affordability; and accessibility. This is especially a problem in the Bay Area.

Despite current challenges, significant improvements have been made in community-based housing services. For example, in partnership with the Golden Gate Regional Center, Brilliant Corners in San Francisco developed a new housing model: 962 homes are small, residential properties that are owned by a trust, separate from the service provider. This guarantees that residents cannot be moved from the property, even if the service provider needs to be changed.

962 homes were developed as part of the closure of the Agnews Developmental Center, in San Jose. Parents had concerns that community-based services would jeopardize their adult children with significant medical needs. Many of these former Agnews residents had spent most of their lives in congregate, institutional settings.

[slide] Charles' Story

Let me tell you the story of Charles, a resident of Gordon Home in Redwood City:

Charles's story is a story of no person left behind. He is 52 years old and was admitted to a state-run developmental center when he was 3 1/2 years old. His mother and brother died, and he lost touch with his father.

Charles is non-verbal, and has a diagnosis of profound intellectual disability. He also has complex medical needs. He has spastic quadriplegia, and does not control his arms or legs. He gets his food through a tube in his stomach. He has difficulty moving his bowels, and has severe sleep apnea. He needs to be monitored because he often needs oxygen.

Charles communicates a lot with his eyes and smile.

A year and a half ago, a regional center team made up of social workers, service providers, consultants and me, came together. We developed a community-based service plan that would integrate medical care and personal growth.

It was challenging and time-consuming, but not impossible!

The institution where he had lived his entire life outlined his needs:

- He can't tolerate being upright because that makes his breathing bad, so he has to stay in a hospital bed at all times. OK. We need a gurney van so he can go to day program.
- If the electricity goes out, his equipment will fail. Ok. We need a generator.
- He needs to be monitored by a nurse at all times. Ok. We have a day program with a nurse as well as a home in a neighborhood, a beautiful home, with 24-hour nursing care on site.
- His bones are fragile. Ok. We have a ceiling mounted lift and an adaptive bathroom.
- He needs a doctor who knows about developmental disabilities. We have Dr. Kripke, Director of Developmental Primary Care at UCSF. She has been caring for people like Charles for over ten years. She already does home visits every couple months and is available by cell phone whenever we need her. She is also training the next generation of health care providers. We also have specialists and a hospital team we work with and a very experienced nursing staff. The local first responders know the residents in the home.

Charles has intense, individual needs, but so do many others. With resources that are locally available, if Charles can live successfully in the community, so can everyone else. With well-designed services and a solid infrastructure beneath those supports, people like Charles can thrive. We can create an array of reliable resources to support personal growth and community integration.

There is another aspect of this care model that goes largely unreported. By meeting Charles' individual needs in the community, we not only improve his quality of life, we save the state money and stimulate local economies. While this model is expensive, it is still cheaper than serving Charles in a developmental center.^{4, 5} This is truly a win-win situation. With good policy and appropriate funding, it can be sustained indefinitely.

Charles moved to his new home after we had everything in place. With good planning, he was able to attend a day program in a gurney. Even from a hospital bed, he participated. At the first team meeting after his move, his day program coordinator, talked about how he especially liked bowling. Bowling? Really? He's in a hospital bed?

"Oh, yes, she said. We have a ramp for the ball. I rigged up a poll so he can push with hand-over-hand support."

[clip-Charles bowling]

In California, everybody, no matter how profound their needs, has a right to a meaningful life and to the services and supports they need to maximize their potential. No person left behind.

Charles is still fragile. He had a serious hospitalization, and required a tracheostomy to be placed so he can breathe. When he was stable, the hospital team suggested he move to a skilled nursing facility because he needed 1:1 nursing care to suction his throat. But his team said, "No." We will hold a meeting with Dr. Kripke, and representatives from his health insurance plan and regional center. We will get the additional equipment and nursing hours we need to meet Charles' needs. Charles came home. And he is recovering well. And we have built his tolerance so he uses a wheelchair now. He has come a long way in a short time. But we are only beginning to explore the rich life which is possible. An assessment to see if he can learn to use a voice output communication device is next.

When we move people from developmental centers into the community, our commitment is that they will be better off on day one. And with the right attitudes and values and teamwork, we can do it. It's up to us as Californians to continue to fearlessly implement the Lanterman Act!

[slide] Dispersed Housing

How do we support people who live in dispersed housing? If people with disabilities exercise their right to make choices, their needs are going to change as they learn, grow, and have new experiences. They are going to develop new relationships. Their needs are also going to change as they develop medical problems, and as they age.

⁴ Chattopadhyay, A, et. al. Cost-efficiency in Medicaid long-term support services: the role of home and community based services. SpringerPlus. 2013. 6(2):305. <http://www.springerplus.com/content/2/1/305>

⁵ Harrington, C, et. al. Do Medicaid home and community based service waivers save money? Home Health Care Serv Q. 2011. Oct;30(4):198-213.

That means that any system of support is going to need to be flexible enough to evolve over time.

I want to put something in place for my son before I die. I want it to continue to meet his needs as long as he is alive.

Unfortunately, I can't. And if I try, I am going to create something so inflexible, that it won't provide him with the opportunity to live a rich life. I can't know now who he will be in 10 years, much less in 30.

It is challenging to set up services and supports, especially for people like my son who need 1:1 care. Parents do a lot of coordinating care.

What will happen when I can't do it anymore? Will my son be left to the state? Is the state going to meet its obligation? Is my kid going to be bored, sick, forgotten, overwhelmed, imprisoned, abused, or lonely? It is scary to think about that. But Charles' story gives me hope.

[slide] Regional Center System

The regional center system has many challenges to face in the coming years. There are 21 regional centers for a population of 38 million. When the system was established, each regional center was to serve a population of 1 million. So technically, we're 17 regional centers short.

One issue that is important in the Bay Area is that the state does not reimburse more in areas where cost-of-living is more expensive.

Social workers are required to have advanced degrees and work experience. They are underpaid. This leads to high turn-over rates. They have heavy caseloads. This violates federal requirements. This could jeopardize federal matching funds to the state.

Service programs have struggled with stagnant budgets and further cuts.

Legislators need to step-up to their own legal mandates. They are described in the Lanterman Act! The regional center system brings in 2 billion dollars in federal money. The state needs to do its part in supporting an important, world-class system.

Fortunately, regional center leadership has partnered with local services to develop responsive, cutting-edge program models that we can all be proud of. They help carry out the mandates of the Lanterman Act and can help address these challenges.

The Office of Developmental Primary Care's CART model is one example of a program that needs support.

[clip-California's system is better]

[slide] Who Sets the Policy Agenda?

The most impressive result of the work of the Lanterman parents is that the children who we welcomed into the community and educated over the past 40 years are now setting their own policy agenda.

[slide] The white paper, “Keeping the Promise: Self-Advocates Defining the Meaning of Community-Living” is one, influential example.⁶ It is the basis of new federal rules defining community.

We need to listen, support and follow. I know not everyone with an intellectual disability is able to participate equally in policy discussions. But if you go to meetings that are run by and for self-advocates; where the power dynamics and structure of the meeting is designed for access; where people listen to each other carefully; where people have received training and encouragement to speak for themselves and get support for their decisions; you would be amazed at how many people meaningfully participate—even people with significant intellectual disabilities and communication challenges.

The same people often have little to say when in settings controlled by non-disabled people. We are only beginning to learn how to listen, and how to support decisions. People with disabilities are showing us how.

These are new opportunities, for a new generation. We have to adjust. Today, young adults with disabilities are different. And so are the non-disabled peers with whom they grew up and went to school.

They never lived in institutions. They take it for granted that people with disabilities have a right to access. They got educations, and adaptive equipment, and iPads, and email addresses, and experience. They organized their peers. They joined youth leadership groups, and learned to speak for themselves... and they vote.

Now they aren't happy with a day program, or shredding paper all day for less than minimum wage, or living with roommates they didn't choose. They want regular jobs and families, and a chance to pursue their interests....a chance to contribute, as well as to receive support. They want to direct their own services and to have supports designed around their needs.

They want the ABLE Act passed so they can save money to achieve goals without losing the public benefits they need to fund their supports. The ABLE Act allows people with disabilities to establish tax-exempt accounts to pay for qualified disability expenses. Currently, people with disabilities can never escape from poverty. They need to stay poor in order to access the help they need. That isn't right.

Group homes, day programs and vocational programs which are smaller, sometimes still function much like an institution. They fit clients into the structure of the program instead of supporting self-direction and choice. They were a step in the right direction for a generation who grew up in institutions; but they are not good enough for today.

It isn't intuitive, but it actually turns out to be cost effective to give people exactly what they want and need instead of plugging people in programs that provide more support and structure than necessary. Supporting choice means more 1:1 attention, but there are fewer, fixed administrative costs.

⁶ Self Advocates Becoming Empowered, Autistic Self Advocacy Network, National Youth Leadership Network. Keeping the Promise: Self Advocates Defining the Meaning of Community Living. 2009. Available at: <https://autisticadvocacy.org/wp-content/uploads/2012/02/KeepingthePromise-SelfAdvocatesDefiningtheMeaningofCommunity.pdf> . Accessed 11/9/14.

Too much help or the wrong type of help actually leads to dependency. In fixed programs, supports remain in place, even when they are no longer needed. When the people who get paid to provide support are the ones who develop the plan, they rarely ask for less. Too much help can lead to protest behaviors when staff try to get clients to comply with their program. Parents and staff are used to doing things *for* people with disabilities and to making decisions *for* them. This is often easier than to step back and support. It is easy to underestimate people's competence and potential. Let's hear from Melissa Crisp-Cooper and her husband, Owen.

[clip of Melissa and Owen]

[slide] **Risk Taking**

Protecting people with disabilities from abuse and neglect is important. In congregate care, if there is a problem, you can't just shut the place down. There is too much at stake for too many people. You need proof and due process to fire people. In dispersed models, if a resident doesn't like a service provider, they can simply replace them.

We need to protect, but too much protection means people can't take risks. Without risking some bad experiences, we can't grow.

There are some things parents can't do, like care for our kids forever. But there is a lot we as parents and community members can do. We can make sure the people who we entrust to take over when we are gone, share our values and our vision. We can leave them the infrastructure they need to deliver high-quality services.

We can also honor the sacred trust that parents willed to us. We can protect and uphold the Lanterman Act. And we can honor the legacy of the Lanterman parents by being good neighbors to their kids.

We can model, through our actions, how we want people with disabilities to be treated now, and in the future.

We can make sure that adults with developmental disabilities are welcomed in our churches, mosques and synagogues; we can invite them to our homes; we can offer them jobs; and buy the products of their microenterprises; we can visit them when they are sick; we can speak up about access problems; we can make a place for them at the table when issues that impact them are discussed; and we can listen and honor their experience and wisdom.

We can also give them rides when we go to Sacramento to talk to legislators!
People with developmental disabilities are getting help, many of them very beautiful supports. We can do better. We can distribute the services more equitably. There are serious disparities. But again, there is no question the lives of people with disabilities are markedly better today than they were before 1977, when the Lanterman Act was passed.

If we do the work, the next generation will live better still. There are a lot of strengths to California's system. One of them is the entitlement.

Nobody is left behind, no matter how humble their origins or how great their service need. That is built into the system. And it is one of its most important features. No matter what happens, as long as there is an entitlement, nobody is left behind.

We aren't starting from scratch. We have 40 years of experience and civil rights work behind us. And we have a plan.

So let's begin to talk about what tools we have at our disposal and what we still need to build.

In addition to the **Lanterman Act**, the **American's with Disabilities Act** and the **Olmstead decision** are powerful tools.

The American's with Disabilities Act prohibits discrimination and ensures equal opportunity for people with disabilities in the areas of: employment; government services; public accommodations; commercial facilities; and transportation.

Olmstead v. L.C., is a Supreme Court ruling that requires states to eliminate unnecessary segregation of people with disabilities. It ensures the right to receive services in integrated settings.

No more congregate care. No going back. Full access to community life.

The Affordable Care Act is also a tool. We are reshaping how health care services are funded and delivered. We can ensure that the needs of people with complex disabilities are addressed. This will require spending more on primary care. We need new payment models to support better ways to deliver health care for people who need it the most.

The most recent tool is the new **Home and Community Based Services** regulation from the Federal Centers for Medicare and Medicaid Services. Self-advocates fought to ensure this regulation defines community not just in terms of the location and size of housing and programs, but in terms of the **ability of people to direct their own lives**.

It includes new standards for privacy, choice, integration, and access to real jobs in the community. This is a powerful tool to hold our legislators and regional centers accountable.

Your handout has links to resources that describe how to use this to access the services your family needs. If the resources your family needs for good jobs, social activities, transportation and staffing currently don't exist; take a look at the tool kit that was produced by the Autistic Self-Advocacy Network. It tells you your rights and how to exercise them. This is new so it will take time to see results, but it isn't too early to begin.^{7, 8, 9}

⁷ Home and Community Based Services Toolkit. Autistic Self-Advocacy Network. <http://autisticadvocacy.org/hcbs/> Accessed 11/2/14.

⁸ Accessing Home and Community-Based Services: A Guide for Self-Advocates. Autism Now Center and Autistic Self-Advocacy Network. <http://autismnow.org/wp-content/uploads/2014/09/9-3-14-HCBS-tool-FINAL.pdf> Accessed 11/2/14.

⁹ Autism NOW Center and Autistic Self Advocacy Network. Accessing Home and Community-Based Services: A Guide for Self Advocates. Available at: <http://autismnow.org/wp-content/uploads/2014/09/9-3-14-HCBS-tool-FINAL.pdf>. Accessed 11/11/14.

[slide] Funding

There are many models of excellence that are cost effective, and can be scaled and expanded. Our spending should be based on what we know from 40 years of experience.

We are a wealthy country. Yet, the money isn't getting spent on the right things.

Maybe that has something to do with mindboggling income inequality. The gap between what the richest people earn and what everybody else earns, has grown significantly since the early 1970's. Half the US population lives in poverty or is low-income.¹⁰ Most of the economic growth over the past 40 years has been with top earners. An unprecedented amount of our nation's wealth is concentrated in the hands of a few individuals. [slide] In 2009, the top 1% of households owned 35.6 percent of the nation's private wealth which is more than the combined wealth of the bottom 90 percent.¹¹ **Our tax laws need to reflect our values and priorities.**

With some individuals in the Bay Area worth more than the budget of the entire regional center system that serves over 300,000 people, it's hard to believe that we can't properly fund cutting-edge service models!

[slide] Building a Future

What are some of the things we need to build?

Housing is a major issue!

Where is all this dispersed housing going to come from? We need to work on a variety of strategies to increase the housing supply—in-law units; section 8; set asides in new developments; and better mechanisms to leave money and property in our estate plans. For example, Pooled Special Needs Trusts allow us to leave some money, even a few thousand dollars, without making our kids ineligible for public benefits.

But right now, more than half of adults with developmental disabilities live with their families. And that trend is likely to continue. It isn't a trend unique to adults with disabilities.

Many non-disabled adult children are living with their parents too. That is being driven by a number of forces such as aging baby boomers, income inequality, and the high cost of housing and education.

We need to figure out how to take care of people, both parents and their children, who are living together in multigenerational households.

¹⁰ Yen, Hope (December 15, 2011). "US Poverty: Census finds nearly half of Americans are poor or low-income" The Huffington Post. http://www.huffingtonpost.com/2011/12/15/census-shows-1-in-2-peopl_1_n_1150128.html. Accessed 11/2/14.

¹¹ <http://inequality.org/wealth-inequality/>. Accessed 11/2/14. Creative Commons license 3.0 <https://creativecommons.org/licenses/by/3.0/>

Parents can't do it alone, and we don't have to. Like the generation before us, we can go back to the state, and share the responsibility more equitably with other taxpayers.

The State is there to set policy, not provide the services. We have successful public/private partnerships that need our support to remain flexible and responsive.

We can also evolve the system to work more for families.

We can beef up the services we provide in the home so families are assessed regularly.

We can provide more support as parents age.

We can employ people with disabilities in real jobs, earning real wages.

We can change the laws which trap people in poverty as a condition for accessing public benefits.

We can deliver health care in the home and train doctors.

To achieve this, we need to build a solid infrastructure beneath the supports. The new **Home and Community Based Services** regulations are leverage to make that happen because states are going to lose federal funding if they don't.

[clip-Stacey talking about SNF]

[Slide] **CART Model**

Since 2007, local stakeholders, in collaboration with the Office of Developmental Primary Care, have been developing the **CART Model**. The CART Model is an organized system of care. The CART Model is part of the infrastructure that enables quality, community living.

The **CART Model** is a new way of delivering health care services to people with developmental disabilities.¹² [slide] CART stands for **C**linical Services, **A**dvocacy, **R**esearch and **T**raining.

The **CART model** is more than just medical care. It is a holistic approach to improving quality of life. One of the main reasons why people end up in institutions or moving away from home is that their medical needs aren't met. Our goal is to make sure everyone has access to the health care services they need to maximize their potential.

[slide] There are four functional components of the CART model:

The first component is **enhanced primary care**. These are primary care services that are designed to meet the needs of adults with complex disabilities.

¹² Kripke, C. et al. The CART model: Organized systems of care for transition age youth and adults with developmental disabilities. Int J of Child and Adol Health. 2011;3(4):473-77.
https://www.novapublishers.com/catalog/product_info.php?products_id=22988

The second component is **health advocacy services**. Health advocacy services are the direct support to help people partner effectively with their health care providers—going to appointments, supporting communication, and following through on the health care plan.

The third component is a **yearly nurse health assessment**. This is a comprehensive, standardized assessment by a developmental disability nurse with recommendations. With your permission, the results will be fed back to your family, your doctors, and your case coordinators. Data from these assessments will also help us understand what services people need.

The fourth component is a **CART Center**. The CART Center is a hub of experts in developmental primary care that provide clinical service, policy advocacy, research, training and technical assistance.

If you want to learn more about the work of the Office of Developmental Primary Care, visit our website odpc.ucsf.edu. The web address is on your handout.

[slip-Stacey talking about nursing supports]

[slide] **MySupport**

Another part of the infrastructure we need to build to support self-direction, is the **technology** to find and manage direct support workers.

Right now, if people want to choose their own supporters and design their own services, they are forced to become a mini-Human Resources department. There is a heavy responsibility for hiring, scheduling, supervising, and training workers. It is complicated to manage payroll.

We can help people find compatible workers and pay them without requiring people with disabilities and their families to understand the details of employment law and public benefits.

[slide] A group of disability advocates has developed a start-up venture called **MySupport** to meet this need.

[clip-Stacey talking about choosing staff]

[slide] **Proposals for System Change**

Within the CART framework, we have developed a comprehensive series of proposals for system change.

[slide] For **clinical**, the proposals include two types of primary care service: **consultation and assessment services** to support people using mainstream doctors, and **home care services** for people who have more intensive medical needs.

For **health advocacy**, the **Autistic Self Advocacy Network** and the **Arc of California** are working to introduce **Supported Health Care Decision Making** agreements.

These agreement would create a new legal status for people who provide support to people with disabilities to make health care decisions and implement health care plans.

It is voluntary. Unlike a power of attorney or conservatorship, it does not transfer health care decision-making to another person; but with the consent of the person with a disability, it allows supporters to access confidential information to provide support.

It also provides legal protection to clinicians who respect choices made with that support. It requires a notary, but no legal proceedings to implement an agreement. People with intellectual disabilities who might not be considered competent to sign other types of contracts can still enter into an agreement.¹³

We are also working on helping people complete their own **advanced directives** to ensure their wishes for end-of-life care are respected. With help from a supporter, the “Thinking Ahead” program helps people with intellectual disabilities make decisions and complete the documents.¹⁴ Let’s see how clinicians can support the communication and decision making of people with disabilities.

[clip-Aaron and Gerri Collins-Bride, NP]

[slide] For **research**, we have proposals to study the health status of the population of people with developmental disabilities and to study the effectiveness of our innovations.

For **training and technical assistance**, we have a proposal to develop a CART Center to grow our successful training programs and technical assistance resources. We train clinicians and provide health education to self-advocates, direct support staff, professionals, and families.

[slide] **Case Study**

To illustrate the CART Model, let me present a hypothetical case study:

Let’s say you are a parent of a man who has graduated from special education.

Currently, your regional center case coordinator might ask *you* what *your* goals are for your adult child. She might show you various group homes, day programs and vocational programs. If you want your child to remain in your home, your case coordinator might offer you some respite hours.

You may not like everything you are shown. Most likely, it will only be a partial fit. If you don’t like what you see, your case coordinator basically puts it back on you to come up with an alternative. You might think about conservatorship, because you fear you won’t be able to support your son’s health care needs without it. That feels overwhelming. It doesn’t have to be this way. With a few tweaks, and targeted investments in some new infrastructure, we can build on 40 years of success. We can adjust the system to current realities.

Once we have the infrastructure built, our vision, will lead to a different outcome. It is based on **Person Centered Planning**. **Person centered planning** is an ongoing problem-solving process used to help people plan for their future.

¹³ Model Supported Health Care Decision-Making Legislation. Available at: <http://autisticadvocacy.org/2014/07/asan-unveils-toolkit-for-advocates-on-health-care-and-the-transition-to-adulthood/>. Accessed on 11/11/14.

¹⁴ Coalition for Compassionate Care of California. Thinking Ahead: My Way, My Choice, My Life at the End. <http://coalitionccc.org/tools-resources/people-with-developmental-disabilities/> accessed 11/9/14.

[slide] The first thing your regional center case coordinator does is invite your child's family, friends and supporters to a person-centered planning meeting.¹⁵

In person centered planning, the group focuses on your *son's* vision of what *he* wants to do in the future. The team meets to identify opportunities to develop personal relationships, participate in community, and increase control over *his* own life. It supports him to develop the skills and abilities to achieve his goals.

The team has information to work from, because your son has been getting his **yearly nurse health assessments**. There is comprehensive information available about his support, medical and behavioral needs.

Your son is able to participate in the meeting because your family did training in **supported decision making**. Your family has been practicing. He does better when he knows in advance what questions he will be asked, and when he is given examples and choices.

Let's say your son says that he wants to find a girlfriend; work with animals; improve his fitness; and live in the in-law unit downstairs.

Instead of plugging him into an existing program, a program can now be built around his goals. He can go to the monthly dance at the **Arc**, and attend the health class on sexuality offered by the CART Center.

There is a group of other adults from his old school who he used to hang out with. The team assigns someone to contact them to see if they want to use some of their personal assistance hours to hire an aide who can organize a club that meets in their homes in the evenings. One of the circle-of-support members has a good collection of DVDs he is willing to loan to the club.

The team also looks into Special Olympics swim team.

The state has developed incentives and supports for employment in real jobs, as required by the new **Home and Community Based Services regulation**. There are three ideas for working with animals: a vocational program at the zoo; or supported employment in a therapy-dog-training program or the local aquarium shop where your son often visits to look at the fish.

The case coordinator will get your son signed up with vocational rehabilitation to look into the zoo program. Others are assigned to make inquiries at the dog training and aquarium shops.

Your son also has some significant medical and behavioral needs. He has seizures that can be serious, and he has been having severe meltdowns. He hasn't been eating as much since he graduated from school.

The regional center case coordinator budgets that you will need 4 hours per day of personal assistance hours and 4 hours per day of job coaching to implement this plan. Also the case coordinator offers transportation and a referral to the **CART Center** consult clinic. The experts at the CART Center can help diagnose the meltdowns and decreased appetite.

¹⁵ Pacer Center, Person Centered Planning. <http://www.pacer.org/tatra/planning/personal.asp>. Accessed 11/2/14.

[slide] To hire the personal assistant and job coach, you help your son log onto **MySupport**. You put in the hours you need, and answer questions that help you match with a worker who is compatible. Your son doesn't like female aides who baby him. The matching algorithm helps you find two staff: a hip, young man who also likes animals, and a woman who is a nursing student.

Once you select your workers, **MySupport** helps them get their employment paperwork done to get paid by **various agencies**, and helps you with scheduling and tracking the hours the staff can work.

Your son and your son's workers get text messages from **MySupport** to remind them of their shifts.

You have loaded old assessments, medical records and other key documents onto **MySupport**, and you help your son grant his new workers access to the ones they need.

There is also a seizure and a bowel movement tracking form on **MySupport** that you and the aides keep updated.

You are also taking care of your mother, so you can't accompany your son to appointments. Your son fills out a **Supported Health Care Decision Making** agreement with his aide, who agrees to help him with his medical care.

This plan works until your son has a bad seizure and ends up in the hospital. Your son's "**Thinking Ahead**" advanced directive was filled out at his **yearly nurse health assessment**. It was uploaded onto the **MySupport** site. Your son's worker was able to give it to the doctors when he arrived at the hospital along with the summary of his medical care from his **CART Center Medical Consult**.

The members of the club, including your son's girlfriend, come to visit in the hospital and send cards.

After discharge, your son's health is more fragile. He is incontinent, and you are exhausted. A new **person-centered planning meeting** is convened. Your son is referred to the **CART Center's home care service**.

[slide] A **CART Center** primary care doctor does a home visit every 2 months and as needed. She consults by phone with the neurologist so your son doesn't have to make as many follow up appointments. If he doesn't feel well, the **CART Center nurse** comes to do assessments.

The home care service administrative staff works with the disability care manager at your son's health plan to expedite getting a hospital bed with safety rails.

Your son's personal assistance hours are increased to 12 hours per day, and he becomes a client of the **Arc's Professional Health Advocacy** program. A professional health advocate now helps your son manage his health care.

You log onto **MySupport** to hire a new worker for the additional hours.

Your son cancels the **Supported Health Care Decision Making** agreement with his old aide and develops new agreements with the health advocates from the Arc.

Your son has his **yearly nurse health assessment**. As part of her assessment, the nurse does a vision screen and recommends a referral for new glasses.

She also notes worsening dental hygiene and recommends **CART Center** training for your son's aides and a referral to the **special needs dental clinic**. She also does a caregiver assessment and learns that you have been depressed since your mother died, and haven't been able to provide as much attention to your son.

Your regional center case worker adds a services broker to your son's plan, to assist with coordinating all of his services and workers.

The nurse encourages you to get some supportive counseling. After talking about it, your family agrees to go to church together every week to reconnect with each other and with your community.

The planning process and infrastructure is flexible, and allows you to ramp up services as needed to meet your individual needs, up to and including full staffing.

You and your son retain choice of staff, but you don't have to become an employment agency.

[slide] The Regional Center, Vocational Rehab, Community Agencies, MySupport and the CART Center work together as a system to ensure your family needs are met.

No longer do you need to rely on rigid, one-size-fits-all programs that don't have the flexibility to respond to your son's changing needs.

Self-directed planning, combined with modular community-based services, give your son just the right amount of care and support. It provides the foundation for your son to live his life to the fullest. People with disabilities are the experts in what is best for them. If we will follow, they will lead.

[slide] **Networking**

This infrastructure that I am describing isn't yet built. We need your help to build and fund it. Because of the lessons we have learned through experience and research, this is the direction that public policy is going.¹⁶ The sooner we embrace it, the stronger it will be. If you want to support this vision, you can make a donation to the **Office of Developmental Primary Care**. This will help us promote comprehensive, community-based policies. Financial contributions translate directly into quality care for our most vulnerable citizens.

Also, if you join our email list, our policy partners, the Arc of California and the Autistic Self Advocacy Network, can provide you with action alerts.

Thank you to:
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¹⁶ National Council on Disability, *Deinstitutionalization: Unfinished Business*, Companion Paper to Unfinished Business Toolkit (2012), available at <http://www.ncd.gov/publications/2012/Sept192012/>. Accessed 11/11/14.

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