

DEPARTMENT OF HEALTH AND HUMAN SERVICES
OFFICE OF DIRECTOR

ACTION REFERRAL

TO <i>Meldrop</i>	DATE <i>7-24-12</i>
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DIRECTOR'S USE ONLY	ACTION REQUESTED
1. LOG NUMBER <i>400036</i>	<input type="checkbox"/> Prepare reply for the Director's signature DATE DUE _____
2. DATE SIGNED BY DIRECTOR <i>cc: Mr. Beck, Singleton, Post Change to N/A, see attached e-mail.</i>	<input checked="" type="checkbox"/> Prepare reply for appropriate signature DATE DUE _____ <input type="checkbox"/> FOIA DATE DUE _____ <input type="checkbox"/> Necessary Action

APPROVALS (Only when prepared for director's signature)	APPROVE	* DISAPPROVE (Note reason for disapproval and return to preparer.)	COMMENT
1.			
2.			
3.			
4.			

SHAWNETTA LEWIS
527 ORANGEBURG RD D3
SUMMERVILLE SC 29483
843 695-8262 (H)

843 801-7421 (C)

July 17, 2012

State Director at SCDDSN

P.O. Box 4706

Columbia SC 29240

Dear Beverly A.H. Buscemi, Ph.D.

I have received a notification of reduction of service for my son Michael Lewis. **(Read Michael's story)** Michael's CPCA hours have been reduced from 25 to 16 hours weekly per State Office Review of Annual Service Authorized. **(See Reduction of Service Form)** The state office indicated that Michael Lewis has adequate services. I am confused why these hours have been reduced. I am told that it's because Michael has adequate service with 16 hours, but for the last two (2) years I am to assume 25 hours was inadequate. These hours where solicitude to me by my 2010 Service Coordinator Jennifer Horaz. Our Respite hours had just been reduced on July 13, 2010 to 68 hours a month. The hearing office over that case said an I quote :

- ❖ "The Petitioner has a need for constant hands-on/direct care and supervision due to a medically complex condition, and I so find"
- ❖ **"Petitioner's Mother does not work and indicated Petitioner sleeps 4-6 hours per night, and I so find"**
- ❖ The PC Aid provides the following tasks: changes him; bathes him; washes his hair; feeds him by mouth; stretches him; washes his clothes; and cleans his rooms, and I so find;"
- ❖ "Petitioner has not requested additional nursing hours as she did not know she could, and I so find"
- ❖ **"Petitioner has not requested more PC Aid hours as she did not know she could, and I so find"**
- ❖ "Petitioner has the ability to arrange her schedule for respite weekend coverage. Petitioner can eliminate the overlap between the two services freeing up more service units, and I so find;"
- ❖ Respite services are not intended to fill all gaps for total care, but for relief for the car-giver, and I so find;"
- ❖ There is sufficient support services in place for the Petitioner, and I so find;"
- ❖ **The Respondent's decision to deny Petitioner's request for a Respite Limit Exception is Affirmed. And it is so Ordered.**

End quote. When Mrs. Horaz suggested the additional hours they became a God sent. Michael could now have a Proficient, Vigorous. Beneficial daily schedule. One that strengthens his body, stimulate his senses, and maintain his health. **(See Daily Schedule A - ~~Michael's~~)** I have also been able to secure a position at Family Resource Center as a Peer Parent Mentor. **(See Employment Letter)** I do get paid but my hours fluctuate weekly even monthly my appointments and meeting are mainly before, during, and right after school hours. When I schedule (PCA) Personal Care Giver service and Nursing it is for this time of the day so I can work.

Since 2010 there has been a swallow study conducted for Michael the results conclude **(See Swallow Study Letter)**

- ❖ May continue puree consistency of up to 1oz 3x/day for swallow practice
- ❖ No liquids at this time
- ❖ **Continue aggressive feeding therapy**

RECEIVED

JUL 24 2012

Department of Health & Human Services
OFFICE OF THE DIRECTOR

SHAWNETTA LEWIS

527 ORANGEBURG RD D3
SUMMERVILLE SC 29483
843 695-8262 (H)

843 801-7421 (C)

Michael has a letter from Dr. Mark McCall requesting additional (PCA) Personal Care giver hours to do as per Barium Swallow Study. **(See Doctor's Letter)** As instructed Michael oral feeds three (3) times a day by myself or caregivers. It takes 45 minutes to an hour to feed Michael 4oz. Food has to be cooked, and or diced then pureed in the blender.

Michael has also been hospitalized four times since 2010 because of his seizures are not under control with medication. Michael also has been diagnosed with Scoliosis in 2011 by Dr Moony of Pediatric Orthopedics at MUSC. March 2012 Michael has had surgery at MUSC Charleston where his back and stomach was cut open so he could receive a Baclofen Pump. Michael's Scoliosis is so severe Dr. Mooney is recommending Corrective Spinal Surgery in the fall of 2012. More than 16 hours of PCA will be needed after this back surgery.

Michael Lewis is unable to care for himself and with the relief assistance through Medicaid Michael can live in the community and avoid institutionalization. Michael Lewis needs constant hands-on direct care and supervision due to his medically complex condition and severe disability.

Due to my sons health condition school was not an option living in Dorchester District II. These schools were unfit and unwilling to accommodate Michael's needs. Just recently this same District was fined by the Federal Government for their unwillingness to spend money meant for disable children. I have been home schooling Michael since 2009. It is prejudicial of anyone to assume a profound severe disable child like mine fits in with what you would normally consider school. My curriculum is based on, the only school in the Low Country's curriculum for profound disable children, P.A.C.E. **(Read P.A.C.E Pamphlet)** I have spoken with teachers, doctors and Therapist to create Michael's goals. Michael can't attend P.A.C.E because we don't live in Charleston County.

Do not reduce. Michael Lewis needs 25 hours of Personal Care Services. Thank you for your time and consideration in this matter.

Sincerely,



Shawnetta A Lewis

cc: Celeste Richardson, Executive Director, Dorchester County BDSN

Pam Furman, Service Coordinator, Dorchester County DSN Board

Anthony Keck, Director of SC Department of Health and Human Services

Jerri S Davidson, Attorney, Protection and Advocacy for People with Disabilities, Inc.

SHAWNETTA LEWIS
527 ORANGEBURG RD D3
SUMMERVILLE S.C. 29483

July 17, 2012



This is Michael

Michael Lewis Story

Michael is a 6 year old boy who was Diagnose with Polymicrogyria. With this diagnosis he has many abnormalities and disorders. Michael has Cerebral Palsy, Chronic Lung Disease, Seizures Disorder, Cortical Vision Impairment, Global Developmental Delays, recurrent aspirations and Non-Compaction with normal function. He was diagnosed three years ago with Cardiomegaly (Enlarged Heart). Unfortunately Michael has a progressive developmental delay with Spastic Quadriplegia and G-tube dependent. Michael takes over ten (10) medications that we administer several times a day via G-tube. Michael is also currently going through Precocious Puberty. 2011 he was diagnose with Scoliosis.

We have instruction from his therapist to exercise him daily with range of motion, his limbs become extremely stiff if this does not happen. Michael has marginal head control and no trunk control. He uses a manual wheelchair for all mobility and requires maximum assist to propel his wheelchair. Michael is dependent for all self help skills. He cannot sit, transfer, stand or maneuver in his environments without maximum support and adaptive equipment. We stand Michael up daily in his stander. He also wears Bilateral wrist splints and leg splints (AFO's) for about 6 hours a day. One hour a day he wears pneumatic elbow splints to prevent further contractures and improve ROM. Michael has Occupational, Speech, and Physical Therapy for 1 hour a week.

We build Michaels social skills through 4 weeks of camp at P.A.C.E in the summer, Miracle League every Saturday in the Spring and Fall, and once a week he has physical therapy at P.A.C.E he is able to interact with the kids there. I have learned to think outside the box when it

SHAWNNETTA LEWIS
527 ORANGEBURG RD D3
SUMMERVILLE S.C. 29483

comes to School and Education so I home school Michael. We work for 1-2 hours daily and if my week is full we have school on the weekends. Its prejudice to imply that my special needs child's school curriculum has to mirror that of a normal child. Home schooling for Michael is geared more towards communication, understanding, and interpretation. We attend church most Sunday's depending on the weather. I try to keep a calm atmosphere around my son, certain things will upset him and induce seizures.

Thank you for taking the time to get to know my son Michael Lewis.

S.C. DEPARTMENT OF DISABILITIES AND SPECIAL NEEDS
MRR/RD WAIVER

NOTICE OF REDUCTION OF SERVICE

To: Shawnetta Lewis

Address: 527 Orangeburg Rd Apt. D-3
Summerville S.C. 29483

Participant's Name: Michael Lewis DOB: 4/03/2006 Medicaid #: 1780589503

YOU ARE HEREBY NOTIFIED TO TERMINATE THE PROVISION OF THE FOLLOWING SERVICE(S) TO THE PERSON NAMED ABOVE. ONLY THE NUMBER OF UNITS RENDERED PRIOR TO OR ON THE EFFECTIVE DATE OF 7/13/12 MAY BE BILLED.

- | | |
|---|---|
| <input type="checkbox"/> Adult Attendant Care Services | <input type="checkbox"/> Environmental Modifications |
| <input type="checkbox"/> Adult Day Health Care | <input type="checkbox"/> Nursing Services |
| <input type="checkbox"/> Adult Day Health Care Nursing | <input checked="" type="checkbox"/> Personal Care Services |
| <input type="checkbox"/> Adult Day Health Care Transportation | <input type="checkbox"/> Personal Emergency Response System (PERS) |
| <input type="checkbox"/> Adult Companion Services | <input type="checkbox"/> Prescribed Drugs |
| <input type="checkbox"/> Adult Dental Services | <input type="checkbox"/> Private Vehicle Modifications |
| <input type="checkbox"/> Adult Vision Services | <input type="checkbox"/> Psychological Services |
| <input type="checkbox"/> Audiology Services | <input type="checkbox"/> Residential Habilitation |
| <input type="checkbox"/> Behavior Support Services | <input type="checkbox"/> Respite Care |
| <input type="checkbox"/> Career Preparation Services | <input type="checkbox"/> Specialized Medical Equipment, Supplies and Assistive Technology |
| <input type="checkbox"/> Community Services | <input type="checkbox"/> Speech-Language Pathology |
| <input type="checkbox"/> Day Activity | <input type="checkbox"/> Support Center Services |
| <input type="checkbox"/> Employment Services | |

Reason:

- | | |
|---|---|
| <input type="checkbox"/> Change in need; no longer justifies original request | <input type="checkbox"/> Medical condition has improved |
| <input type="checkbox"/> No longer meets ICF/MR Level of Care | <input type="checkbox"/> Participant/legal guardian requested |
| <input checked="" type="checkbox"/> Other: <u>State office annual review of authorized services has reduced Michael's CPCA services from 25 to 16 hours weekly.</u> | |

Comments (required): Michael's CPCA hours have been reduced from 25 to 16 hours weekly per State office review of annual services authorized.

Service Coordination Provider: Dorchester DSN Board Service Coordinator Name: Pam Furman

Address: PO Box 2950
Summerville S.C. 29484

Phone # 843-871-1285

Signature of Service Coordinator Pam Furman

Date 7-12-12

MICHAEL'S DAILY SCHEDULE

6:00AM		Change diaper/change pad/clean up bed and room/vacuum floor
6:00AM	Range of Motion	Arms, legs, elbows, hands, and feet stretching for 20min
6:45AM	Take out of bed	Put slippers on/sit in chair
7:00 AM	Feeding machine ends	Disconnect from machine
7:00AM	Oral feeding	Cream of Wheat/Rice Cereal, Fruit
8:00AM	Medicine-Inhalation-CPT Regiments	Make and administer meds- 15 min inhalation 15 min CPT'S
8:30AM	Wash-Dress-Brush	Chang diaper-wash and lotion-dress apply ointment-brush teeth-place in wheelchair
9:30AM	Bolus feeding-100ml milk-100ml water	Clean up feeding
9:40AM	Walk	Put jacket, hat on(if needed) walk around complex for 25min
10:00AM	Sesame Street	Turn TV on channel 11
10:10AM	Hand splints- leg braces (AFO'S)	Place splints on wrist and legs
10:10AM	Side stretches	30min stretch on left and right sides in Grasshopper unit
11:10AM	Stander	Place full leg braces on/strap into stander-1hr 15min
11:10AM	Pneumatic elbow/arm splints	Put on & blow out splints
11:00AM	Vision Therapy	Set up black board-draw shades
11:30AM	Sterilize syringes	Boil water/ clean meds & feeding supplies
12:00AM		Check diaper
12:15AM		Take out of stander
12:15AM	Occupational Therapy (Mondays) Speech Therapy (Wednesday)	Therapy comes to work for 1hr/Range of motion
1:00PM	Oral Feeding	In wheelchair or activity chair- 4oz puree food
1:45PM		Changes diaper
1:50PM	Medicine-Bolus Feeding	Give the mid day meds 100ml milk-100 ml water
2:00PM	Physical Therapy (Thursday)	Go to P.A.C.E for therapy
2:00PM	Workshop	45 movement therapy (setting will be instructed)
3:00PM	Nap-rest time	Down time
3:30PM	Walk/Swing	Walk around complex/put in swing 25 min
4:00PM		Change diaper
4:30PM	Tube bath	Place in bath chair wash body/hair
5:00PM	Bolus feeding	He is elevated-100ml milk-100 ml water
5:00PM	Oral feeding	Blend 4oz food/fruit
5:30PM		Stack supplies/organize room
6:00PM	School/or (Saturday 12-2:00PM)	Follow home school curriculum 1 ½ hr
7:30PM	Rest	Down time
8:00PM	Medicine	Give the evening meds
8:00PM		Change diaper
9:00PM	Bedtime	Change clothes-clean diaper
9:00PM	Feeding Overnight (9pm-7am)	Set up feeding machine-hook up Milkey-start feeds



FOR DISABILITIES AND SPECIAL NEEDS, INC.

1575 Savannah Highway - Suite 6

Charleston, SC 29407

(843) 266-1318

(843) 266-1941

www.frcdsn.org

July 17, 2012

Pam Furman
Dorchester County Board of Disabilities & Special Needs
P.O. Box 2950
2717 W. 5th North Street
Summerville, S.C. 29484

Dear Ms. Furman,

Please allow this letter to act as confirmation that Shawnetta Lewis has completed the mandatory training required to contract as a provider of Peer Parent Mentor services with the Family Resource Center's Parent Training and Resource Center (PTRC). The PTRC, a federally funded program through the US Department of Education, provides direct training and assistance to families of children with disabilities in Berkeley, Dorchester, and Charleston Counties. The PTRC delivers this service by providing specialized training to parents or close family members of children with disabilities who then mentor other parents. Peer Parent Mentors who contract with the FRC must participate in mandatory training annually and they are compensated for their work with other parents.

Ms. Lewis received her first 2 day training in November 2011 and received training again in May 2012. She has contracted with the Family Resource Center to provide mentoring services and is available to assist families as assigned. Her responsibilities include a flexible schedule that allows her to accompany parents to Individual Education Program (IEP) and other meetings held during regular school hours. The number of contracted hours with our center fluctuates and is predicated on staff assignment of partnerships with Mentors.

Sincerely,

A handwritten signature in black ink that reads 'Beverly McCarty'. The signature is written in a cursive style with a large, prominent 'B'.

Beverly McCarty
Executive Director, Family Resource Center
Project Director, Parent Training and Resource Center

cc: Shawnetta Lewis



TERAPISTIC SERVICES

Medical University Hospital Authority
Charting Report

NAME: LEWIS, MICHAEL
ROOM: 814:
BED: ""

Account ID: 260873716
Date of Birth: 4/3/2006
Med. Record # : 001581714

Date/Time: 1/20/10 3:45 pm **Room/Bed:** 814,""
Start Time: 0:00 **End Time:** 0:00
Session Duration: 0

Pediatric Modified Barium Swallow Study
MUSC Evelyn Trammell Institute for Voice and Swallowing
Pediatric Modified Barium Swallow Study

Patient Information

Patient: MICHAEL LEWIS
MRN: 001581714
Date of Birth: 4/3/2006
Date of Evaluation: 01/20/10
Patient Age: 3 years
Gender: Male
Referring Physician: David White, MD
Reason for Referral: h/o aspiration
ICD-9 Code: 343.9, 783.42, 527.7, 518.89, 429.3, 530.81, 787.20
Current Diet: primary nutrition/hydration via GT - Nutramigen Jr - 100ml TID and 400ml qh - gets small volumes stage 1 baby food by mouth
Pain Assessment: Patient/caregiver reports an analog pain scale rating of 0/10
Ambulatory Status: Wheelchair
Barriers to Learning: Language, ? cognition
Precautions: GT

Diagnosis and History:

Michael is a 3 y.o. male with PMHx significant for spastic CP, global developmental delay, sialorrhea, CLD, GER, cardiomegaly and dysphagia with aspiration.

MBSS on 9/15/2006 revealed a timely pharyngeal swallow of nectar thick and thin liquids with occasional laryngeal penetration of thick liquid. there was evidence of deep laryngeal penetration, worsening with fatigue, for thin liquids. Minimal residue after the swallow was noted with thick liquids; however cleared on subsequent swallows. It was recommended that Michael's liquids be thickened to nectar consistency.

MBSS on 10/09/2007 revealed delayed A-P oral transit time, premature spillage of the bolus over the base of the tongue, incomplete epiglottic inversion, and laryngeal penetration with aspiration of purees. ALTMNH recommended. Michael was admitted to the hospital for peg tube placement

MBSS in April, 2008 was cancelled.

MBSS 11/7/08 showed delayed swallow initiation, but no penetration or aspiration for thin liquids or puree. Recommendations were for puree up to 1oz 3x/day and small sips liquid of up to 1/2 oz 3x/day, feeding therapy and repeat MBSS in 3-4 months.

Michael returns today for MBSS accompanied by mother. She reports that he is taking small volumes of puree by mouth each day, but no liquids. Home based OT is reportedly working on feeding skills with Michael.

Exam Information General

Exam Original Date: 01/20/10



THE PEDIATRIC SERVICES

Medical University Hospital Authority Charting Report

NAME: LEWIS, MICHAEL
ROOM: 814:
BED: ""

Account ID: 260873716
Date of Birth: 4/3/2006
Med. Record # : 001581714

Last Modified Date: 11/07/09
Examining Facility: Medical University of South Carolina
Exam Type: Videofluoroscopy
Radiologist Present: Paula Keslar, MD
Patient Position: Seated 80 degrees in Tumbleform chair
Imaging View: Lateral
Patient Status: Awake
Patient Fed By: mother
Consistencies: thin liquid via straw pipet and puree via spoon
Oral Stage: severely impaired - poor oral transit with majority of bolus lost anteriorly, poor lingual control, premature spillage into hypopharynx, delayed swallow initiation
Pharyngeal Stage: aspiration prior to the swallow as a result of pooling in pyriform sinuses and delayed swallow initiation; adequate airway protection when swallow triggered
Exam Comments: no cough response to aspiration

Impressions and Recommendations:

Micheal continues to present with severe oropharyngeal dysphagia characterized by poor lingual control, poor oral transit, premature spillage and pooling in hypopharynx, delayed swallow initiation and aspiration before the swallow. Adequate airway protection was appreciated when patient triggered swallow in timely manner. Of note, all liquid presentations were completely lost anteriorly. In addition, child with poor acceptance of bolus presentations today with tightly clenched teeth. Mother states he is often more accepting of food at home.

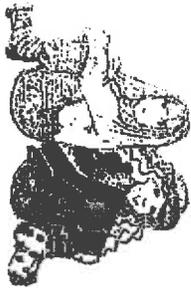
Recommend:

- may continue puree consistency of up to 1oz 3x/day for swallow practice
- no liquids at this time
- continue aggressive feeding therapy
- upright supportive position with supervision for all intake
- if child showing signs of disinterest or refusal for food presentation, discontinue at that time and try again later when child more accepting.
- monitor respiratory status closely
- repeat MBSS in 6 months or sooner if indicated

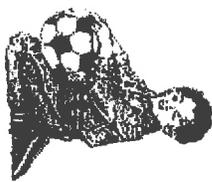
Thank you for allowing me to participate in the care of this patient. If there are specific questions or concerns regarding this evaluation or therapy recommendations, contact the Department of Speech Language Pathology (843) 876-7200.

Stacey deVries MS, CCC-SLP
Speech-Language Pathologist
11462

cc:
David White, MD
Carissa Carie, CPNP



SUMMERVILLE PEDIATRICS, P.A.
Mark J. McCall, M.D.
312 Midland Parkway
Summerville, SC 29486-8114
Phone (843) 875-6262



May 17, 2010

Dorchester County Board of Disabilities and Special Needs
Attn: Shelli Quenga
P. O. Box 2950
Summerville, SC 29484

RE: Michael I. Lewis, DOB: 4/3/06

Dear Ms. Quenga,

Due to the fact Michael requires intensive feeding, he is requiring at least 25 hours of personal care a week.

Thank you,

A handwritten signature in black ink, appearing to read "Mark J. McCall".

Mark J. McCall

Brenda James

Log # 36 ✓

From: Teeshla Curtis
Sent: Friday, July 27, 2012 10:37 AM
To: Brenda James
Cc: GEORGE MAKY; KARA WAGONER LEWIS
Subject: Log 36

Brenda,

Please change **Log 36** to necessary action or simply add the following as our response:

The program area was briefed by DDSN on the beneficiary's situation. The beneficiary's mother is requesting reconsideration of a service reduction by DDSN. The letter is addressed to Dr. Buscemi; we were simply copied. The next step, would be a formal appeal to SCDHHS Appeals and Hearings. DDSN is preparing a response to the letter.

Thanks,

Teeshla Curtis

Administrative Coordinator
Office of Information Management
South Carolina Department of Health and Human Services
1801 Main Street
Columbia, South Carolina 29202
(803) 898-2502

Brenda James

From: Teeshla Curtis
Sent: Thursday, July 26, 2012 2:30 PM
To: Brenda James
Subject: FW: Log 000036

Can we get an extension on Log 36? The staff member that oversees that waiver program is out of the office until August 1st. She will need data from DDSN in order to answer the log. Can we have until the August 8th?

Thanks,
Teeshla

From: Margie Hickerson
Sent: Thursday, July 26, 2012 1:48 PM
To: Teeshla Curtis; GEORGE MAKY
Cc: KARA WAGONER LEWIS
Subject: RE: Log 000036

Teeshla,

I have forwarded the attachment to Kara. We will need to request an extension because Kara will be out of the office until 8/1/12 and she will need to request info from DDSN.

Thanks
Margie

From: Teeshla Curtis
Sent: Thursday, July 26, 2012 10:41 AM
To: GEORGE MAKY; Jocelin T Dawson
Cc: Margie Hickerson
Subject: Log 000036

This is log 36 due 8.3.12. I have the PACE brochure if you need that.

Teeshla Curtis

Administrative Coordinator
Office of Information Management
South Carolina Department of Health and Human Services
1801 Main Street
Columbia, South Carolina 29202
(803) 898-2502