

## Nothing about us without us!

## Testimony of Autistic Self Advocacy Network Senate Budget Subcommittee 3 on Health and Human Services March 23, 2023

On behalf of the Autistic Self Advocacy Network, I am grateful for the opportunity to provide written testimony regarding the Autism Services Branch proposed in the new budget of the state of California. The Autistic Self Advocacy Network (ASAN) is a national advocacy nonprofit created and operated by autistic adults to ensure that policies reflect the needs of the autistic community and foster greater inclusion of autistic individuals in the policymaking process.

We welcome California's recognition of the need for greater support for the autistic community's needs which this proposal reflects. We believe that now is a particularly critical moment in ensuring that autistic individuals are given the support and resources they need to live in their communities. However, we also have some serious concerns about the approach to providing these services represented in this proposal. In general, we support approaches to autism-related services that prioritize the services and supports that autistic individuals identify themselves as supporting their needs- services that are self-directed, individualized, and support community living. Most often, this also means shifting away from deficit-centered models that focus on a narrow set of supports and often focus on changing autistic behavior, and towards a broader set of supports that meet autistic people's individualized needs and goals.

We share many of the concerns previously raised by Disability Rights California in its February 22nd letter to the committee that the description of the Autism Services Branch included in the proposal reflects a concerning misalignment of priorities with those of the autistic community. While the proposal recognizes the unmet service needs of the autistic community, the staffing and objectives of the proposed autism services branch do not appear to fully reflect these needs. We are particularly concerned that the emphasis on early intervention, combined with the deficit-focused descriptions of autistic living throughout this

proposal, suggests priorities that may lead to a too-restrictive focus on ABA and similar behaviorist approaches to the exclusion of viable community-identified supports. We have written in the past¹ to the State of California to raise many of our concerns regarding approaches to providing support that is restricted to these therapeutic approaches, which many autistic individuals have identified as harmful and unhelpful. For more information on our concerns about the use of ABA and similar approaches, please refer to our white paper on the topic, *For Whose Benefit?*: *Evidence, Ethics, and Effectiveness of Autism Interventions.*²

ASAN's recommended approach to providing community supports for the service needs of autistic individuals starts with identifying what those needs are according to autistic individuals. As such, it is essential that autistic people be an integral part of the decision-making process for any such entity. We strongly urge the explicit inclusion of autistic community members and service recipients in the proposed stakeholder group and to ensure that the feedback and guidance of autistic individuals guide the autism services branch's activities.

Finally, we commend this proposal for its recognition of the importance of supporting the needs of autistic individuals across the lifespan, including during the transition to adulthood. However, given this recognition, it is especially concerning that this proposal contains limited language supporting either self-directed services and community living. Support for community living is especially important at this moment to ensure that we do not fall back into failed institutional models for service provision. Similarly, self-direction of services is a critical element of ensuring a successful transition from youth to adulthood for autistic individuals receiving services, as discussed in our policy brief, The Transition to Adulthood for Youth with I/DD: A Review of Research, Policy and Next Steps.<sup>3</sup> We strongly encourage efforts to provide a greater orientation of this program's activities and outcomes to support community living and self-direction to a greater extent, including a greater focus on improving accessibility to services, provider network adequacy, acceptability of supports, and addressing other needs related to community living.

We thank you for the opportunity to provide our feedback on the

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<sup>&</sup>lt;sup>1</sup> https://autisticadvocacy.org/2014/10/asan-letter-california-should-cover-more-than-aba/

<sup>&</sup>lt;sup>2</sup> https://autisticadvocacy.org/policy/briefs/intervention-ethics/

<sup>&</sup>lt;sup>3</sup> https://autisticadvocacy.org/policy/briefs/healthcare-transition/

budget proposal for the development of the autism services branch. I welcome the opportunity to discuss these issues further and to provide the autistic community's priorities when it comes to services that meet our needs. I can be contacted at <a href="mailto:grobinson@autisticadvocacy.org">grobinson@autisticadvocacy.org</a>. Thank you for your time and consideration.

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