The Arc Oregon

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Oregon Special Needs Trust (**OSNT**)
Oregon Training and Consultation (**OTAC**)
Guardianship, Advocacy and Planning Services (**GAPS**)

March 2, 2023

To: Senate Judiciary Committee

From: Em Braman, Executive Director, The Arc Oregon, and National Certified Guardian

**RE: Opposition to Senate Bill 793**

Chair Prozanski, Vice-Chair Thatcher, and members of the committee,

The Arc Oregon is an affiliated chapter of The Arc, the nation's oldest and largest organization for people with intellectual and developmental disabilities (IDD). For 65 years The Arc Oregon has advocated with and for people who experience IDD and their families while also offering innovative programs, services, and training. Through our Guardianship, Advocacy and Planning Services (GAPS) program we provide professional guardianship people with disabilities and aim to provide them with the greatest amount of autonomy and dignity possible within guardianship. Our executive director, Em Braman, was previously the GAPS Program Director and a guardian, and remains a National Certified Guardian. Ensuring the autonomy of protected persons and honoring their values and choices is central to our identity and mission.

**Senate Bill 793 is vague and overbroad.** As we have experienced supporting people with IDD and providing professional guardianship, many medical professionals maintain an outdated paternalistic approach toward people experiencing IDD. This often leads to a significant difference in how a physician would interpret the phrase "ordinary and necessary" for these individuals compared to how they would interpret it for those without IDD.

As an example, many people with IDD struggle with dental hygiene, leading to tooth decay. Dentists will often recommend pulling even healthy teeth as a "preventive" measure—a procedure typically not recommended for those without IDD with tooth decay. This affects their eating, their speaking, and how they are treated by other people, in addition to the considerable pain of the procedure itself. If a dentist deems this invasive and life-altering procedure "ordinary and necessary," Senate Bill 793 would create the legal presumption that all protected people with IDD consent to it.

**The presumption of consent undermines the autonomy of a person with IDD.** Our professional guardians consider the preference of the people they support with every decision, attempting to give them as much choice in how they live their lives as is possible. Indeed, ORS 125.300 requires that guardianship be "designed to encourage the development of maximum self-reliance and independence of the protected person." As written Senate Bill 793 implies that a protected person's wishes are last in line, behind both physician and guardian. It is unclear how a protected person is meant to provide clear and convincing evidence that they do or do not want the care their medical professional has recommended, but it appears that they must rely *entirely* on their guardian also objecting to it and going through the court system to override the provider opinion. This is contrary not only to the principles of autonomy and self-determination Oregon disability law is meant to uphold, but existing Oregon statute[1].

Compounding this erosion of autonomy, **the burden of overriding a physician's opinion is onerous.** The "clear and convincing" standard is far too high, requiring the protected person or a guardian to prove not only that it is more likely than not that the protected person would refuse the recommended treatment if able, but that the evidence shows it is *highly* probable. This is an excessively high burden for the protected person or a guardian to meet.

Moreover, even when the protected person or a guardian can easily overcome this burden, they very well may never get the chance to try. **Filing in court is expensive, time consuming, and often confusing to laypeople.** Many people with IDD survive on Social Security and possibly a small income from employment and many guardians are family members with limited funds that may have already been strained by the cost of establishing guardianship. These protected people and guardians would be unable to afford to repeatedly approach the court. In fact, a protected person or guardian told by a medical professional that the person they support is presumed to consent to a treatment that a medical provider deems "ordinary and necessary" may not even know they have the right and duty to approach the court for instruction.

Healthcare is a human right. Implicit in this statement must be that **the opportunity to refuse treatment is a human right.** This right does not disappear when a person is placed under guardianship. While we recognize the necessity of procuring health care for people with IDD and others under guardianship even when a guardian unreasonably objects, Senate Bill 793 attempts to accomplish this narrow goal with a blanket diminution of autonomy, trust, and informed consent.

**The Arc Oregon urges you to reject SB 793 as written.**

The Arc Oregon does not object to sections (3) and (5) that help clarify current law.

Thank you for considering this testimony.

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[1] ORS 125.315(g): "The guardian shall promote the self-determination of the protected person and, to the extent practicable, encourage the protected person to participate in decisions, act on the protected person's own behalf and develop or regain the capacity to manage the protected person's personal affairs."