



May 4, 2019

To: All ODDS Staff and Stakeholders

From: Lilia Teninty, Director, Office of Developmental Disabilities Services

Today, *The Oregonian* published two stories about Oregon's intellectual and developmental disabilities (I/DD) system. One was about [health care representatives](#) and another about [a specific provider agency](#). *The Oregonian* told us the article started when a mom contacted them with concerns about decisions around her adult son's health care.

It's important that the I/DD community is kept informed when these types of stories publish and to hear directly from the Office of Developmental Disabilities Services.

We were as helpful as possible with the reporter. We couldn't answer specific questions due to privacy laws, even whether or not the person receives I/DD services. In situations like this, it's possible some of the details in the story may be inaccurate.

Responding to the reporter's questions has reinforced my belief that people who are not attached to the I/DD system often don't understand our values, why we operate the way we do, and the deep community-based approach to our work. Let's continue to work together to educate and inform our broader communities about the 'why' behind our services.

I hope to use this opportunity to clarify some important information about the I/DD system in Oregon and to address some of the issues mentioned in *The Oregonian's* coverage.

I encourage you to share this information.

Guardianship

In some states, when a person with I/DD reaches adult age, guardianship is immediately sought. In Oregon, we want, and support, people with I/DD

to be as independent as possible. We don't assume all people with I/DD need a guardian. We know that many people with I/DD can make decisions for themselves. Others can make those decisions with assistance and support.

Health care representatives (HCRs)

For those who can't make their own health care decisions, a health care representative (HCR) may be appointed. Oregon Administrative Rule 411-365 outlines the process in detail.

The rule has safeguards, including limits on who can be appointed and the HCR's authority. The Individual Support Plan (ISP) team can appoint the HCR. An ISP team includes the person with I/DD, the case manager, family members, service providers and others who are involved in the person's life.

HCRs for people with I/DD in many ways are no different than HCRs for everyone else. No training is required to hold that role. The HCR should make decisions based on their best judgment of what they think is appropriate in the current medical situation, what the person would want, and in the best interest of the person.

Senate Bill 1039

Our process, which has been in effect for more than 20 years, is supported by the state's general health-care decision-making statutes, Oregon Department of Human Services' responsibility to provide protective services for people with disabilities and an ISP team's responsibility to provide the supports needed for each person.

The many questions from the reporter helped us see it would be a good idea to strengthen the current rule with a statute specific for people with I/DD and to be explicit about the ISP team's role in appointing an HCR. It will be also be helpful to distinguish our work from the HCR process for the general population.

We were able to get legislation introduced this session for a Health Care Advocate specific to people in the I/DD system. (The bill uses the term "advocate" to better distinguish this role from an HCR for the general population.) During the Senate hearing, I/DD advocates made a strong

case about how having the current HCR rule in place helped people get important treatment that might not have otherwise been provided.

SB 1039 also broadens the health care advocate option to all persons served by ODDS, not just those in group homes, foster homes and supported living. The bill passed the Senate unanimously.

Quality assurance

The operation of the state's I/DD system is a partnership between ODDS and its partners. ODDS issues rules and provides oversight. Our contracted partners are required to follow those rules.

Our oversight roles related to issues raised in the story about HCRs are twofold: reviewing group homes and their records and reviewing the case files of our partners in Community Developmental Disabilities Programs and Brokerages. In both instances, when ODDS quality assurance or licensing staff see that someone may be making decisions for a person with I/DD they follow up with either the provider or the case manager to ensure the documentation is accurate and up to date.

Family involvement

For people who have family, we want them to be involved in the person's life to the extent the person wants and consistent with the ability and interest of the family. This includes being a member of the person's ISP team. We encourage family that want to be included to contact the person and the case manager to get involved.

If the person needs an HCR, family members are among those who may serve in that role. Examples of when family members are not appropriate for that role include if they are not readily available to respond to healthcare needs, come and go from the person's life, make decisions that conflict with the person's wishes, or have lost parental rights.

Any family member concerned about what may or may not be happening for a person with I/DD should raise the issue with the ISP team. They may also file a complaint or even seek to become the guardian if needed. If they think abuse or neglect may be happening, they should report it to 1-855-503-SAFE (7233).

Case management system

Given the I/DD system is locally based, it's not a surprise that there is no centralized electronic case management system. Each CDDP and Brokerage operates its own IT system, either home-grown or purchased, to keep individual records, ISPs, case notes, etc.

We do have a centralized billing system (eXPRS). We do not have a system to provide ready access to data to identify trends or collect and analyze information about people's daily lives. When we need data or information not connected to billing, we send out a request and gather the information via email or Excel spreadsheets. Not having a system hampers our ability to look at data across that system, identify trends and take action.

The Legislature provided funding several years ago to begin planning for the centralized system. However, other priorities or budget constraints led to the funds being used elsewhere. Much of those other needs were important to I/DD services. For example, extensive technology changes were needed to implement the K Plan and to comply with the US Department of Labor rules that substantially changed payment methods and recordkeeping for Personal Support Workers. The Centralized Abuse Management system is also a current significant IT project that when completed will provide consistent data and information on abuse allegations and findings. It will also house data on serious incidents for people with I/DD.

We submitted a request for the case management system for the 2019-21 biennium to ensure adequate funding would be available and support for development of the new case management system would be a known priority. That request did not make it into the Governor's Budget. Regardless, we are hopeful the work will begin soon; but keep in mind that the availability of IT resources and the pressure of other priorities will always impact plans, as happened in the past.

Provider agencies

It's not uncommon in the I/DD community for family members to work in the field, even in the same organization. Our provider agencies sign a Medicaid Provider Agreement and we expect that their leaders or boards of director's carry out their oversight consistent with the agreement's requirements. Provider agencies that receive more than \$1 million in funding are required

to submit audited financials every biennium, which we review. The Charitable Activities Section of the Oregon Department of Justice reviewed arrangements of the provider in the story and did not indicate any specific concerns.

Many of you will recall that when the Fairview Training Center was closing in the late 1990s incentives were provided to encourage providers to open new homes to support people leaving the institution. The conditions of the loans were that as long as the property was used continuously and exclusively as a location in which people with developmental disabilities reside and receive services approved by the Department of Human Services for a period of not less than 12 years the debt would be forgiven. DHS did not expect to be repaid unless the homes were no longer being used as group homes during the 12-year period which has since expired. The homes in this story met that obligation.

What's next?

Whether SB 1039 becomes law or not, we will review our processes and rules about HCRs. That will include the need for second opinions, especially around conditions that may be seen as life-threatening. We are also working closely with the DHS budget and IT leaders to get the planning for the case management system prioritized.

We will explore options to determine if HCRs are being appointed and reappointed appropriately.

We also want to remind you that if you have concerns about services you or a family member receives, you may file a complaint. If there are problems we need to know about them early so they can be addressed. An easy step-by-step guide is online at

<https://www.oregon.gov/DHS/SENIORS-DISABILITIES/DD/Pages/File-a-Complaint.aspx>

We – all of us – have a responsibility to ensure the safety of each person we support and to be responsive to their strengths, needs and choices, while they live and thrive as valued members of their community.

If you are interested in educating others in Oregon about I/DD services and the importance of community inclusion and self-determination, we want to hear your ideas. Feel free to email us at DD.Directorsoffice@dhsosha.state.or.us.

Sincerely,

A handwritten signature in black ink, appearing to read "Lilia". The signature is fluid and cursive, with a large loop at the beginning.

Lilia Teninty
Director
Office of Developmental Disabilities Services

Previous ODDS Director's Messages are available at
<http://www.oregon.gov/DHS/SENIORS-DISABILITIES/DD/Pages/messages.aspx>

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You can get this document in other languages, large print, braille or a format you prefer. Contact the Oregon Office of Developmental Disabilities Services at 503-945-5811. We accept all relay calls or you can dial 711.