

Galia Spychalska
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Dear MSB board,

Thank you to the MSB board president and members for allowing me to speak today in public comment. My name is Galia Spychalska and I am an RN/FNP with over 25 years of clinical nursing experience including over a decade as adjunct faculty at the CU College of Nursing before my son was born and am currently a family advocate, parent caretaker and a nurse for my 11 year old son Casper currently. I would like to state at the beginning of my public comment that I am formally asking for whistleblower protection under the law as the concerns and information that I am about to share may expose the state of Colorado and HCPF in an unfavorable matter of importance and I am in fear of being denied pediatric PDN PAR now and in the future or risk losing HCBS services under the CES disability waiver as half of the families that have testified at these MSB meetings are still being denied PDN services and awaiting appeals and court dates with almost 50 families that I am aware of and therefore many families are choosing not to testify sadly. I am here to update the MSB board on the current issues with pediatric PDN PARs and continuing pediatric PDN PAR denial rates of 20% being reported by the majority of pediatric home health agencies who are now also not submitting pediatric PDN PARs at all if patients are not technologically dependent due to the current state of matters.

The MSB rule 21-11-17-B that was passed was a PAR pause ruling on pediatric long term home health benefits period. HCPF then further independently redefined that rule as excluding PDN PARs however I would like the MSB board the AG office to fully investigate this further as PDN is part of LTHH services and support programs under HCBS waiver services which is federally funded. The state of Colorado is receiving close to \$1 billion dollars in ARPA funding through CMS and HCPF has submitted the quarterly progress reports as part of the agreement to not decrease any services and to maintain the HCBS program and not "impose stricter eligibility, standards, methodologies or procedures for HCBS programs and services that were in place on April 01, 2021." See attached comment. With the evidence presented to the MSB board in past and current meetings the PDN PAR denials and continuing in decrease in the LTHH services where pediatric patients only qualify for PDN services under the HCBS waiver

program then I would like to state that the MSB rule does encompass PDN services and that needs to be enforced or will ask HCPF to pause the pediatric PDN PAR at the next MSB meeting.

From August to November 2022 last year we had hundreds of families that were denied pediatric PDN PAR denials in the state of Colorado and the MSB has heard our families' stories and struggles. We have asked HCPF to provide the pediatric PDN approval denials raw data and numbers for the past 9 months and we still do not have the accurate data. HCPF refuses to provide that information specifically separated for pediatric and adult PDN PARs with multiple HCPF presentations where HCPF has stated 948 PDN PARs total together with pediatric and adult PDN PAR submissions with almost a two-year time span of data since November 2021 which is not accurate data and therefore totally statistically skews the data presented. The administrative approval process done by HCPF from November 2023 until April 2024 which required all pediatric home health agencies to resubmit pediatric PDN PARs which was more than 400 pediatric patients which then created BRAND NEW Identification numbers in their system therefore DOUBLE counting and increasing the approval rates by 50% therefore using that data to skew the percentages identified in the HCPF PDN PAR approval rates in the attached document for your review by providing false data and information to multiple agencies, media, legislators, constituents, taxpayers and all of us and I have attached the story by Jennifer Brown on the story of continued pediatric PDN PAR denials. HCPF now also is refusing to provide the accurate data and information to pediatric PDN PAR approvals denials and raw data numbers due to the HIPAA Safe Harbor Law which is being used out of context and therefore denying access to important information that is very important to continue to advocate for our families.

HCPF has stated in multiple meetings that pediatric PDN PARs are not being paused to allow for internal revisions and quality process improvement issues since the hiring of the new UM vendor Kepro which has recently changed its name yet again due to multiple class action lawsuits nationwide against Kepro specifically for denials of PDN services in multiple states where families have won. HCPF has also stated that PAR pauses will only happen when policy changes are being done and here we are in the middle of PDN Rule Making Stakeholder meetings and HCPF has now hired a company to create a new PDN acuity tool and therefore pediatric PDN PAR needs to be paused while we continue all of this. We also

have almost 50 families due in court for pediatric PDN PAR denials and how can we continue to stress our families through this process while there are so many changes taking place.

Our families need engagement from Governor's office, the Attorney General office and a commitment from HCPF to commit to pause the pediatric PDN PARs.

The current PDN Rule Making Stakeholder meetings are not going well with HCPF proposals being presented with none of the feedback or input making the needed changes to the wording of the PDN rules. There are no medical professionals, physicians, nurses, home health agencies, researchers, experts, Board of Nursing representatives, Attorney general representation to clarify legal framework and over reach. It is not guided by facts, evidenced based practice, data or in adherence of the Colorado State Nurse Practice Act. We need medical professionals, experts and one of the MSB board members to be present at these meetings to truly help and advocate for our families and our medically fragile children otherwise this process will fail.

Sincerely,
Galia Spychalska RN, MS, FNP

Supporting documentation:

ARPA Quarterly report link

<https://hcpf.colorado.gov/sites/hcpf/files/ARPA%20Spending%20Plan%20Narrative%20Q3%202023%20to%20CMS-%20Resubmitted%20February%2028%2C%202023.pdf>

Jennifer Brown The Colorado Sun story on pediatric PDN denials

<https://coloradosun.com/2023/05/10/medicaid-in-home-nursing-care-children/>

HCPF PDN Approval rates and new data all in percentages timespan from November 2021- current

<https://hcpf.colorado.gov/sites/hcpf/files/Private%20Duty%20Nursing%20PAR%20Approval%20and%20Denial%20Rates-June%202023.pdf>

HIPAA Safe harbor Law cited by HCPF to deny PDN data and information

<https://www.hipaajournal.com/hipaa-safe-harbor-law/>