



# National Academies

Supporting Children with Disabilities: Lessons from the Pandemic  
Emergency Planning Panel

By: Leslie Rogers IV



# Why Am I Passionate About Disability Em

- I have been in the disability community since my parents adopted my brother and sister in the early 1980s
- I have a daughter Gloria that experiences Infantile Spasms/West Syndrome and de novo Cardio Facio Cutaneous Syndrome a Rasopathy
- Seizures and the inability to get the medication ACTH in a timely manner left her with Cerebral Palsy and tube fed
- I see some common sense policy solutions that can really help improve and stabilize supports and protect families like mine when disaster strikes



# Oregon Emergency Preparedness Conference

- [Beyond Checking Boxes Report](#) 2019
- [Workshop Report](#) 2019
- COVID derailed implementation of some of the work but now work is advancing
- Disability Emergency Management Advisory Committee
  - Disability Services Advisory Council feedback
- The Federal Medicaid Match FMAP increase during COVID made much of what worked in Oregon possible

2019

## >> Oregon Inclusive Emergency Planning Workshop

Summary and next steps  
July 2019



# Medicaid and Private Insurance Policy on DME

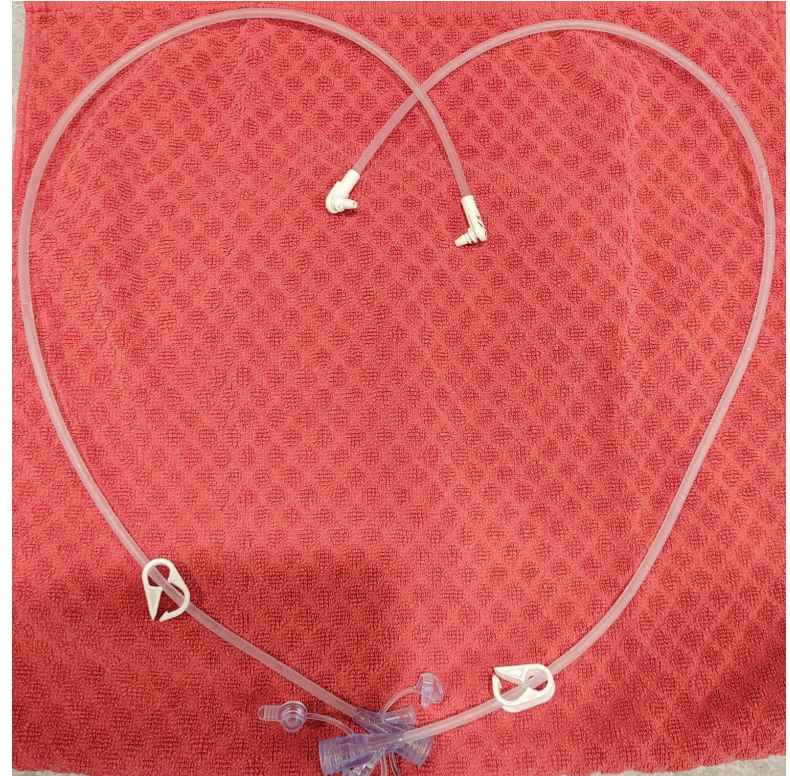
- Limiting critical prescribed medical supplies to 31 day deliveries at a time
- If you order late you are out of luck
- Delays from fires, snow storms, COVID, and now the formula shortage have put serious strain on TPN and Enteral dependent children and their families
- This leaves families always running out at the end of the month
- We need to move to CMS rules and state implementation that permits families to always have a 31 day supply on hand by delivering 62 days on the first delivery and 31 on all following deliveries

## **Just In Time Is Not Working**

- The folly of just in time in critical medical supplies was exposed by COVID
- Just in time delivery does not work in emergency situations we need to create capacity for families to form their own resiliency

# Post Emergency Risks to HCBS the Workforce

- The public health emergency may be ending but the workforce has not recovered
- Paid Parent and Family Caregivers of children receiving Home and Community Based Services (HCBS) through Medicaid Waivers etc.
- This was done through Oregon's 1135 waiver in response to the public health emergency and the caregiver workforce crisis that persists
- Need to recognize the unique circumstances of families supporting children experiencing disabilities through HCBS
- We need to support Federal Medicaid Matches FMAP sufficient to maintain these programs to keep children with their families at home and not in higher cost settings



# Other Key Issues

- CMS DME rules Inflexibility led to children not getting equipment - Many relied on OSU [Go Baby Go](#) to fill the gap in Oregon
- Expansion of telehealth helped in rural healthcare deserts
  - Tapping waiver resources to support acquiring equipment for telehealth



# Next Steps

- We need to create a more efficient communication system nationally to share the needs on the ground and lessons learned
  - Efforts devolved into frantic outreach to federal legislator staff offices about needs
- I see a better option for Oregon in which we could utilize our current structure and create a more uniform reporting structure
  - Regional Disability Services Advisory Councils
  - Disability Emergency Management Advisory Committee
  - Flowing eventually to the [National Council on Disability](#) and/or FEMA

National Council on  
Disability/FEMA?

Disability Emergency  
Management Advisory  
Committee

Regional Disability  
Services Advisory  
Councils in Oregon