

# GM581

Measure Title: Submitting for consideration and confirmation to the State Council on Developmental Disabilities, Gubernatorial Nominee, SHANA METSCH, for a term to expire 06-30-2021.

Report Title: State Council on Developmental Disabilities

Current Referral: CPH

(1) Why do you want to be a member of the Board?

I have been a health advocate for over a decade. During that time, I have worked with children with disabilities and their families. I have had productive relationships with physicians, nurses, special education teachers, and many other healthcare professions. I have a wealth of experience and skills to put to good use. I have been sharing these skills in smaller venues— one person and family at a time. I now feel ready and committed to sharing my knowledge and my perspectives as the mother of a child with disabilities with a broader range of people in Hawaii. I would also welcome the opportunity to help to craft policies that are realistic and that will have a positive effect on everyone with disabilities in the state.

(2) What do you perceive are the roles and responsibilities of a member of the Board?

If I were to be selected to work as a member of the board, I would view my primary responsibility as helping to execute the board's mission to "to support people with intellectual and developmental disabilities to control their own destiny and to determine the quality of life they desire." I am aware that the category of people with intellectual and developmental disabilities covers a very broad range of individual, each of whom may see and understand their life preferences and choices in unique ways. But all of these individuals deserve to have their human rights addressed and met. I very much value the board's mission statement's emphasis on individual self-determination and family-centered approaches. I understand that the board works within guidelines established by the federal government but does so with a careful eye to Hawaii's needs and traditions. Included in the board's mission statement is the triad of activities involving advocacy, capacity-building and systemic change activities. These are precisely the sorts of activities that I would love to be pursuing on a larger basis. In addition, I have a particular focus on educational efforts with people with disabilities and their families—a passion that results from my encounters with so many individuals and families who simply do not know how to address the needs they have for surviving, much less thriving. I hope to be helpful in informing the board of the needs of the disabled community and helping implement concrete actions that would provide needed support.

(3) In what ways do you feel that you can help protect the consumer?

My ability to be helpful rests on over a decade of forced on-the-job training. When our daughter was born, my husband and I had no background experience in the complexities of medical diagnosis, or insurance needs to support her. We quickly learned that, without this knowledge, our daughter would not get the care she needed to remain in her home and community. I made it my mission to become well-versed in all components of her care and the services available so we could assure her medical and insurance needs would be met. In turn, we've made it our family mission to help others in the community who need access and understanding about insurance and Medicaid law & how to access prescribed services. I have developed a deep compassion for consumers in the general arena of disabilities. At the same time, I have also developed a strongly realistic understanding of possibilities and limitations related to services for this population.

(4) Given your understanding of the roles and responsibilities of a Board member, why do you believe that you are qualified for the position? Please include a brief statement of your skills, expertise, and knowledge that would aid you as a member of the Board.

My experience as a parent of a child with disabilities has taught me a great deal about the needs of this population in medical, educational, social, and financial domains. My experience has been from the ground up, and it has gone well beyond the boundaries of my daughter's specific needs. I have become familiar with the most relevant federal and state laws. I have

argued with insurance companies. I have advocated for and educated other families. I see things from a broad perspective. I can bring all of these strengths to the board. I can also bring my skills as a quick-study, someone who can see the personal and the social at the same time, someone with a great deal of common sense, a businesswoman's perspective, and a deep commitment to serving this population.

(5) What do you hope to accomplish during your term of service?

It's imperative that our legislature has a good understanding of the everyday needs of people in Hawaii who live with disabilities. Some laws make sense on paper, but not in "real life." With my advocacy efforts, I have met hundreds of people in the state who have conveyed what is working and what is not working for them to live productive, independent lives. I'm eager to share stories and help structure new bills that will help to make people's lives with disabilities a little easier and more dignified.

(6) Name three qualities that best describe you and how these qualities will benefit the Board.

**Determination and Persistence:** I have always been able to continue moving forward in achieving goals, even when I encounter obstacles. This skill carries over in everything I do in life and would be beneficial to the board in overcoming obstructions that require resolution.

**Communication Skills:** Communication skills are essential in healthcare advocacy. It is critical that we have this skill set in all areas of life including advocating for the disabled. I am very aware that communication skills mean listening well as well as speaking well.

**Problem-Solving Skills:** Over the past 11 years, it has been critical to our daughter's care that I'm motivated and challenged to take on new obstacles with minimal direction and react accordingly. It has been critically important to have worked effectively with no roadmaps and little in the way of encouragement. I have done this over and over and, as a result, I have developed solid problem-solving skills.

(7) Name a previous experience you've had that will be beneficial as a Board member. Because of my own advocacy for my daughter and my efforts to help other people with disabilities and their families, I have developed an extensive understanding of Hawaii and federal laws related to disabilities, including but not limited to IDEA, EPSDT, Medicaid (state-run and private), and private insurance carriers. It is critical that advocates can understand and implement laws to assure they can access the supports they are federally entitled to receive. I have become one of the "go-to" persons for people who are seeking information on health care, Medicaid, Department of Education, etc. I am eager to help provide education and supports to more citizens in our state who are motivated to learn.

(8) Can you foresee any possible conflicts of interest that could arise during your service on the Board? How would you overcome conflicts of interest?

No, I do not foresee any conflicts of interest that are likely to arise. However, I have a strong sense of personal ethics and a good deal of common sense; if any such conflicts were to emerge, I would disclose them to the board immediately and work with the board to eliminate both conflicts and the appearance of conflicts.



**STATE OF HAWAII**  
STATE COUNCIL  
ON DEVELOPMENTAL DISABILITIES  
1010 Richards Street, Suite 122  
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March 7, 2018

The Honorable Rosalyn H. Baker, Chair  
Senate Committee on Commerce, Consumer Protection  
and Health  
Twenty-Ninth Legislature  
State of Hawai'i  
State Capitol  
Honolulu, Hawai'i 96813

Dear Senator Baker and Members of the Committee:

**SUBJECT:** GM 581 - State Council on Developmental Disabilities  
Gubernatorial Nominee Shana Metsch

The State Council on Developmental Disabilities (DD) **STRONGLY SUPPORTS GM 581** to confirm the nomination of Shana Metsch for a term to expire June 30, 2021.

The Council's Federal mandate (P.L.106-402) is clear in determining the composition of this body to ensure that all the players involved in the development, implementation, and use of DD supports are represented. The law specifically requires that 60 percent of the membership of the Council be comprised of individuals with DD, their parents, or family members. Additionally, the following agencies are required to be on the Council: Department of Health; the agencies that administer funds provided under the Rehabilitation Act of 1973; the Individuals with Disabilities Education Act; the Older Americans Act of 1965; Titles V and XIX of the Social Security Act; the Protection and Advocacy Agency; the Centers for Excellence in DD Education, Research, and Service; agencies and private non-profit organizations concerned with services to individuals with DD. The Governor's nominee meets all the Federal requirements for Council membership.

Ms. Metsch is the mother of a young daughter who was born with special needs. Her appointment to the Council would fulfill the Federal requirement of parents represented on the Council. We are fortunate to have Ms. Metsch nominated to serve on the Council to represent families living on Kaua'i. Her accomplishments as an active

The Honorable Rosalyn H. Baker  
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participant for the Epilepsy Foundation of Hawai'i , a strong advocate for her daughter in supporting her to live at home and advocating on her behalf to receive appropriate family-centered care will serve as a model for other parents who may need support to keep their son or daughter at home.

Her wealth of knowledge and experience as a parent and keeping abreast of legal and social developments related to disabilities and health care will assist the Council to address its State Plan Goal for Children and Health and Youth (Early Childhood), "Parents and family members with children, 3-5 years of age, who are at risk for developmental delays or who have intellectual and developmental disabilities will have timely access to standardized developmental screening, appropriate services, and supports."

The Council welcomes the appointment of Ms. Metsch, and we look forward to her contributions toward the Council's State Plan activities and systems advocacy.

Thank you for the opportunity to express our strong support for **GM 581** to confirm Shana Metsch to the State Council on Developmental Disabilities.

Sincerely,



Daintry Bartoldus  
Executive Administrator

*Laurel Loo*  
2870 Aheaha Street  
Lihue, Hawaii 96766  
(808) 977-8015  
[Laurel.Loo@hawaiiantel.net](mailto:Laurel.Loo@hawaiiantel.net)  
February 23, 2018

Hawaii State Council on Developmental Disabilities  
Attn: Daintry Bartoldus  
Via e-mail: [Daintry.Bartoldus@doh.hawaii.gov](mailto:Daintry.Bartoldus@doh.hawaii.gov)

Dear Council:

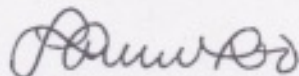
It is with great honor that I write in support of Shana Metsch as the Kauai advocate for the state council.

I came to know Shana while I was the Kauai Program Specialist in 2016-2017 for the Council. I had heard Shana was an advocate for her daughter with special needs and invited Shana to a meeting. Thereafter, Shana came to almost every public meeting that I attended as the program specialist, whether it was at night or in the middle of the day.

Shana has spent years learning the bureaucracy and how to be an advocate for her family. She does so honestly, tirelessly, with integrity and the facts, and therefore has become a resource for many others who need the knowledge she has gained. She is so willing to share.

Shana would be an invaluable resource for the council and, I believe, a great voice for Kauai, for families, and for Hawaii's efforts in making the world better for everyone. She has my highest regard and I ask you to support her in becoming a member of your council.

Sincerely yours,

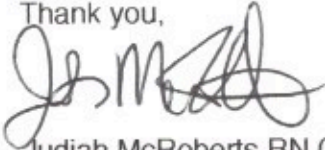


Laurel Loo

Dear DD Council,

I am writing to recommend Shana Metsch to the Hawaii DDID Advisory Board. As a Registered Nurse Clinical Manager for Bayada Home Care, I have worked directly with Shana numerous times over the past five years. In my professional observation and opinion, Shana has been a strong advocate for her daughter Hannah who is part of the Hawaii DDID med-waiver program. Having a daughter who is DDID, Shana has acquired a strong knowledge base of the laws and requirements surrounding the DDID program and is acutely aware of the benefits it provides to DDID community. Shana has also been an amazing resource for other parents of DDID children who have questions about the program and its benefits or, who need general guidance. I have sat down with Shana during multiple ISP meetings and observed her professionalism and collaborative efforts with the interdisciplinary team including members of the DOH, PT, OT and Special Education Teachers. It is for these reasons and many others that I believe Shana Metsch would be a welcome and valuable addition to the DDID Advisory Board.

Thank you,

A handwritten signature in black ink, appearing to read 'J. McRoberts', written in a cursive style.

Judiah McRoberts RN CM  
PO BOX 1142  
Kilauea, HI 96754  
(808) 651-1899s

March 1, 2018

RE: Letter of Reference for Shana Metsch

Dear DD Council,

I am honored to recommend Shana Metsch to the Hawai'i Developmental Disabilities Division Advisory Board. I have known Shana since August 2017 when I reached out to her via email to ask for advice concerning our own challenges advocating for our daughter.

Last summer my husband and I were informed by our daughter's urologist that she had two large epidermoid cysts on her spine. He suggested we contact her neurosurgeon, who we had just seen the same day, to discuss how he would like to proceed. After waiting several weeks for the neurosurgeon in Honolulu to return our phone call I emailed the neurosurgeon in Philadelphia at the Children's Hospital where she had fetal surgery at 21 weeks gestation. The neurosurgeon from Philadelphia called the next day and informed us that we had to have the cysts removed immediately. He also mentioned they were the "second largest he had ever seen." The next day, the neurosurgeon from Honolulu finally returned my phone call and suggested we wait another year to see how much more the cysts would grow. Our daughter's pediatrician immediately sent our insurance company a request to take her to the Children's Hospital of Philadelphia for surgery. Our insurance denied this request.

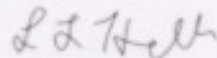
This is when a friend from Maui suggested I contact Shana to me. Shana has been an invaluable support for my family. She is my mentor and has shown me how to advocate for my daughter in more effective ways. Under Shana's guidance, I learned how to increase the likelihood of successfully appealing denials from the insurance company. She willingly shared all of her knowledge and resources that she has gained by being a fierce advocate for her own daughter.

Shana taught me how to keep proper records of phone calls with our insurance, how to write a timeline, and connected us with a lawyer. She emailed and phoned regularly to check in on me and never hesitated to answer all of my questions. I firmly believe that if I had not met Shana our daughter's cysts would still be growing rather than being successfully removed.

Shana Metsch would be a voice for those who have none and advocate for those who are unable to navigate the red tape and bureaucracy facing families with children who are disabled. All of what I have described about Shana illustrates her commitment to helping the families in Hawai'i learn how to advocate and help their children. For all of these reasons I strongly recommend Shana for this position.

If I can provide any additional information or clarification please contact me at [hellerl@hawaii.edu](mailto:hellerl@hawaii.edu) or I can be reached by phone at 808-932-7294.

Sincerely,




Lindsay Heller



March 7, 2018

TO: The Honorable Rosalyn H. Baker, Chair  
The Honorable Jill N. Tokuda, Vice Chair  
Senate Committee on Commerce, Consumer Protection, and Health  
Twenty-Ninth Legislature  
State Capitol  
State of Hawaii  
Honolulu, Hawaii 96813

FROM: Waynette K.Y. Cabral   
[ddadvoc8@yahoo.com](mailto:ddadvoc8@yahoo.com)

SUBJECT: GM 581 – State Council on Developmental Disabilities  
Gubernatorial Nominee Shana Metsch

I am submitting testimony in strong support of **GM 581** to confirm the nomination of Shana Metsch to the State Council on Developmental Disabilities (DD).

As the former Executive Administrator (retired on December 31, 2017) of the State Council on DD, I understand the Council's Federal mandate (P.L.106-402 - DD Assistance and Bill of Rights Act of 2000) of having parents represented on the Council. Ms. Metsch as a parent of a daughter with special needs would provide the voice of parents and families of family members with DD who live on Kaua'i. Her advocacy experience and knowledge of Medicaid regulations and the Individuals with Disabilities Education Act would assist the Council in sharing information and connecting parents and family members with appropriate resources that are family-driven and family-centered.

Thank you for the opportunity to convey my strong support to confirm Shana Metsch to the State Council on Developmental Disabilities.

**Karen Raforth, Ph.D.**  
**Licensed Psychologist**  
**1282 Lambert Circle, Lafayette, CO 80026**  
**(303) 521-0930**

March 1, 2018

Office of the Governor  
State of Hawai'i

**RE: State Council on Developmental Disabilities nominee Shana Metsch**

Dear Governor, Senators, and staff,

This is a letter of recommendation for Shana Metsch to the State Council on Developmental Disabilities. My experience with disabilities comes from several years serving as a psychologist who has worked with special needs children through young adults and their families in K-12 public schools, universities, and hospitals.

I have known Shana Metsch for decades. She would be an outstanding choice for the DD Council. She and her husband raised an infant born with disabilities who has now grown to a child and soon to be a pre-teen; Shana has a range of experience as an active parent of an individual with disabilities.

Shana has not been a passive parent. She made it her passion to gain specialized knowledge and experience that will be useful to the DD council. Over the past decade she had learn about and keep abreast of medical terminology and procedures, hospital bureaucracy, changing insurance policy and procedures, Medicaid, local, state and federal laws, education systems with teachers and staff, ancillary medical support personnel, Individual Education Plans (IEPs), and adjust to different schools. At times she has researched the literature and literally been on the cutting edge of experimental drug or procedural treatments and educational best practices which she has participated in or suggested to medical or educational staff to improve care for her child and other children. A no-nonsense business woman, Shana has figured out how to knock down barriers herself and worked in collaboration with others to do so including working with local and state governmental officials.

She has dealt with all this while trying to keep her family together, juggle personnel and medical appointments, work, and make difficult and sometimes heart-breaking decisions in an environment of constantly changing medical, educational, insurance, and governmental information. I have watched Shana develop and then hone her disability, legal, medical and educational knowledge over the past decade. These different knowledge and experience bases are successfully coupled with Shana's personality traits of perseverance, clear thinking, creative problem-solving, assertiveness, advocacy, attention to detail, conscientious approach, and compassion. This is a mix which would result in a successful DD council leader.

For several years Shana has been an unofficial advocate for other parents in Hawaii and across the nation. She has done this without formal recognition but simply driven by her own passion and commitment to children with disabilities. She has been thinking of a way to be a more effective conduit of information to parents and the DD Council is likely a great match. I have heard her talk with parents

about their experiences and then patiently and clearly offer sound and compassionate advice or a plan to move forward after carefully listening to the parent. She is an advocate for not only her child but for many others. She has at times been a reminder to administrators, staff and governmental officials that they could and should do better for children and adults with disabilities. She has grown into a diplomat with a treasure trove of information for parents in Hawaii and beyond. This position on the DD Council will make it easier for her to assist others across the state more efficiently and to broader effect.

I know that Shana is extremely enthusiastic about this opportunity to serve the state and citizens of Hawaii. She carefully researched the mission, membership, committees, mission implementation and activities. This is a perfect fit for her. I believe her broad knowledge, skills, and abilities are sharpened to the level of not just being an advocate. She views things on the micro and macro level. She and her family have had to live with well-intentioned policy, procedure, or law that has unintended negative consequences. On the DD Council she would help craft useful policies and law for those with disabilities, advise and build coalitions to create useful laws and improve the lives of all citizens and families dealing with disabilities.

I have written many letters of recommendation in my career, and I am pleased to give Shana Metsch my highest recommendation to you for membership on the DD Council. I believe you will find that she becomes one of your more active members and one who distinguishes herself in a way that will reflect that she was an outstanding choice.

Please do not hesitate to contact me if I can be of further assistance in advancing Shana's candidacy.

Sincerely,

*Karen Raforth, Ph.D.*

Karen Raforth, Ph.D.  
Licensed Psychologist  
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