

NFMLP Stakeholders, Supporters, Advisors, 4th Quarter 2018 (April, May, June), Report Submitted Sept. 4th, 2018, by Katy DeBriere, Managing Attorney, NFMLP, katy.debriere@jaxlegalaid.org

I. <u>OPERATIONS</u>

A. TRAININGS, EDUCATION, AWARENESS

Completed Events:

June 28th: First Annual Bridges to Justice for Children's Health Endowment Fundraiser @ Nelson Mullins (honoring Wolfson Children's Hospital Chief Medical Officer, Dr. Jerry Bridgham)

July 12th: Guardian Advocacy and its Alternatives Training for Community PedsCare's social work team

July 18th: Housing Basics presented by Jacksonville Area Legal Aid, Inc. attorney, Katherine Hanson, at UF Health's Pediatric Multi-Specialty Center

July 24th – July 26th: Georgetown University's Center for Children and Families ("CCF") Annual Conference. CCF is an independent, nonpartisan policy and research center founded in 2005 with a mission to support access to high-quality, comprehensive and affordable health coverage for all of America's children and families.

Upcoming Events:

September 6th: Advanced Topics in Special Education Training, presented by Ann Siegel, Disability Rights Florida at UF Health's Pediatric Multi-Specialty Center

September 6th: Meet with Dr. Terrie Andrews regarding development of tool to screen for health harming civil legal aid needs, and more specifically, service needs for Medicaid enrollees with behavioral health concerns.

October 5, 2018: Meet with Dr. Mark Toney regarding (1) development of tool to screen for health harming civil legal aid needs, and (2) measuring the impact of an MLP intervention in reducing average length of hospital stay.

<u>Periodic Stakeholder Notifications and Education</u>: The NFMLP managing attorney communicates two to four times per month with medical and legal stakeholders. These email updates provide information on upcoming trainings, discussion opportunities, and updates on policy and legislative changes that may impact patient populations.

B. CASE REFERRALS

<u>Methods of referral</u>: Medical providers serving children may refer patients directly to the managing attorney of the NFMLP via the online referral resource, email, or fax.

Patients Referred: 84 Legal Issues of Patients: (95)

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SSI/SSDI (15)
Family Law (6)
Guardianship (13)
POA/Healthcare Surrogate (2)
Medicaid/Med-Waiver/ACA (24)
Healthcare Benefits (4)
Housing (9)
Immigration (4)
Education (11)
Civil and Disability Rights (5)
Nutrition (1)
Employment (1)
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II. <u>OUTCOMES</u>

Cases Referred to Pro Bono (4): placed (3); awaiting placement (1) Referred to JALA Attorney (7) Brief Services/Advice & Counsel from NFMLP (37) Full Representation by NFMLP (12) Did not show for appointment (2) Referred to other legal/social services agencies (9) Awaiting Callback (15)

III. INDIVIDUAL CASE STORIES

- A. N.E.'s is a child who has significant developmental delay and was previously diagnosed with failure to thrive. In April, the Social Security Administration (SSA) sent notice that N.E. would be ceased from his Supplemental Security Income (SSI) benefits because he no longer met the criteria for disability as defined by the SSA. N.E.'s mother, having previously been referred, contacted the NFMLP, who walked her through filing a request for reconsideration (1st tier of an SSA appeal) within 10 days of the cessation notice in order to retain benefits during the pendency of the appeal. N.E. requires a special diet due to his condition and the family uses the SSI benefits to ensure his access to those specialty foods as well as pay for needed supplements and supplies not covered by insurance. In addition to assisting with a timely appeal to stay benefits, the NFMLP filed the substantive request for reconsideration on behalf of N.E., including a summary of his condition and providing supporting medical records. N.E.'s records were reviewed by the Division of Disability Determinations who referred him to two consultative exams. After attending the exams and submitting additional medical records, the SSA found that N.E. continued to meet the definition of disability and reinstated SSI benefits.
- B. K.T. is a mother of two children, one of whom was recently born with medical complexity. K.T. also has a disability and uses a wheelchair to get around. K.T. was referred by Community PedsCare when she attempted to enroll her infant with medical complexity in Children's Medical Services Network (CMS). The infant was denied on the basis that the infant may one day require private duty nursing. CMS, because of its inability to pay competitive reimbursement rates for home health services, is unable to ensure network adequacy for enrollees who require those services. As a result, the Agency for Healthcare Administration (AHCA) is not allowing CMS to enroll new members

who have home health needs. In this instance, the possibility that the infant may one day need private duty nursing was enough for AHCA to refuse CMS enrollment to the infant. The NFMLP filed an appeal with CMS and also an AHCA complaint arguing that the agencies were acting under an un-adopted rule, the Medicaid member was entitled to free choice among MCOs, and the infant did not, in fact, require private duty nursing necessitating use of AHCA's policy. AHCA relented and CMS notified the NFMLP that K.T. could enroll the infant. The infant was successfully enrolled in CMS and K.T. is satisfied with the plan and its benefits.

In meeting K.T., as is common, two other legal issues arose. First, K.T. had been denied SNAP benefit aka food stamps for herself because the Department of Children and Families found that she was not cooperating with the Department of Revenue (DOR) to pursue child support. Although K.T. had followed all of the instructions of DOR to obtain child support enforcement, DOR had failed to process her paperwork or follow up on her case. As a result, DOR notified DCF that K.T. was "uncooperative" and food assistance for herself ceased.

Additionally, K.T.'s pregnancy Medicaid had been recently terminated after her three months postpartum ended. However, as a person with a disability who receives Social Security Disability Insurance (SSDI) benefits, she qualified for a Medicare Savings Program (MSP) administered through the state Medicaid program. The MSP pays her Part A premium because she is low income. As with any Medicaid program, it is DCF's obligation to review an enrollee's eligibility for all other Medicaid programs before terminating them from Medicaid outright.

Based on the termination of K.T.'s food stamps and the failure of DCF to transition her from pregnancy Medicaid to the appropriate Medicare Savings Program, the NFMLP filed an appeal with DCF arguing K.T.'s eligibility for both programs. Within two months, K.T. was found cooperative with child support and received an increase in her SNAP benefits. She also now receives a higher SSDI benefit because her Medicare Part A payment is no longer withheld. With the additional money, K.T. can better support herself and her two children.

C. A.H. and her stepson, K.T., were referred by Community PedsCare because the garage door in their rental home was broken and the landlord refused to fix it. The garage egress was the only way by which K.T., diagnosed with cancer and currently using a wheelchair, could get in and out of the home. A JALA fair housing attorney jumped into action and requested a reasonable modification to have their garage door fixed in an expedited manner. After the garage door was fixed within 24 hours of the request, A.H. remarked to the attorney that: "if it weren't for you, I think the garage door still would not be fixed."

After speaking with A.H., a separate JALA fair housing attorney stepped in to submit another reasonable accommodation. This time, the request asked that the family be allowed to modify their front door entry so it is wheelchair accessible. Prior to the attorney's request, the landlord simply did not respond to the family's requests. After a month of negotiation between the JALA attorney and the landlord, the landlord agreed. Construction on the entryway has begun.

D. The NFMLP, as it does with many JaxHATS patients, consulted with K.L. and her mother about changes to K.L.'s Social Security benefits and how that may impact her health insurance. K.L. is diagnosed with Down Syndrome and has other physical health issues. The NFMLP warned that K.L.'s Medicaid may be erroneously terminated because of an increase in her benefits but to contact the NFMLP right away if that occurred. A week before K.L. was scheduled to see a specialist about her kidney problems, K.L.'s mother contacted the NFMLP frantic, saying that, in fact, K.L.'s

Medicaid had been terminated. In partnership with JaxHATS, the NFMLP was able to file for an expedited hearing request and have K.L.'s Medicaid reinstated within less than two days. K.L. did not miss her appointment with the kidney specialist and, more importantly, K.L.'s mother got a small, but much needed sense of relief.

From April to early July 2018, the NFMLP has filed three (3) total requests for expedited hearing in Medicaid termination cases. Expedited hearings are only allowed in instances where a loss of insurance could result in significant harm to the enrollee's health. In all three cases, Medicaid was reinstated within the week and the request for hearing became moot.

In one instance, the Medicaid enrollee, an infant, was admitted to Wolfson Children's Hospital during the loss of his Medicaid eligibility. The NFMLP was able to have the child's coverage reinstated prior to discharge. This allowed the child to pay for medications required upon discharge at the hospital pharmacy.

- E. D.S. and his wife were referred to the NFMLP by The Player's Center for Child Health. D.S. and his wife experienced the unthinkable; they lost their child a couple months after his birth. The child had received Medicaid coverage during part of his hospital stay, but in the first couple of weeks, only had coverage through primary insurance. Several months after their infant son passed, D.S. and his wife continued to receive medical bills they were unable to pay. The Player's Center did all it could to secure retroactive Medicaid coverage for that two week time period, but were unsuccessful. Upon referring the case to the NFMLP, the NFMLP met with D.S. and filed an appeal on behalf of the family based on DCF's failure to process their request. After filing the appeal, DCF processed the request and found the infant eligible for Medicaid during the entire time the infant was hospitalized. The family was extraordinarily grateful to The Player's Center and the NFMLP for their help and said that the assistance through both organizations allowed for "such a huge burden off our backs."
- F. K.B. was referred by Wolfson Children's Hospital to assist in securing housing so that she and her son could resettle in Jacksonville after being discharged. K.B. wanted to ensure that the apartment she lived in with her medically fragile son was safe and sanitary. She chose an apartment complex that participates in the Extended Low-Income Housing Tax Agreement and, therefore, receives a tax break for offering affordable housing based on a tenant's income. Even though K.B. met the requirements of the complex's application criteria, the complex still demanded that she prove receipt of monthly child support through court order and that no other proof would be acceptable. The NFMLP intervened, contacted the apartment complex and its attorney, and stated that K.B. was not required to verify receipt of child support through court order and, instead, her statement or the statement of the person providing support was sufficient. The complex relented and approved K.B.'s application. An apartment opened up at the time K.B.'s son was ready for discharge allowing the family to move safely out of Wolfson and into their new Jacksonville home.
- G. The NFMLP was able to successfully argue to the Social Security Administration that a client's overpayment in the amount of \$3500 should be waived. The client, referred by JaxHATS, incurred the overpayment after being re-determined under the adult disability standards and ceased. The client, still believing himself to meet the standards of disability, asked that his payments continue during the pendency of his appeal. Since he did not have representation for the cessation appeal, he ultimately lost and the SSA asked him to repay the benefits he received while his appeal was pending. The NFMLP argued he should not be liable for the overpayment because he acted in good faith belief that he continued to be eligible and that being required to pay back the debt would be a significant hardship.

- H. Another JaxHATS patient referred to the NFMLP for assistance was recently approved for Social Security Disability benefits. The patient is diagnosed with sickle cell anemia and is often in and out of the hospital with pain crises. The patient was denied on her initial application for benefits, but after the patient and her mother contacted the NFMLP for assistance, the NFMLP was able to argue why the patient met the disability criteria and should be found eligible. Since the benefits were granted at the reconsideration level, the patient now does not have to wait a year or more to argue her disability at the hearing level. The NFMLP is currently working with the client to apply for a special Medicaid waiver program so that she can have subsidized health insurance while she awaits her Medicare eligibility.
- I. J.G. called the NFMLP from an out of state rehabilitation center where she was seeking treatment with her medically fragile son. J.G. was a previous NFMLP client and she needed help again. Her Homeowner's Association had filed a complaint against the family for failing to pay HOA fees. The total principal balanced owed was less than \$1,000 but the HOA decided to proceed against the family putting their home in jeopardy. Jacksonville Area Legal Aid's consumer law unit accepted the case, reviewed the complaint, and counseled J.G. and her family on the best strategy to avoid potential foreclosure given that they could not satisfy the total judgment out of pocket. The Consumer Law unit then contacted the firm who filed the complaint and asked them for the payoff balance. Once the unit learned the total amount owed to satisfy the claim, it reached out to the City of Jacksonville who agreed to donate the full amount so the family could remain in their home. On August 27, 2018, the HOA dismissed its suit and J.G. and her family can remain in their home while their medically fragile son continues to receive therapies and treatment.
- J. Nemours Children's Specialty Care contacted the NFMLP attorney about a very special family of siblings, ages 12-20, who lost both of their parents and had no court appointed guardian. The 17 year old sibling had experienced a leg injury which required surgery. Unfortunately, under current Florida law, the older, 20 year old brother, M.C., could not consent to the surgery nor could the 17 year old. The only way in which Nemours could provide the surgery was if a court order custody or guardianship ordered were entered for the 17 year old.

The 20 year old brother met with the NFMLP attorney. At the meeting, the older brother expressed that he attempted to petition for custody on his own and when unsuccessful, began to save money to pay for an attorney. The brother also said that his mother passed without a will and he was unable to determine the amount of her assets or how they would pass. He also was told by the Social Security Administration that he could not apply for survivor benefits without birth certificates for all of the children. Most 20 years old would have given up, but M.C. was dedicated to his siblings and cares for them as best he can. The NFMLP referred M.C. to Jacksonville Area Legal Aid's pro bono unit for assistance with both custody and probate.

Within the week, the pro bono unit had placed M.C. with a family law attorney to petition for custody over his 17 year old brother. A court order was entered on August 27th and the 17 year old is scheduled for surgery. The pro bono unit was also able to secure an attorney to handle the probate for the family so that the mother and father's assets can pass down rightfully to their children.

The NFMLP also reached out to the Social Security Administration to obtain correct information for M.C. in the application for the children's survivor benefits. The NFMLP encouraged M.C. to contact Social Security right away as the children were eligible without the need for providing a birth certificate or other supporting documentation.

Without the assistance of the pro bono unit, M.C. would still be saving up his small earnings to pay for an attorney so that his younger brother could have surgery.

IV. <u>NFMLP REFERRAL DATA</u>

Pediatric Focus of NFMLP (During January – June, 2017, NFMLP transitioned processes to onsite services and pediatric focus; 81 patient referrals and placements were also completed.)

Fiscal Year	1 st Quarter (July-Sept)	2 nd Quarter (Oct-Dec)	3 rd Quarter (Jan-Mar)	4 th Quarter (April-June)	Annual Total	% Increase over 2009 level of service (60 referrals per year)
2017-18	49	61	91	84	285	375%
2018-19						

Referral Data of NFMLP Prior to Pediatric Focus:

[In the beginning years of NFMLP (2009 and before) approximately 60 patients were referred annually. In the 2010 and 2011, the NFMLP received partial funding from the Florida Bar Foundation to increase patient referrals and legal services to patients through the involvement of pro bono attorneys. In 2010, NFMLP received 135 referrals. In 2011, NFMLP received 212 referrals. In 2012 and later, no dedicated funding was available for NFMLP but the level of patient service has remained high and new medical providers are encouraged to use this valuable resource in patient care.]

Calendar Year	1 st Quarter	2 nd Quarter	3 rd Quarter	4 th Quarter	Annual Total	% Increase over 2009 level of service (with no dedicated funding for NFMLP)
2012	43	56	55	34	188	213%
2013	39	41	51	67	198	230%
2014	69	49	36	43	197	228%
2015	64	70	70	73	276	360%
2016	88	69	93	82	332	453%

The Northeast Florida Medical Legal Partnership is a project of Jacksonville Area Legal Aid with financial support provided in part by Wolfson Children's Specialty Hospital.