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Including Individuals With Disabilities in Creating Policy Recommendations

Lessons From California’s Master Plan for Developmental Services

Jonah P. B. Frohlich, Senior Managing Director
Anna Lansky, Senior Advisor
Claudia Page, Senior Advisor
Aliza Aitchison, Consultant
Manatt Health

Elena Tiffany, Master Plan Committee Member/Self-Advocate
Olivia Raynor, Disability Policy Consultant/Master Plan Self-Advocate Facilitator Lead

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Jonah P. B. Frohlich
Senior Managing Director
Manatt Health
415.291.7440
jfrohlich@manatt.com

Anna Lansky
Senior Advisor
Manatt Health
415.291.7465
alansky@manatt.com

Claudia Page
Senior Advisor
Manatt Health
415.291.7419
cpage@manatt.com

Aliza Aitchison
Consultant
Manatt Health
212.790.4592
aaitchison@manatt.com

Elena Tiffany
Master Plan Committee
Member/Self-Advocate
213.259.6910
elenatiffany88@gmail.com

Olivia Raynor, Ph.D
Disability Policy Consultant/
Master Plan Self-Advocate Facilitator Lead
805.341.0337
oliviaraynorphd@gmail.com

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Table of Contents

Executive Summary 5

Introduction 7

- The Master Plan Process 8
- Leading With Equity and Inclusion 9
- Supporting Self-Advocates 10

Successes 11

- Broad and Diverse Community Representation 11
- Inclusive and Effective Workgroup Leadership Structure 12
- Diverse Public Engagement 12
- Meaningful Participation 12

Challenges 13

- Some Self-Advocates Were Hard to Reach and Were Left Out 13
- It Was a Significant Commitment for Workgroup and Committee Members 14
- Making Things Equal and Accessible Also Takes Planning and Time 14
- Maintaining Equitable Relationships Is Complex 14

Including Individuals With Disabilities in Creating Policy Recommendations

Lessons From California's Master Plan for Developmental Services

Lessons Learned/Recommendations 15
  Include Self-Advocates as Leaders, Not Just Participants 15
  Communicate Clearly and Often 15
  Create Safe Spaces So All Voices Can Be Heard 15
  Establish Support Systems at the Beginning of the Process 15
  Start Early and Plan Ahead in Reaching Out to Community Members 16
  Plan to Spend Extra Time Making Things Accessible 16
Conclusion 16

Executive Summary

This paper provides recommendations on how to include community partners in creating policy solutions to improve the developmental services system. It focuses on meaningfully including people living with intellectual and developmental disabilities (I/DD). It provides lessons learned from the experience creating the California Master Plan for Developmental Services (Master Plan).[i] It is intended to help other states, agencies, and organizations that work with people with I/DD.

The Master Plan was created to improve the systems that serve people with I/DD. People with lived experience, known as "self-advocates," led the creation of the Master Plan. Manatt Health, the California Health and Human Services Agency (CalHHS), and the Department of Developmental Services (DDS) supported the work.

It was not always easy to make sure people with I/DD could participate fully and equally in creating the Master Plan. We had to try different approaches and make changes and adjustments as we went. The self-advocate leaders and participants in our process showed us the way.

This paper describes ways to make sure you have an inclusive process when creating policy and systems solutions. For example:

- Create respectful spaces for self-advocates to voice their thoughts and share their experiences.
- Create diverse and inclusive committees and workgroups.
- Provide easy to understand materials and accessible meetings.
- Support self-advocates at every step in the process in the ways that work best for them.

It also provides recommendations to help other states and agencies, such as:

- Involve self-advocates as leaders, not just participants.
- Establish support systems at the beginning of the process.

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[i] The California Master Plan for Developmental Services (https://www.chhs.ca.gov/home/master-plan-for-developmental-services/).

- Work hard to reach community members who may be difficult to reach.
- Spend the extra time to make meetings and materials accessible.

Including as many perspectives as possible takes intention, planning, and resources. There is no "one-size-fits-all" approach. The learnings and lessons shared here are intended to get you off to a strong start.

Introduction

California created the Master Plan to collect suggestions and thoughts from the I/DD community about what they want for the future of service delivery and supports.[i] The final plan has 170 policy and program recommendations that go beyond the developmental services system. It includes recommendations on housing, education, social services, and health care. It was created by a broad group of community partners, including people with I/DD ("self-advocates"), their families, advocacy organizations, providers, and Regional Centers.

We understand people with I/DD have diverse ways of describing themselves. In this document and in the Master Plan, we use the terms "people with intellectual and/or developmental disabilities" (I/DD) and "self-advocates."[ii]

CalHHS and DDS funded and guided the process to create the Master Plan. Manatt Health provided content and policy expertise, project management, facilitation, and technical support. A team of state leaders and consultants also made sure the structure supported the meaningful engagement of self-advocates.

We learned valuable lessons about how to include self-advocates in discussions that will impact their lives. We wrote this paper to share what we learned with states, agencies, and organizations that serve and work with people with disabilities. This will help make their work more inclusive and respectful.

The Master Plan and this paper are written in "plain language." Plain language is a way of writing that makes information easier to understand. It uses short sentences and simple words. This helps more people understand the content and makes it easier for everyone to participate in the process. We also want to show that plain language can be clear and thoughtful—without losing meaning.

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ii. We know that not everyone with I/DD wants to be called a self-advocate. During the Master Plan process, this term was talked about with people with I/DD. As a group, they agreed to use the term "self-advocate" for the purposes of this work.

During the Master Plan process, people with I/DD and their families talked about what they go through in their everyday lives. Hearing these real stories helped make the recommendations better and more meaningful. We call this "lived experience." It means learning from real life, not just from studies or reports.

The Master Plan Process

The Secretary of CalHHS appointed a 40-member Master Plan Committee. This Committee met every month for a year. They created five Master Plan priorities:

1. People with I/DD and families should experience person-centered service systems they trust;
2. People with I/DD should receive timely, inclusive, and seamless services across all service systems;
3. People with I/DD and their families should receive services from a high-quality, stable, and person-centered workforce;
4. People with I/DD and their families should experience consistent, transparent, accountable, and data-driven systems that focus on outcomes; and
5. People with I/DD are entitled to life-long services with adequate resources.

Five workgroups were formed to create recommendations for each priority. Each workgroup had about 20 members. Each workgroup was led by two co-chairs, a self-advocate, and a family member of someone with I/DD.

Workgroups met at least monthly. They used different strategies to create recommendations. They used survey tools to provide a private way for members to voice support or disagreement. They invited outside experts to share policy knowledge and current research, and they formed smaller sub-groups to divide up the work. Workgroups also had facilitators who met with the co-chairs every week to help prepare them for each workgroup meeting.

Hundreds of community members participated in the monthly committee and workgroup meetings. People could observe meetings in person or online, and each meeting had one or more public comment sessions. Because self-advocates are the ones being served by the developmental services system, they were invited to speak first in these sessions. This made sure their input was a high priority.

Leading With Equity and Inclusion

The process for creating the Master Plan began with a commitment to equity. This included establishing a shared understanding of what equity means. This is how the Master Plan defines equity:

- Equity means giving each person with I/DD the help they need to lead the lives they want.
- Equity means understanding that people have different starting points in life.
- Equity aims to correct unfairness.

> "Silence is 'not' golden. We need to be seen 'and' heard."
>
> —Elena

For self-advocates, equity also meant being treated as equals. They wanted to be listened to and not just invited. They wanted their way of speaking and sharing to be respected. Equity meant having the time, information, and support to fully take part in decisions. It also meant not having to prove their voice matters.

We worked with many different people from across California to help create the Master Plan. This included people with I/DD, their family members, providers, researchers, advocates, and other members of the community. We know we did not get everything exactly right. But we listened and made changes along the way.

Supporting Self-Advocates

Self-advocates played a key role in creating the plan. Their ideas and suggestions made the Master Plan more real and connected to what people need in their everyday lives.

Some self-advocates needed more support than others to participate. From the beginning, there was a strong commitment to making sure everyone could understand the information and participate fully.

We learned that all meeting materials had to be in plain language so that everyone could understand them. This was hard to do. Most policies are written using complicated words. Most charts and graphs are confusing. We worked with self-advocates to review materials before they were presented, and we updated the materials if they were not quite right.

We made sure that people who are deaf, blind, and/or speak a language other than English could access information. We provided American Sign Language interpreters and translators at all meetings. Financial and other support was also provided so self-advocates could travel to meetings.

We created a role called a "Support Facilitator." These facilitators held meetings just with self-advocates to prepare for all meetings. These smaller meetings gave the self-advocates a supportive space to review materials and decide what they wanted to say or ask during the larger meetings. Facilitators also offered one-to-one support before, during, and after meetings. Each self-advocate chose the type of individual or group support that worked best for them.

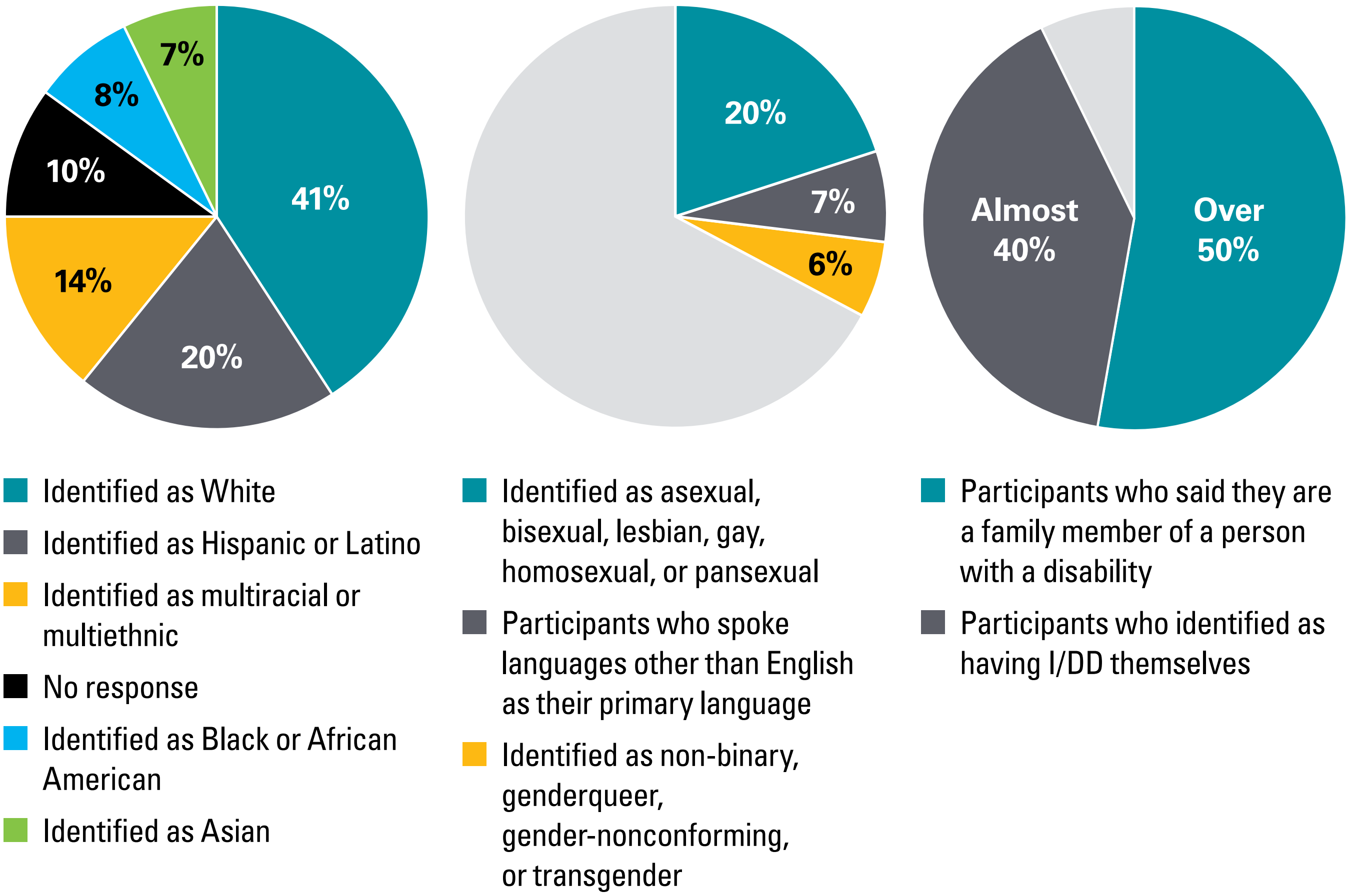
Successes

There were many successes throughout the Master Plan development process.

Broad and Diverse Community Representation

We received over 850 applications from people wanting to be in one of the five workgroups. We were able to include people with a diverse mix of races, ethnicities, languages, gender identities, sexual orientations, geographies, and disability statuses:

850+ Applications



Inclusive and Effective Workgroup Leadership Structure

Each workgroup had a co-chair who was a person with a disability. Having a self-advocate leader meant the perspective of someone with I/DD was represented at the highest level in the workgroups. This structure also helped us make sure meetings and materials were inclusive for everyone.

Diverse Public Engagement

To reach as many people as possible, CalHHS had a public engagement campaign during the Master Plan process. The goal was to better understand people's hopes and dreams for an improved developmental services system. State leaders went out into the community to learn from community partners at 45 different events across the state. Thousands of people from diverse communities shared their ideas during these meetings. The participants represented various cultural communities, professionals, and organizations led by families and self-advocates. Meetings were held in English and Spanish. Written summaries were provided, and ideas and suggestions were shared with the Master Plan Committee and workgroups.

Meaningful Participation

The Master Plan was created "for the community, by the community." That meant it was important to have self-advocates participate in real and respectful ways.

To support meaningful participation for people with disabilities, we learned what accommodations they needed. Accommodations are adjustments or changes that helps people with different needs fully take part in meetings and decision making.

For example, we learned the Zoom chat was an important way for people who are nonspeaking to communicate and participate during meetings. Some found it overwhelming if members of the public were also using the chat at the same time. To support self-advocates, we asked them before meetings if they wanted the chat limited to just the committee or workgroup members. Controlling how the chat was used helped all self-advocates communicate in a way that worked for them.

We also provided accessible materials and ways for self-advocates to express their ideas privately such as through surveys. We made the meetings longer and provided group and one-to-one support for self-advocates. These steps made full participation more possible and respectful.

Challenges

The Master Plan process had some challenges, like any big project with many people involved. We are sharing them here because we learned from them—and others might too.

Some Self-Advocates Were Hard to Reach and Were Left Out

Even with strong outreach, we were not able to include all communities who are impacted by I/DD. A diverse mix of individuals participated in the workgroups and the committee. But some communities were not well represented in the process. These included:

- People who are involved in the criminal/legal system
- People who live in residential settings, such as group homes or long-term care facilities
- Children and youth
- People who live in rural communities
- People experiencing homelessness
- People who are nonspeaking

If other states want the process to be inclusive, outreach to underserved or hard-to-reach communities should happen early. Even if the first efforts do not work, it is important to keep trying. Real-life experience will help to make sure recommendations are stronger and more impactful.

It Was a Significant Commitment for Workgroup and Committee Members

The Master Plan process lasted a full year. Many participants spent more than 100 unpaid hours in a lot of meetings. Many also had responsibilities for full-time or part-time jobs, other volunteer positions, school, caregiving, and personal lives. This is a lot of time to ask of people who have busy lives. The level of commitment required also means that some people will not be able to participate. It is important to be clear from the beginning of the process about how much time the work will take and to respect the participants' time. For this reason, a stipend was paid to self-advocates whose employers did not support their time. This approach shows we respect their time, knowledge, and skills.

> "Each one of us in our own way, represents thousands of other self-advocates who, for whatever reason, didn't have the ability or the time or the interest to show up for multiple Lisa meetings. In our own way we got to be their voice and represent their needs and interests."
>
> —Lisa

Making Things Equal and Accessible Also Takes Planning and Time

One reason the Master Plan process took so much time was its focus on equity and inclusion. This meant having more and longer meetings to make sure everything was accessible to everyone. When we started, we did not give everyone enough time to review and discuss materials. We also did not make the material we developed accessible enough. It also took us time to figure out how to write things in plain language. We worked directly with self-advocates to help make materials accessible. Because of their help and guidance, we made it work.

Maintaining Equitable Relationships Is Complex

Participants brought different experiences to creating the Master Plan. Some spoke for themselves from their own experience and others represented groups of people. Some were familiar with policy work and others were new to it. Some already had connections while others formed new relationships. At times, this created power differences that made it harder for some people. This was especially true for people with disabilities or people who were less experienced. Not everyone felt equally valued or heard. It takes effort to create environments where everyone feels respected, heard, and able to speak for themselves.

Lessons Learned/Recommendations

Include Self-Advocates as Leaders, Not Just Participants

Self-advocates need to be meaningfully engaged in planning and leading the work. Trust them to speak for themselves. This will empower them to be self-determined. Their ideas can improve the system for everyone. Their contributions matter, with or without policy training.

Communicate Clearly and Often

Let people know what to expect and be flexible when things need to change. Adjust based on what people need to fully participate.

Create Safe Spaces So All Voices Can Be Heard

Self-advocates are not always heard equally, even in spaces designed to include them. Being in meetings with family members, employers, professionals, or others in positions of power can make it harder for self-advocates to speak freely. Create safe spaces where everyone can share their ideas freely. Offer ways to share ideas outside of group settings. Make sure people don't use their voice to try to make others have the same opinion.

Establish Support Systems at the Beginning of the Process

Provide one-to-one and small group help, plain language materials, flexible ways to communicate, and space for privacy when needed.

Start Early and Plan Ahead in Reaching Out to Community Members

Reaching people from underserved or rural communities takes time and trust. Outreach needs to be built into the timeline. Keep trying even if early outreach efforts do not work. Make sure that there are many kinds of organizations represented and limit the number of people from the same organization.

Plan to Spend Extra Time Making Things Accessible

Making meetings accessible often means longer timelines and more review. Build extra time into agendas to make sure people do not feel rushed. Be sure to include materials in multiple languages and to provide language interpretation in meetings. This helps everyone to fully participate.

Conclusion

Including as many perspectives as possible takes intention, planning, and resources. People communicate and take in information in different ways. There is no "one-size-fits-all" approach to making it possible for people with I/DD to meaningfully contribute to creating policies and strategies to improve their lives. Be open to trying new things so that everyone feels included and valued. Equity is not easy, but it is always worth the effort.

> "We are very knowledgeable in our own lives and how we want to be. We understand each step of our life. So, we're the best experts, and sometimes these agencies don't give us enough credit where credit needs to be given."
>
> —Tracey

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