

Jan. 14, 2021

To the judges:

Nominator: I am Jill Jorden Spitz, editor of the Arizona Daily Star, which produced and published this project, State of Denial, with the ProPublica Local Reporting Network. I am proud to nominate this work for the Anthony Shadid Award for Journalism Ethics.

Reporter: Amy Silverman, amysilvermanaz@gmail.com.

The project, [State of Denial](#) (please also see the attached pdfs of the Daily Star's print version; and the project [as it appeared on ProPublica's](#) site): Arizona has long enjoyed a reputation for having the best services in the country for people with intellectual and developmental disabilities. But years of mismanagement, funding shortfalls and turnover at every level of the state's Division of Developmental Disabilities have resulted in a much different story. The Arizona Daily Star, in partnership with ProPublica's Local Reporting Network, reviewed thousands of pages of documents, analyzed data and interviewed more than 100 people with disabilities and their family members as well as advocates, caregivers, attorneys, doctors and bureaucrats to reveal the system's inadequacies, including:

- Routine denials of eligibility for services that have led to several reversals in the state Court of Appeals.
- Turnover that leads, in some cases, to families having as many as five support coordinators in a year.
- Children waiting years for communication devices.

- A caregiver shortage so severe that one woman said she hadn't left the house alone in four years because there was no one to help care for her adult brother in law, who has Down syndrome.

Subsequent stories in the project reported the [demise of independent oversight](#) committees designed to provide outside accountability, and the [failure of the state](#) to fulfill recommendations made by a governor's task force on abuse and neglect of people with developmental disabilities.

One of the project's main goals was to include people with intellectual and developmental disabilities in the reporting of these stories in meaningful ways, rather than focusing on family members, caregivers and bureaucrats.

Conflicting values encountered: The original plan was to spend a great deal of time in person with people with intellectual and developmental disabilities — in private homes, day treatment programs and state-funded residential settings — to really capture what their lives are like.

We also considered asking people with I/DD to participate in a storytelling event where they spoke directly about subpar conditions in group homes, being refused services and enduring abuse.

Options considered to resolve the conflicts: COVID-19 put an unfortunate stop to the idea of immersing in group homes and other settings. Even Zoom interviews proved more difficult than anticipated, although we did plenty of them. We also learned that some questions are not appropriate. For example, one man with a seizure disorder and Alzheimer's, who lives at home with his mother, was not completely aware of his situation. The state had asked his mom to put him in adult diapers to avoid having to pay

nighttime caregivers and she didn't want to worry him by telling him, so we couldn't ask him about it.

Final decisions and rationales behind them: Instead of a storytelling event featuring horror stories, we backed up and thought about this on a much more basic level. Many readers have never considered that people with intellectual and developmental disabilities have something to say — on any topic.

And so we worked with a local theater company for people with disabilities and with ProPublica's audience engagement team on a storytelling event, held virtually, where people with intellectual disabilities shared stories about their lives. We used that as a way to crowdsource additional stories and were able to gather important reporting that way.

We also realized that it was not enough to feature people with disabilities in our stories. In order to be truly meaningful, the stories needed to be accessible to those people, as well. So we hired an expert who translated the stories into "[plain language](#)," a format that streamlines and clarifies information, rather than dumbing it down. This was the first time a mainstream media organization made such an attempt, and the editors explained this decision and others we made in a [note to readers](#). The Nieman Lab [wrote of the project](#) that the Star and "ProPublica's translation appears to be the first time a plain language version has been produced by a news organization that isn't specifically produced by and/or for people with intellectual and developmental disabilities."

We also provided audio recordings of most of the stories in both the original format and plain language.

Finally, in an attempt to be sure that the targeted audience was being reached, we held a final event in December where we presented excerpts in both original text and plain language. We also interviewed people with disabilities who we'd featured in the stories, to ask them what it was like to be included in the

project.

We also shared [results](#), including the story of an 11-year-old girl with cerebral palsy who waited 18 months for a communication device. Her mother got a call the day after the story was published; the device was ready.

Sincerely, and thank you,

Jill Jordan Spitz