



Feb. 24, 2022

**Subject: Letter regarding paid parent caregiving to minor disabled children under Medicaid Home & Community Based Services**

To the policymakers of Oregon,

We the undersigned feel that it is time for Oregon parents of disabled children to have direct access to the money taxpayers have dedicated to their children.

Oregon Medicaid has an expensive and dysfunctional program for in-home caregiver supports of disabled children broadly known as K-plan. Since 2014, Oregon parents have tried to make this program work for their minor children — but for most it has been a mirage of support, wasting time and energy they could have been spending on their children’s care.

In 2021, through the temporary federal public health emergency, parents were suddenly allowed access to these caregiver dollars. The changes have been stunning. Families who were reduced to single-income households due to the birth or adoption of a child with significant disabilities were suddenly able to pay their bills. Mothers who hadn’t been able to earn a paycheck for years due to the extraordinary care needs of their children suddenly had economic capital and freedom.

But, most importantly, the love, care and stability that Oregon’s disabled children received grew immeasurably. Families could afford to buy specialized toys, clothes, equipment or fund needed therapies or ABLE accounts. Some children were likely even saved from medical foster care and homelessness.

We refuse to go backwards. No more mirages of support. No more hoops to jump through. No more discrimination against parents.

We call on Oregon policymakers to adopt a Medicaid program that includes biological and adoptive parents as candidates for in-home caregivers — “Personal Support Workers” or “Direct Support Professionals” — to their minor disabled children. Whether this is a program like Colorado’s or California’s or Oregon’s own innovation, it is past time for policymakers to do what is best for the state’s most vulnerable families.

Sincerely,

### **Elected Officials**

**Sen. Lew Frederick**, Senate Majority Whip

**Sen. Chris Gorsek**, Full Joint Committee on Ways and Means

**Sen. Tim Knopp**, Senate Minority Leader

**Sen. Deb Patterson**, Chair, Senate Committee on Health Care

**Sen. Kim Thatcher**, Senate Interim Committee on Judiciary and Ballot Measure 110

**Sen. Lee Beyer**, Senate Interim Committee on Finance and Revenue

**Sen. Rachel Armitage**, Senate Interim Committee on Finance and Revenue

**Sen. Bill Hansell**, Co-chair, Senate Committee on Conduct

**Sen. Bill Kennemer**, PhD, retired clinical psychologist, Senate Interim Committee on Human Services, Mental Health Recovery

**Sen. Brian Boquist**, Vice Chair, Senate Interim Committee On Finance and Revenue

**Sen. Akasha Lawrence Spence**, Co-chair, Joint Interim Committee On Ways and Means Interim Subcommittee on Transportation and Economic Development

**Sen. Dennis Linthicum**, Senate Interim Committee On Health Care

**Sen. David Brock Smith**, Senate Committee On Natural Resources, Joint Committee On Ways and Means Subcommittee On Public Safety

**Rep. Sheri Schouten**, House Interim Committee on Human Services

**Rep. Christine Goodwin**, House Interim Committee on Health Care, House Interim Committee on Behavioral Health

**Rep. Duane Stark**, Joint Interim Committee on Ways and Means, Subcommittee on Human Services

**Rep. Barbara Smith Warner**, House Interim Committee on Education

**Rep. Susan McLain**, Joint Interim Committee on Ways and Means

**Rep. Dr. Cedric Hayden**, Vice-Chair, Oregon House Committee on Health Care  
Rep

**Rep. Jessica George**, House Interim Committee on Education

**Rep. David Gomberg**, Co-Vice-Chair Joint Interim Committee on Ways and Means

**Rep. Courtney Neron**, Vice-Chair, Oregon House Committee on Education

**Rep. Rachel Prusak**, Chair, Oregon House Interim Committee on Health Care

**Rep. Anna Williams**, Chair, Oregon House Interim Committee on Human Services

**Rep. Greg Smith**, Joint Interim Committee on Ways and Means

**Rep. Travis Nelson**, House Interim Committee on Behavioral Health, House Interim Committee on Human Services

**Rep. Jack Zika**, House Interim Committee on Early Childhood, House Interim Committee on Housing

**Rep. Paul Evans**, Co-Chair, Joint Interim Committee on Ways and Means, Interim Subcommittee on Public Safety.

**Rep. Ron Noble**, House Interim Committee on Health Care, House Interim Committee on Human Services  
**Rep. Mark Owens**, House Interim Committee on Human Services  
**Rep. Raquel Moore-Green**, Vice Chair, House Interim Committee on Behavioral Health  
**Rep. John Lively**, House Interim Committee on Behavioral Health  
**Rep. Wlnsvey Campos**, Joint Emergency Board Subcommittee On Human Services  
**Rep. Boomer Wright**, House Interim Committee On Behavioral Health, House Interim Committee On Early Childhood, House Interim Committee On Education  
**Rep. Dacia Grayber**, Oregon State Representative  
**Rep. Anna Scharf**, Co-Chair, House Interim Committee on House Services  
**Betsy Johnson**, former Oregon State Senator, Gubernatorial Candidate  
**Christine Drazan**, Gubernatorial Candidate, Former Minority Leader of the Oregon House of Representatives  
**Mayor Rick Hobart**, Vernonia, OR  
**Julie Parrish**, former Oregon State Representative  
**Chloe Eudaly**, former Portland City Commissioner  
**Paul Anthony**, former Portland Public Schools board member  
**Mike Rosen**, former Portland Public Schools board member  
**Christy Thompson**, school board member

#### **Community Leaders/Disability advocates**

**Laddie Reed**, Oregon Disability Justice Advocate  
**Joe Wykowski**, founder of Community Vision  
**Jill Escher**, President, National Council on Severe Autism  
**Katherine Ball**, Family Services Director, UCP Oregon  
**Jess Lindley**, self-advocate  
**Allen Hines**, Director of Real Choice Initiatives  
**Nico Serra**, Disability Justice Organizer  
**Cheryl Green**, Media Accessibility Advocate  
**Jake French**, Professional Speaker and Disabilities Advocate  
**Nicolas Brown**, Self Advocate & Board Member of YASA (Young Self Advocates of America)  
**Shasta Kearns Moore**, Medical Motherhood, Clackamas DD Council, parent  
**Ian Jaquiss**, ADA Coordinator, OHSU  
**Emily Fern Dayton**, MS, parent  
**Lisa R Ledson**, RN, BSN, SERV-OR, Clackamas DD Council, parent  
**Gabriel Triplett**, Spiritual Director, Community Advocate  
**Jenny Hoyt**, UCP Oregon Board of Directors  
**Kårun Virtue**, Chair of Advancing Consumer Experience (ACE) - Voices of Consumers Advocating for Life (VOCAL), Medicaid Advisory Committee member  
**Cameron Herrington**, Living Cully (affiliation for identification purposes only)

**Penny FitzMaurice**, Former Oregon State Ambassador, Rare Action Network  
**Kelsey Smith**, foster parent/advocate  
**Hayley Palmer**, parent advocate  
**Lenore Eklund**, parent advocate  
**Sylvia Triplett**, parent advocate  
**Tina Stracener**, parent advocate  
**Calli Ross**, Parent advocate  
**Jennifer Murphy**, parent advocate  
**Michael Paruch**, parent advocate  
**Mellani Calvin**, ASSIST Program Founder/Director  
**Tamara Bakewell**, Former Medicaid Advisory Member, advocate for Children and Youth with Special Health Needs  
**Elaine Piper Vardas**, parent and disability advocate  
**Matt Faler**, parent and podcast host Mindful Inspiration Champion  
**G Cody QJ Goldberg**, parent and Co-Founder of Harper's Playground  
**Kristina Gollier**, parent & advocate

#### **Medical Professionals**

**Kurt Freeman**, PhD, ABPP, Director of the OHSU Institute on Development and Disability, Professor of Pediatrics, OHSU Doernbecher Children's Hospital.  
**Dr. Benjamin Hoffman**, M.D., FAAP, FCCM, Professor of Pediatrics, OHSU Doernbecher Children's Hospital, Director Oregon Center for Children and Youth with Special Health Needs  
**Dr. Dana A. Braner**, M.D., FAAP, FCCM, Credit Unions for Kids Chair, Professor and Chair, Department of Pediatrics, Physician-in-Chief, OHSU Doernbecher Children's Hospital  
**Stephanie Hunter**, Behavior Professional and Child Foster Provider  
**Raelynne Virshup**, RN, BSN, nurse manager, EQC Home Care Agency  
**Dr. Adebimpe Adewusi**, pediatrician and parent  
**Debra Kannan**, parent, Licensed Mental Health Therapist Intern, DSW.  
**Kimie A Frakes** Mental Health Therapist MSW, LCSW  
**Dr. Pari Faraji**, Assistant Professor, OHSU Child and Adolescent Psychiatry  
**Dr. Cedar Levine**, DPT, early intervention specialist/physical therapist  
**Christy Fawcett**, MSN, RN, complex needs nurse  
**Richard Keuneke**, RN, retired  
**Gerald Keuneke**, RN, Retired  
**Carl Edward Stracener Jr.**, MA/QMHP  
**Pamela Keuneke**, RN, retired  
**Karen Keuneke**, MSN, RN, CIC  
**Dr. Gail Watnick**, DPT, early intervention specialist/physical therapist  
**Dr. Aishwarya Deenadayalu**, MD, pediatrician  
**Erin Cochran**, MA, OTR/L, occupational therapist

**Katherine L. Criswell, MSN, RN**  
**Bethany M. Sloane, PT, DPT, physical therapist**  
**Dr. Felicity Case, PT, DPT, PCS, pediatric physical therapist**  
**Dr. Britta Gurgel, PT, DPT, PCS, pediatric physical therapist**  
**Dr. Heather Higashi, PT, DPT, pediatric physical therapist**  
**Julia Waschow, RN, BSN pediatric complex care manager**  
**Courtney Lackey, speech language pathologist and parent**  
**Sheila Stahl Butler, PT, physical therapist**  
**Jennifer Siegel, Teacher of the Deaf**  
**Alicia O'Leary, Teacher of the Deaf**  
**Julie Hargreaves, Licensed Clinical Social Worker**  
**Karma Clarke-Jung, Autism consultant**  
**Michael Millard, BPharm, MS, Pharmacist and Professor Emeritus, Pacific University**  
**Marissa Nicole Merrill, X-ray technologist, B.S., R.T. (R)(ARRT)**  
**Candice Elliott, M.S., Licensed Professional Counselor**  
**Leslie B. Andrews Licensed Child Protection M.S.W**  
**Romi Ross, M.S., Board Certified Behavior Analyst**  
**Sarah Sahl, Registered Dietician**  
**Diane Robinson, RN, FNP Family Nurse Practitioner/Community nurse**  
**Capt. Chad Ledson, Tualatin Valley Fire & Rescue**

### **Medical and Disability Organizations**

**Oregon Disabilities Commission**  
**Oregon Pediatric Society**  
**Oregon Family Support Network (OFSN)**  
**Oregon Family to Family Health Information Center**  
**Metropolitan Pediatrics , LLC**  
**Jill Brown, executive director, NW Kidney Kids**  
**Julie Hutchinson, President/Co-Founder, Chelsea Hutchinson Foundation**  
**Mike Graglia, MBA, MA, Co-Founder & Managing Director, Syngap Research Fund**  
**Shawn Satterfield, CEO/Founder, Shine Music Festival**  
**Jill Foster, Development Director, Wheel to Walk Foundation**  
**Seth Kannor, CEO and President, Enabling Devices**  
**Jill Escher, President, National Council on Severe Autism**  
**Tobi Rates, Executive Director, Autism Society of Oregon**

### **Advocacy Organizations**

**Family Forward Action**

### **Organized Labor**

**Oregon AFSCME Local 328**  
**Oregon Federation of Nurses & Health Professionals**

**Service Providers and Professionals**

**Jill Chuculate-Welch**, Owner/Founder Joieful Connections (provider agency)  
**Tara Dupuis**, Owner, It Takes a Village (provider agency)  
**Jason Kinsey**, Owner, A Helping Hand Support Service (provider agency)  
**Liberty Wecker**, Director, Out of the Box Solutions (provider agency)  
**Trina Hart**, Executive Director DSP Connections (provider agency)  
**Timber Swindell**, Director, T&T Cares LLC, (provider agency)  
**Kathy Legmeyer**, CEO/founder, KIDS NW (provider agency)  
**Kim Elliott**, Director of Programs & Services, Community Vision  
**Stephanie Cammack**, Benefit Coordinator Manager, OSH, Parent  
**Alicia Ratto**, Supported Living Director, Community Vision  
**Mike Bates**, regional director, NuMotion (durable medical equipment)  
**Abigail Regan**, nursing student and direct support worker  
**Angela Fleming**, Owner, Fleming Foster Care (adult IDD)  
**Daniel Fleming**, Owner, Fleming Foster Care (adult IDD)  
**Alisha Langford**, parent and Special Needs Planner at Abeona Group  
**Jennifer Sackey**, case manager, Multnomah County  
**Katheryn Barnett**, early childhood special education specialist  
**Ashley Hrouda**, social service specialist  
**Sherri Vogt**, Early Intervention Specialist  
**Brenda Cox**, personal support worker, foster care  
**Toni Zimmer**, Licensed Clinical Social Worker  
**Amber Wilkinson-Polomsky**, LCSW  
**Nichole Matz**, QMHP, PSS

**Faith Leaders**

**Shaun Konopaski**, executive pastor Garden Valley Church  
**Rick McKinley**, Lead Pastor Imago Dei Community (Portland, Oregon)  
**The Rev. Cecil Charles Prescod**, Ainsworth United Church of Christ  
**Jeanne McKinley**, Spiritual Director and Personal Support Worker

**Others**

**Carrick Flynn**, Congressional Candidate, District 6

In addition to the above community, political, medical, faith and organizational leaders, please note that more than 4,200 people have also signed our [petition](#) asking for this change.

Please contact [Advocates for Disability Supports](#) at [AdvocatesPAC@gmail.com](mailto:AdvocatesPAC@gmail.com).