

Excerpts from over 150 pieces of testimony in OLIS re: SB 1606

Compiled by Senator Sara Gelser

Over the course of 72 hours, letters in support of SB 1606 poured in from every corner of the state. Because there is so much testimony on OLIS, this document simply highlights portions of **just some** of the stories shared by people with disabilities, their families, medical professionals and support staff across the state.

Laura Lonski, Provider, Corvallis

<https://olis.oregonlegislature.gov/liz/2020S1/Downloads/CommitteeMeetingDocument/223520>

In April, an individual that we support was experiencing symptoms including a fever of over 101 degrees; respiratory distress; a drop in oxygen saturation levels; and a worsening cough. He also has an intellectual/developmental disability and chronic respiratory disease. He was transported to the emergency room, with his program manager accompanying. I was in direct communication with the manager throughout the ER visit. We both were surprised when the individual was **not automatically given the COVID-19 test**. We clearly communicated his risk factors, in addition to the fact that he is supported in a congregate care setting, where possible exposure could be highly dangerous and detrimental to a vast amount of individuals. When the COVID-19 test was requested, the hospital staff stated he would not be given it, as he had a history of pneumonia and it "was likely just that." Only after continued, persistent advocacy on our part, was he administered that diagnostic test, even though he checked nearly every qualifying box for possible exposure to a highly contagious and very deadly infection. After he did receive the test, **a member of the hospital staff was agitated and stated in earshot of the individual that it "was a waste of valuable PPE (personal protective equipment)." This individual was made to feel as if they were less worthy of receiving essential healthcare supports, due to the fact that their quality of life was deemed less valuable.**

Gabrielle Guedon, Executive Director, Oregon Self Advocacy Coalition

<https://olis.oregonlegislature.gov/liz/2019I1/Downloads/CommitteeMeetingDocument/222868>

During my weeks in the hospital, my mother was able to stay by my side the whole time. **She was able to help the hospital staff understand all my complicated, underlying conditions and explained all of the medications I was on at the time.** Luckily, my mom was there to help advocate for me. The doctors wouldn't take the time to understand the symptoms that I was trying to explain to them, so they didn't realize that I also had a double ear infection. **They kept giving me too much pain medication and not treating my ear infection until my mother was able to step in and explain. The doctors and nurses didn't have any experience with people who have IDD and I felt scared, confused and frustrated and really relieved to have my mom there to support me. . .**

It is crucial to support LC 52 now and not in a few months because **people with IDD are making plans to not go to the hospital, even if they really sick.** People with IDD have heard that they

will be forced to be alone and not allowed the support they need to understand their care or communicate their needs or in making decisions about their care. **People with IDD are fearful that they will be mistreated and not get the care they deserve because they have a disability.** People with IDD are afraid that they will die alone in the hospital. **Two of our members have been to the hospital, they were not allowed to have support with them and did not feel like they were taken seriously and did not have the same level of care that they would have if they would have had support with them.**

Kathryn Weit, Parent, Eugene

<https://olis.oregonlegislature.gov/liz/201911/Downloads/CommitteeMeetingDocument/222770>

I am writing because I am the parent of a 40-year son who experiences significant disabilities. He is over 6' 2" and nonverbal. He becomes extremely agitated in unfamiliar settings such as medical environments. **In the most "normal" of times, access to health care for Colin is a challenge and when possible involves months of planning.** We must have his trusted people with him at all times both for his safety and the security of others. . . **Several times we have been told by physicians that they did not work with "people like that" or that there was nothing they were willing to do for him because of his disability it wouldn't matter anyway.** And while I write letters, complain to the Medical Board, and get apologies from the medical practice, so many do not have that time or knowledge. **They accept the discrimination as the normal part of being a person who experiences disability. Laws are important.** LC 52 is an important step in fighting the discrimination that people with disabilities often experience in the medical arena.

Patricia Klee, Parent, Hillsboro

<https://olis.oregonlegislature.gov/liz/2020S1/Downloads/CommitteeMeetingDocument/223521>

As a parent of a disabled son who had limited communication skills, I find that frightening and extremely sad. My son passed away suddenly years ago before the pandemic, I was there constantly by his side in the ER, And later in Intensive care. **As his guardian, I had to make many fast decisions, including whether to intubate or not.** At the end of life, I also had to make the decision whether to donate his organs and that was a very long interview with DonateLife NW. As a former Healthcare worker, I also cannot imagine how difficult it would be to take care of a disabled person effectively and safely without a caregiver there by his side to help with communication. **If my son had had to be hospitalized during this time, and I was denied access to him and he passed away, I would be very very sad for the rest of my life with the regret.**

Marie Gerdtz, Personal Agent, Portland

<https://olis.oregonlegislature.gov/liz/201911/Downloads/CommitteeMeetingDocument/222840>

In my previous job as a direct support professional, I supported a man who woke up one day with a sudden, painful growth on his face. I transported him to the ER, where we spent several hours waiting and meeting briefly with triage staff. **I felt that his concerns were being written off because of his difficulty explaining the pain.** When we were finally able to meet with a doctor, he was admitted to the hospital and taken to emergency surgery to treat **a sinus infection that had spread to his eye and brain (causing the swelling).** I believe that if he had

not been allowed a support person, he would not have received the advocacy he needed to get emergency treatment.

Kelly McCauley, Adult with Disability, Corvallis

<https://olis.oregonlegislature.gov/liz/201911/Downloads/CommitteeMeetingDocument/222702>

Health care in itself can be hard to figure out, it is not people with disabilities friendly. And it can plainly be hard to figure out. As far as people with disabilities goes for hospital visits. It can be a very scary situation to go through. Talking about mental health is not as easy as it may sound. If you hear voices or have some other kind of medical issue. Talking about mental health in general, its not an easy topic for one to talk about. I hope I have given the correct information for you. . . But most importantly, ***People with disabilities should always have someone they can trust to help sort out hospital visits.***

Robert Nickel, MD, Developmental Pediatrician and Professor of Pediatrics, OHSU

<https://olis.oregonlegislature.gov/liz/201911/Downloads/CommitteeMeetingDocument/222992>

“I’m writing to express my strong support for Legislative Concept 52 which mandates hospitals allow support people to patients who have disabilities ***as required by the Americans with Disabilities Act***, and consistent with the order recently released by US Health and Human Services and current Oregon Health Authority guidelines. It is critical these individuals receive the support they need to understand and fully participate in their own health care. I am a Developmental Pediatrician and Professor of Pediatrics at OHSU. Working with these families and individuals has been my career and my great pleasure.”

Stacy Fields, Sister of a person with a disability, Eagle Point

<https://olis.oregonlegislature.gov/liz/2020S1/Downloads/CommitteeMeetingDocument/223626>

I'm sure we can agree that everyone deserves access to healthcare and support from people they trust to help them understand their care and communicate with doctors. ***My brother Kyle would not be able to remember entering a hospital, why he was there, what he was there for, etc. This could result in him signing documents about his care that he isn't able to understand or remember.*** It would also result in combative situations with hospital staff or security, without support from someone he trusts.

April Vorhauer-Flatt, AFH Provider, Pendleton

<https://olis.oregonlegislature.gov/liz/201911/Downloads/CommitteeMeetingDocument/222866>

As a Foster Care Provider to an adult with complex medical needs in addition to Intellectual Developmental Disabilities I have spent many days in the hospital with this individual and a Life Flight trip to PDX. ***On more than one occasion this individual was in grave danger of death if not for my presence and advocacy.***

Emily Pundt, Direct Support Professional, Eugene

<https://olis.oregonlegislature.gov/liz/2020S1/Downloads/CommitteeMeetingDocument/223654>

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This is an emergency and directly relates to what is going on with Covid-19 and MUST be passed now so that if any Oregonians with disabilities become hospitalized they will receive the support they need in order to get the care they have a right to. Can you imagine having covid and sitting alone in a hospital bed with nurses asking you questions that you don't understand? Me neither. ***The people I support would not be able to answer medical questions without support of their team. Please don't let people with disabilities die alone because they didn't understand their options.***

Diane Cole, Parent, Bend

<https://olis.oregonlegislature.gov/liz/2020S1/Downloads/CommitteeMeetingDocument/223634>

[We] live in Bend, Oregon along with our daughter Anna. Anna is a 28 year old with spina bifida, hydrocephalus, seizures and a nonverbal learning disability. She qualifies for developmental disability services. Anna lives in our home where we can support her with activities of daily living, supported decision making and medical care. On May 25, 2020 our daughter was admitted to St. Charles for an infection from a pressure sore. When she was admitted she had spiked a fever and was slurring her words. My husband, Jeff was allowed to accompany her into the ER to provide information to them. ***He was told that no one would be allowed to stay or visit due to COVID-19 restrictions. As of today, our daughter has had 4 surgeries, a colostomy and been in the hospital for 25 days.*** During that time, she has been ***asked to sign medical paperwork, make decisions and have more medical procedures than she could count that she did not understand.*** No one was there to help her make any decisions or talk through the procedures in a way she would understand. She did not know what questions to ask, how to ask them or how to best advocate for herself. ***No one was allowed to be there to help her communicate with her medical team.*** When the nurses would help her Facetime us, she was often crying and scared. She wanted one of us there and we were not allowed to be there. ***We as her parents and caregivers received little information and often it was only when we solicited it were given any at all.*** It has been hard for us to even explain things to Anna over the phone because without being there, we did not have all of the information.

Katherine Palmer, Parent, Pendleton

<https://olis.oregonlegislature.gov/liz/201911/Downloads/CommitteeMeetingDocument/222935>

“My son has Intellectual Disabilities and is ***unable to communicate his needs verbally, he needs his primary care provider with him during his hospital stays.*** My son’s Adult Foster provider and myself have been advocating for his right to have “his primary care provider” with him during hospital admission.”

Anna Taylor, Person with a disability, Eugene

<https://olis.oregonlegislature.gov/liz/201911/Downloads/CommitteeMeetingDocument/223178>

My name is Anna Taylor and I am a 35 year old woman with Cerebral Palsy. All throughout my childhood and adult life, I have had to have many surgeries for different issues related to my disability. While my disability only affects me physically, ***I still have a little bit of a speech impediment and this sometimes makes communicating with unknown persons harder.*** . . . I can not imagine myself having to be with out any personal support worker who knows me and

understands my speech and behaviors. . . ***My physical limitations do not allow me to easily reposition my body or push buttons on the bed or easily feed myself while laying down.*** Having someone who already knows how to help me is of the utmost importance with my success while being in the hospital. My parents and sister can only do so much, that's why I have hired people to assist me in the times that my folks need a break.

Emily Braman, GAPS Program Director, The Arc of Oregon, Salem

<https://olis.oregonlegislature.gov/liz/201911/Downloads/CommitteeMeetingDocument/222856>

We had another elderly lady with Down Syndrome who went to the Emergency Department and when she was admitted her support staff was told she could not have any visitors. This elderly woman is non-verbal and uses gestures and a couple signs to communicate. She was left at the hospital for ***two days*** before we were able to convince the hospital that she could have a visitor and by then she was being discharged. ***Without a support person there was no one there who knew her who could relay to the nurses and doctors if she was in pain, hungry, or uncomfortable.*** She did not have anyone available to help her understand her care options nor communicate with her care providers. Additionally, ***due to her disability she is not able to call for or request help, order her meals, nor consent to any treatment.***

Beckie, Parent of adult with Disability from Hermiston

<https://olis.oregonlegislature.gov/liz/201911/Downloads/CommitteeMeetingDocument/222693>

We have dealt with all kinds of doctors and their opinions of how we should allow them to treat him.... ***The only thing that has kept him a live this far is our faith, and our determination to be by his bedside day/night while in the hospital to advocate for him.*** We are his legal guardians and he has a POLST and I pray that in the event that he should ever make it to the hospital without us next to him, the doctors will honor it until we get there and not just make their own decisions, ***due to the fact that our son is cognitively 3-4 years old and will not be able to make decisions for himself.*** He has behaviors, which are his words, and in order to know why he is having certain behaviors you need to know him. He says NO a lot and his NO has lots of meanings. It can mean no, yes, a seizure, (he may be feeling a seizure coming on), it means frustration, (He's frustrated with trying to put a puzzle together or something he's working on). No can mean, he's teasing you. So for somebody to just make the assumption that "He said NO so I didn't do it" would be incorrect, because they do not know our son.

Brent Kell, CEO, Valley Immediate Care, Medford

<https://olis.oregonlegislature.gov/liz/201911/Downloads/CommitteeMeetingDocument/222911>

I serve as CEO of Valley Immediate Care. I am proud to say that we employ several employees who experience developmental and intellectual disabilities. I cannot imagine several of these people alone in a hospital system. It is difficult enough for those of us who do not experience labeled disabilities to navigate in that setting. ***I am also a healthcare administrator and do believe that we can and will provide this needed support safely.*** Every Oregonian deserves access to healthcare and support from people they trust and who know them well to help them understand their care and communicate with doctors and other medical professionals. ***Today,***

too many people experiencing disability are not able to access healthcare are denied support from people they trust while they are hospitalized or having end of life discussions.

Carrie Salehiamin, Parent of person with a disability, Portland

<https://olis.oregonlegislature.gov/liz/201911/Downloads/CommitteeMeetingDocument/222933>

My daughter... ***does not use words to communicate.*** The thought of her becoming ill for any reason and being in the hospital without me is terrifying. She experiences autism and severe anxiety which can, at times, manifest in self injurious behaviors that put herself and others at-risk. She would not be able to function in a hospital environment without someone she knows and trust to ***support her and explain her wants and needs, as well as her complex medical history.***

Cheryl and Anthony Cisneros, Parents, Dallas, OR

<https://olis.oregonlegislature.gov/liz/201911/Downloads/CommitteeMeetingDocument/222699>

“We don’t know if your son will make it through the night.” We were in shock, but rushed back to the ICU room where our 24 year old son was fighting for his life and jumped into action to answer questions of the medical staff from things like how to best secure his IV, to problem solve how he could access the oxygen he so desperately needed – ***the result was that for the next 48 hours my husband and I took turns holding a tube of oxygen in front of his nose and mouth because he would not tolerate any tubes or masks on his face. We were able to prevent the need for a ventilator*** and immediately attend to every need he had. We were a vital part of the incredible team that saved his life, and because we were both allowed to be at Steven’s bedside, we could share in the active care he required. After three days Steven was stabilized and was able to move to another unit of the hospital, where he began to refuse care from the medical professionals and because we were there we could explain that this was his baseline, and actually should be celebrated as a welcome sign of recovery. ***We had the ability to negotiate with Steven to cooperate enough so the doctors and nurses could make an accurate assessment of his health. We were able to keep him calm and alleviate the need for physical restraint.*** After five days in the hospital, we returned home along with Steven – one of the happiest days of our lives!

Dave McCready, Guardian and Parent of a person with a disability, Salem

<https://olis.oregonlegislature.gov/liz/201911/Downloads/CommitteeMeetingDocument/223031>

We have a non verbal son with many health issues who ***would not be able to advocate for himself without a support person at his side.*** With Covid and any other future issue this is of GREAT concern for us as he enters adulthood.

Kevin Bell, Service Coordinator, Medford

<https://olis.oregonlegislature.gov/liz/201911/Downloads/CommitteeMeetingDocument/222828>

I have had several customers on my case load how have had to be hospitalized or accessed emergency room services and their care providers were not allowed to accompany them. Several of the individuals struggle with being able to communicate and process and retain

information and *efforts to treat them were hampered by the inability of those supporting them to be physically present.*

Madhavi Priestap, Sibling

<https://olis.oregonlegislature.gov/liz/201911/Downloads/CommitteeMeetingDocument/223037>

I agree to have an access to the care of people with disabilities As a care provider and a sisiter . ***My brother lives with me full time and he only speaks hindi and I want to be next to him in the hospital and provide the bet care that i can for him.*** Right now the guardians are not with him at all and do not know what is going with him regarding this needs and wants. I communicate with the doctor's but can't make any decisions. My brother lives with me full time and doesn't want to live any where else. I am fighting for his custody and want to have access regarding hospital visits and view his charts and help him make his decisions about what he wants. I am doing the best for him and giving him a healthy life style.

David Oleson, PT, PCS, Associate Professor of Pediatrics, Oregon Health Sciences University

<https://olis.oregonlegislature.gov/liz/201911/Downloads/CommitteeMeetingDocument/222692>

In my professional life, I have seen persons who experience disability unable to access the healthcare they need. ***I have seen people experiencing disability during complex, critical hospitalizations and at the end of their lives denied support and input by trusted caregivers.*** I am pleased to learn that LC 52 includes provisions mandating support of persons with disability at times of critical/crisis healthcare need and at the time of end of life decisions. ***Having advocacy from trusted caregivers is critical to the provision of equal access to health care as required by the Americans with Disabilities Act.***

Desiree Tubbs, Personal Agent, Community Pathways, Portland

<https://olis.oregonlegislature.gov/liz/201911/Downloads/CommitteeMeetingDocument/222867>

I ask that Legislative Concept 52 be passed into law this Special Session so that Oregonians experiencing disability can access healthcare, use support from people they trust while they are hospitalized and have support when making end of life decisions. ***This will help avoidable deaths during COVID (not related to COVID) that could have been prevented if support people were able to be with them while at the hospital.***

Emilie Wylde Turner, CEO, Living Opportunities, Medford

<https://olis.oregonlegislature.gov/liz/201911/Downloads/CommitteeMeetingDocument/222694>

Today, too many people experiencing disability are not able to access healthcare are denied support from people they trust while they are hospitalized or having end of life discussions. ***This is a basic human right.*** I ask that Legislative Concept (LC 52) be introduced and passed this Special Session so that Oregonians experiencing disability can access healthcare, use support from people they trust while they are hospitalized and have support when making end of life decisions.

Emily Dinwiddie, Case Manager/Personal Agent, Portland

<https://olis.oregonlegislature.gov/liz/201911/Downloads/CommitteeMeetingDocument/222700>

I have been safety planning with multiple families in fear of their adult child being forced to seek emergency health care without an advocate. Some of my consumers experience communication and behavioral support needs that are amplified in time of stress, uncertainty, and especially sickness. ***Without an advocate, a person with a disability experiencing a healthcare need may be overlooked, treated improperly, or neglected due to their complex needs.***

Iris Shimizu, Sister of Oregon Adult with Developmental Disabilities

<https://olis.oregonlegislature.gov/liz/201911/Downloads/CommitteeMeetingDocument/222823>

Without the accompaniment of a support person, my brother's hospital experience would be one that is unproductive, harmful, and potentially dangerous. For my brother, he would be consumed with emotions of confusion, panic, anxiety, and helplessness. Oftentimes to an unfamiliar person, these can be identified as negative behaviors which opens the door for them to be addressed poorly and even resulting in him not receiving adequate care. ***He would likely be deemed combative, refusing treatment, or even be restrained. . . A support person would act as a bridge of communication both in the needs of my brother, and to prepare him for potentially necessary procedures or protocol. . .***

It is critical that the term "support person" is separate from the idea that a visitor could assist the member in de-escalation or communication. There are very specific privileges and rights given to support individuals in terms of spaces they can occupy and when, in addition to crucial end of life discussions.

Jacob Dodds, Lead ONA Assessor, Community Pathways, Portland

<https://olis.oregonlegislature.gov/liz/201911/Downloads/CommitteeMeetingDocument/222839>

People from the I/DD population are disproportionately affected by COVID and other illness' and could use all the support they can get once hospitalized. Communication can be particularly difficult for this population, especially in times of illness or stress, so ***having someone with them in the hospital can be lifesaving.***

Janelle Julian, Parent and Nurse, Gresham

<https://olis.oregonlegislature.gov/liz/201911/Downloads/CommitteeMeetingDocument/222836>

Being the bio mom of two developmentally disabled young adults I know it would be devastating if they required hospitalization during this time of Covid-19 and visitor restrictions. Being a healthcare professional (RN) I certainly understand the reasoning behind the restrictions generally, but there needs to be clear exceptions for the DD community during this time. . . ***It would be a huge safety issue to leave them with someone who couldn't possibly understand them or advocate for them.***

Jennifer Hurlburt, Parent

<https://olis.oregonlegislature.gov/liz/201911/Downloads/CommitteeMeetingDocument/222695>

My adult son has autism, he is non-verbal and not comfortable in environments, and with people, that are not familiar to him. If my son needed to be hospitalized, he would panic and be very frightened without myself, his Dad, or caregivers to support him. ***Because of his***

communication limitations it would be difficult for healthcare staff to understand him and vice versa. My son does not grasp abstract concepts, he uses limited modified American Sign Language to ask for food or other items that he wants, he uses gestures familiar to his caregivers, but not familiar or understandable to others. I am writing today because Oregonians like my son deserve access to healthcare and support from people they trust to help them understand their care and communicate with doctors.

Jennifer Carpenter, Parent, Keizer

<https://olis.oregonlegislature.gov/liz/201911/Downloads/CommitteeMeetingDocument/222922>

My son has had many hospitalizations in his life. He needs us with him to communicate for him. He needs us to support him and advocate for him. I can not imagine him having to be in the hospital with us. **He is also non verbal and would not be able to communicate for himself.**

Jessica, Parent

<https://olis.oregonlegislature.gov/liz/201911/Downloads/CommitteeMeetingDocument/222769>

I'm a mother of a daughter that has been hospitalized several times due to her disabilities. It's detrimental for her health and needs for **a familiar person to be in her hospital room at all times.** As it is now that can't happen. **I have in the past paid her Providers out of my pocket to give me relief so I can go home shower, and pick up things.**

Jessica Gentile, Personal Agent, Community Pathways, Portland

<https://olis.oregonlegislature.gov/liz/201911/Downloads/CommitteeMeetingDocument/222863>

I have several adults who are non-verbal and rely on their families and providers, who communicate via sign language, body language, and other non-verbal means that they have adapted. If any one of them were to be hospitalized without their support persons, they would likely also have a psychiatric emergency on top of whatever physical condition led them to be hospitalized. **To feel rushed or pressured to make end of life decisions is simply unethical.** Everyone, regardless of age, gender, race, disability status, etc. should be fully informed of all paperwork that they are asked to sign- no exceptions; they have the right to make informed decisions about what they are signing. . . **Please work to ensure that not one more person with a disability DIE as the direct result of not having the proper support available to them during their most vulnerable times.**

Julie Chick, Parent, Nehalem

<https://olis.oregonlegislature.gov/liz/201911/Downloads/CommitteeMeetingDocument/222838>

My son experiences Down syndrome in Tillamook County. If he were admitted to the hospital he would absolutely need support understanding what is happening to him; to understand what is expected of him; and he would need the same level of support he needs in his daily life at home. **We do not NOT believe this is anything similar to a "visitor" but is equivalent to the support he uses to access his life when making decisions within his community.**

Gabrielle Belmore, Mother of adult with Down Syndrome, West Linn

<https://olis.oregonlegislature.gov/liz/201911/Downloads/CommitteeMeetingDocument/222837>

I have a daughter with Down syndrome and if she were to be in the hospital for any reason without my help people would not understand her as she is pretty much non verbal. I need to assist her with communication and for comfort. She would feel alone and she has severe anxiety issues. Also, ***she has a hard time making decisions and I would not want someone to decide for her based on her disabilities.***

Annette Thompson, Parent, Eugene

<https://olis.oregonlegislature.gov/liz/201911/Downloads/CommitteeMeetingDocument/222691>

My daughter is 36 years old. She has severe disabilities which impact her ability to care for herself and to communicate with others. ***It is necessary for my daughter to have someone she knows and trusts with her to help her to access healthcare, advocate for her needs, and to communicate with doctors and other caregivers.*** I worry that people experiencing disability are not always able to access healthcare, and may be denied support from people they trust while they are hospitalized or having end of life discussions

Darcy Wallace, Health Care Practitioner

<https://olis.oregonlegislature.gov/liz/201911/Downloads/CommitteeMeetingDocument/222862>

Right now, we are amidst a powerful moment where human rights are front and center. ***For too long, we have ignored and oppressed many groups including people with disabilities, people of color and indigenous people, and many others who are not part of the wealthy and/or white majority.*** This is not necessarily intentional, but ingrained in our social and economic system as chronic, systemic inequality. I believe ***legislation that helps others access needed healthcare supports is part of a multi-faceted system helping more Americans achieve equality and dignity in life.***