



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. 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

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](mailto:AdvocatesPAC@gmail.com) at AdvocatesPAC@gmail.com.