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THE NEW ENGLAND GENETICS COLLABORATIVE

Institute on Disability
RESEARCH

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Promoting and Improving the Health and Well-Being of People with Inherited Conditions

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The mission of the New England Genetics Collaborative (NEGC) is to promote and improve health and social well-being of those with inherited conditions through collaborations among public health professionals, private health professionals, educators, consumers and advocates throughout New England.

The NEGC is housed at the Institute on Disability, at the University of New Hampshire. To access the NEGC's website, please visit www.negenetics.org. One of the work groups of the NEGC is the Health Care Access and Financing (HCAF) work group, with an overarching goal of improving healthcare insurance coverage for individuals with genetic conditions.

Surveys of New England Families of Children with Genetic Conditions

In 2012, the HCAF work group designed an online survey of families of children with genetic disorders living in the six New England states. The questions in the survey were intended to identify health insurance coverage and benefits gaps for children with genetic disorders. Key findings suggested that particularly challenging areas of underinsurance included outpatient services, care for emotional, behavioral or substance abuse issues, prescription drug coverage, rehabilitative and habilitative therapies, medical devices, pediatric services like developmental screenings, and prescribed medical foods. Furthermore, families reported cost as a major problem—high deductibles, co-pays and co-insurance were noted in almost every category. Overall, these survey results emphasized the critical need for policymakers to take action to reduce underinsurance for children with genetic disorders. A link to the 2014 policy brief highlighting specific policy implications and recommendations can be found here.

There is an effort to educate policymakers and key stakeholders across the New England region about the challenges families face when seeking to access high quality and consistent care for children born with a genetic condition. A second survey was sent out to families in New England who have children with a genetic, or suspected genetic, condition. The goal of this survey was to gain a better understanding of issues related to health care access and coverage/reimbursement for this population.

Survey results were analyzed both quantitatively and qualitatively and major findings are summarized below.

Methodology & Demographics

Survey respondents were parents or guardians (ages 18+) of children living throughout New England who were under the age of 21 and who had been diagnosed with a genetic condition, or who had been told by a health care professional that there may be a genetic link to their child's condition.

All questions were voluntary and respondents were able to enter into a raffle for a $50 Target gift card. The survey was open from September 8, 2015 until October 31, 2015.

There were a total of 255 responses, from MA, ME, NH, CT, RI, VT, with the majority of responses being from NH; 72 completed the survey in its entirety. The most common average age of children was between 8 – 11 years old. The seven most common genetic diagnoses represented included Down Syndrome,

Phenylketonuria (PKU), Autism Spectrum Disorder (ASD), Noonan Syndrome, Ehlers-Danlos Syndrome, Mitochondrial Disorders, and 'undiagnosed'. Co-existing conditions included ASD, ADHD, anxiety, depression, overall developmental delays, epilepsy, congenital heart disease, dysphagia, seizures, and hearing loss.

Common Barriers to Accessing Health Care

Understanding Health Insurance Coverage

Overall, the majority of respondents were **not very confident** in their understanding about the **appeals process** (for primary and secondary insurance). However, respondents felt significantly more confident in their understanding of eligibility, provider network, benefits, prior authorization, and cost sharing. For those respondents that had secondary insurance, the majority of respondents were also **not confident** about their understanding of prior authorization.

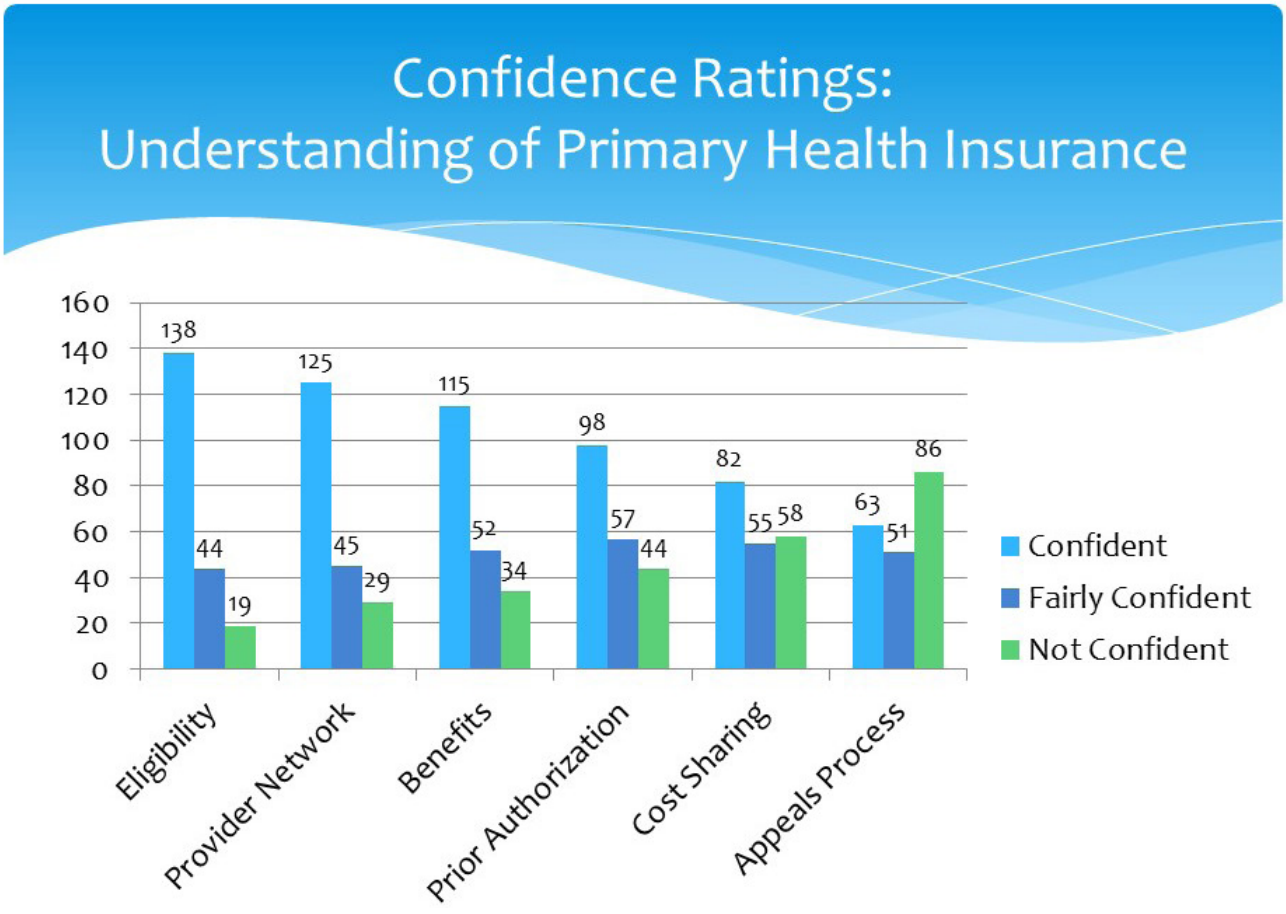
The majority of respondents did not contact an outside agency to help them understand their child's insurance. However, of the minority that did, the outside agency was very helpful answering questions overall. Respondents commonly said the outside agency was **knowledgeable**, they provided **sound advice**, and they were **made aware of benefits they didn't even know about**.

Commonly Denied Benefits & Services

Although the majority of respondents applied for and received secondary insurance, or did not need to apply for secondary insurance, of the respondents that needed to apply for secondary insurance, but were denied, the most common reasons for denial were **income level** and that their **child does not meet eligibility requirements**.

Regardless of primary or secondary insurance, benefits/services most commonly denied included **medications, physical therapy (PT), speech-language therapy (ST), occupational therapy (OT), medical equipment** (hearing & feeding-related), & **evaluations/testing** (MRIs, psychological evaluations and genetic testing). When asked what the reason for the denial was, the majority of respondents said they were simply '**not covered**' or mentioned **out-of-network/out-of-state**. Less frequent, but repetitive responses to denials included *experimental, not medically necessary, pre-authorization necessary,* and *benefit exhausted*.

Figure 1. Confidence Ratings: Understanding of Primary Health Insurance



> **"I was able to get information about my insurance that helped to get my son the coverage that he needed."**
>
> - Quote from a parent respondent

Benefits & Services Families Pay for that are Not Currently Covered by Insurance

When asked what respondents pay for that is not currently covered by insurance, the most common answers were **therapies** (OT, PT, ST, music, behavioral, and hippotherapy, or the use of horseback riding as a therapeutic or rehabilitative treatment) **travel expenses, co-pays, medications** (many over the counter), **medical equipment,** and **feeding/dietary needs**.

Impacts on Families

The most common impacts on the family as a result of the care they have received for their child that has not yet been covered include **difficulty maintaining a full-time job/getting time off from work**, **high caregiver stress**, **travels costs, limited money to do "fun" things**, and **overall financial strains**.

Access to Services

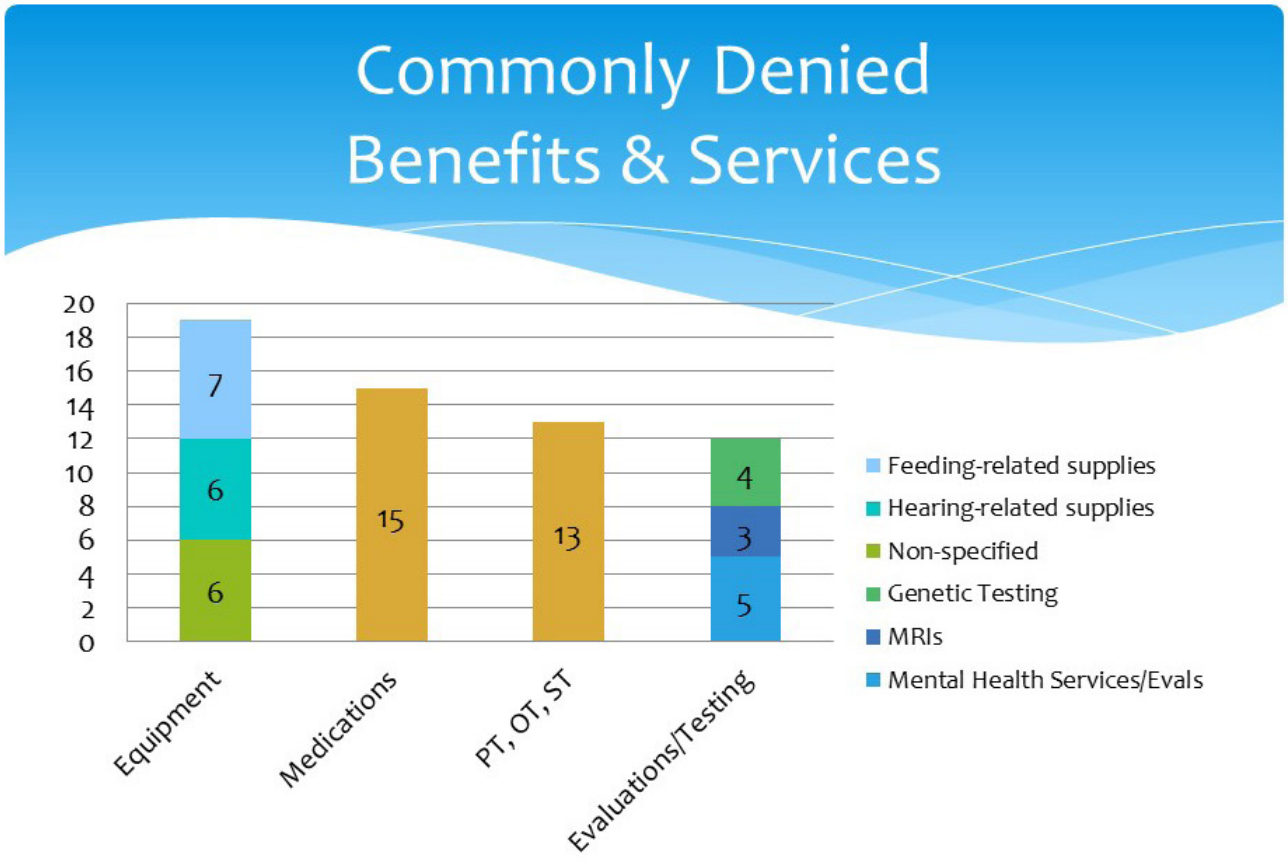
While the majority of respondents did not have difficulty accessing services needed for their child, for those who did, the reasons are outlined in Figure 3.

When asked if there are health care providers that their child sees that are not covered by insurance, the majority of respondents said no. However, out of the respondents that answered yes, the health providers that the **child needs to see the most are therapists & counselors** (OT/PT/ST, behavioral, music, psychologists, counselors, etc.) with the majority of children needing **weekly to bi-weekly services**.

Conclusions

Results from these surveys suggest that health care access and coverage/reimbursement for families with children with genetic conditions remains problematic and needs to be more widely accessible. When children with genetic conditions are denied access to the medical services that are deemed necessary for their health and well-being families' financial stability, and overall emotional wellbeing suffers as a result. By

Figure 2. Commonly Denied Benefits & Services

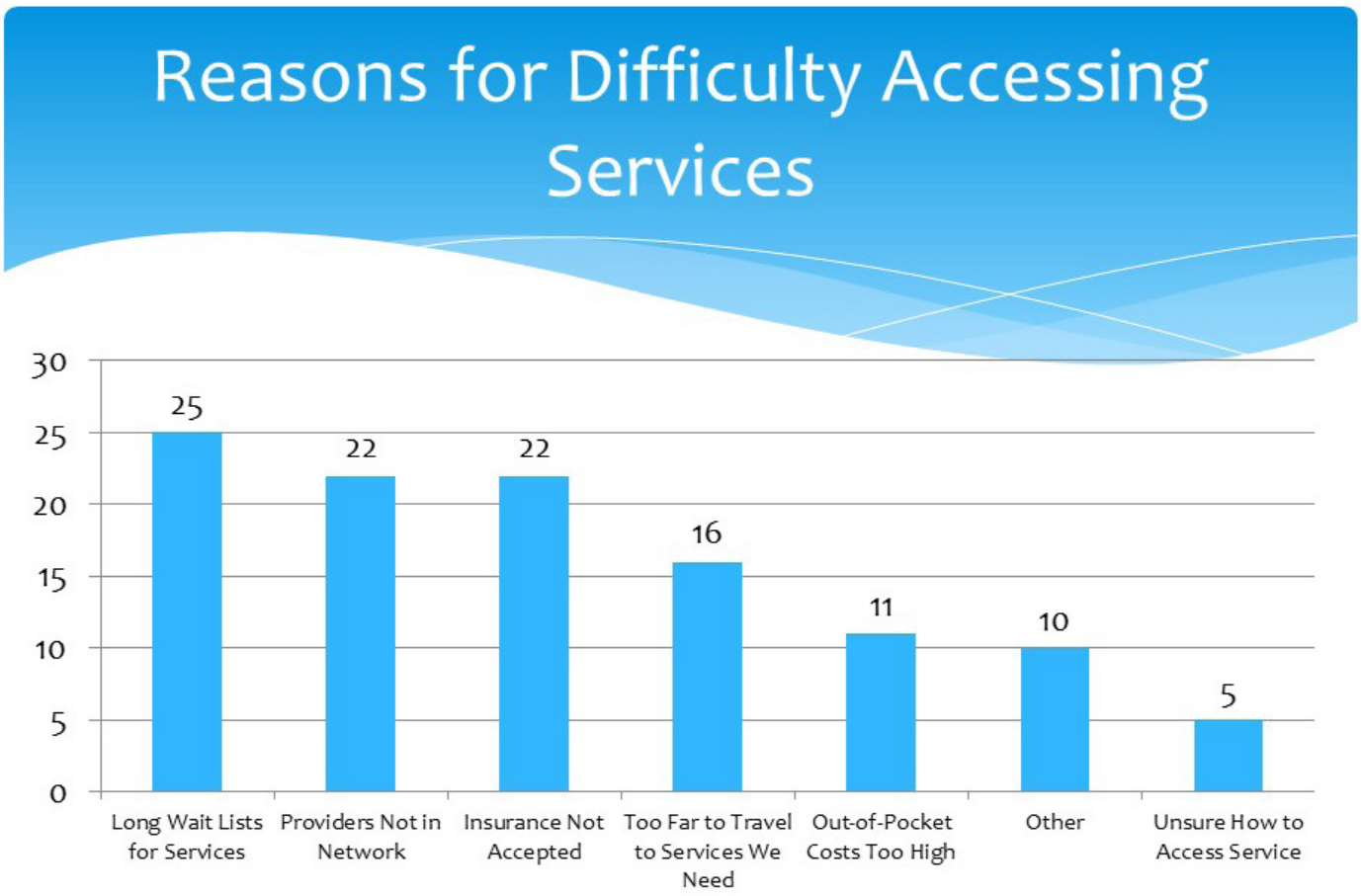


"My son requires 24/7 supervision. As a parent/mother I am unable to commit to a job. To do anything else, I need to source childcare. [I] have spent a large amount on home modification that was not covered otherwise—the equivalent of a college education. There have been times that we have not received premium reimbursement and secondary coverage has cost us anywhere from a low of several hundred dollars per month to a high of $2000 per month, which had a significant impact on our finances."

– Quote from parent respondent

highlighting the aforementioned barriers to accessing health care, we are one step closer to getting children with genetic conditions the care that they deserve in order to grow, learn and thrive in their homes, schools and communities.

Figure 3. Reasons for Difficulty Accessing Services



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