

DEPARTMENT OF HEALTH AND HUMAN SERVICES
OFFICE OF DIRECTOR

ACTION REFERRAL

TO	DATE
Medical Services / Walder	2-1-11

DIRECTOR'S USE ONLY		ACTION REQUESTED	
1. LOG NUMBER	1011330	<input type="checkbox"/> Prepare reply for the Director's signature DATE DUE _____	
2. DATE SIGNED BY DIRECTOR		<input checked="" type="checkbox"/> Prepare reply for appropriate signature DATE DUE 2-10-11 DATE DUE _____ <input type="checkbox"/> Necessary Action	
Ref logs # 38, 52, 88 log attached cc: Mr. Feek			

APPROVALS (only when prepared for director's signature)	APPROVE	* DISAPPROVE (Note reason for disapproval and return to preparer.)	COMMENT
1.	<i>[Signature]</i>	Close per Byrum Roberts	No response 2/10/11
2.			
3.			
4.			

2/8/11
 Byrum / Deedra
 8-02-18 8-26-47
 — we would recommend
 no reply necessary

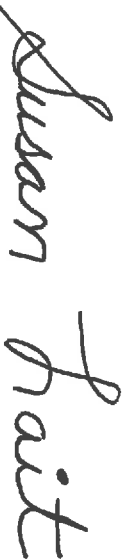
“What Happens When an Ineffective System and Deficit Collide?”

By Susan Lait

In 2005 our family’s personal story appeared in the South Carolina Partnership of Disability Organizations Program for Legislative Advocacy Day. I have attached a copy because it allows you to compare opportunities we had as a state six years ago compared to where we are today. It really is a case of opportunities lost. Our daughter Leah was 15 years old in 2005. Today Leah is twenty-one years old. Leah is unable to make decisions for herself. Prior to Leah turning eighteen, my husband and I appeared before our local Probate Court, to become in addition to her parents, our daughter’s legal guardians. At the probate hearing, the Judge addressed our responsibilities as guardians reminding us to pursue Leah’s rights concerning access to disability supports and services.

The American with Disabilities Act (ADA) and a U.S. Supreme Court Ruling, *Olmstead vs. LC*, provides that Leah have access to medical and community based services that allow her to live at home in her community. During the past two years, the agencies that serve citizens with disabilities have eliminated and/or reduced services creating vulnerability and a threat of institutionalization. We realize we save the State of South Carolina money remaining intact as a family and caring for Leah at home, but our primary reason for caring for our daughter is that we love our daughter. The fiscal challenge facing South Carolina is affecting the entire country. Yet, because we are facing a fiscal challenge as a state, we are not afforded the liberty of ignoring the basic rights and needs of people with disabilities. As a parent, I network with parents across the state. We have formed organizations to speak on behalf of children and adults with disabilities. In exhausting appeal options available on the state level, we are left with the next step in formal resolution which is to contact federal agencies. It is our Southern Tradition to do things on our own and to take care of our own. Yet, as parents and guardians we are obligated to pursue the promise of the **American with Disabilities Act (ADA)** and *Olmstead vs. LC* to access medical and community based services. We ask you to reflect on the responsibility South Carolina has when it comes to our citizens with disabilities.

I am happy to provide you additional information and insight as to the challenges we face as a family. Please do feel free to contact us.



Susan Lait for
Alan, Susan & Leah Lait
308 Turkey Run
Pickens, SC 29671
(864)878-4567

RECEIVED

JAN 31 2011

Department of Health & Human Services
OFFICE OF THE DIRECTOR

PERSONAL STORIES

5

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JAN 31 2011

Department of Health & Human Services
OFFICE OF THE DIRECTOR



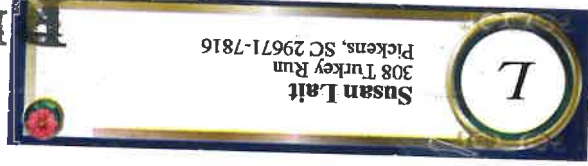
Our daughter Leah is fifteen years old. She entered our lives with the help of an emergency "C" section, weighing 2 pounds, 11 ounces. It was during those first weeks in the hospital that we were introduced to the two faces of the disability system. The hospital staff instilled in us the confidence that we could care for our baby with special needs. But we heard a different message from a social worker: we would not be able to care for our baby without the involvement of the state system.

So we completed the state eligibility process and were told that Leah was eligible for services. Then we were told that due to funding constraints, services were not available. The only service offered was to place our newborn daughter in an institution. My husband and I stared at each other, confused. Like most Americans, we had assumed that there were resources to assist families and individuals facing disability.

We are in the final years of Leah's childhood. We have watched middle income families, like us, deplete family resources and become dependent on state and federal resources. We have prayed we won't be one of the families to go into crisis and need institutional placement. In having two faces, the state is sustaining an ineffective system, adding to the number of families needing help, increasing waiting lists and leading families to eventual crisis by operating as a system that primarily responds to crisis. So as legislators, the question becomes one of do we remain a "crisis system," or do we provide funding for less expensive community alternative services?

It will be the state legislature and the governor who will eliminate the two faces of the state system, by focusing on the needs of constituents, providing effective funding for community based services, and by realizing the crisis that faces us also faces the system.

Susan Lait
Pickens County



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JAN 9 1 2011

Department of Health & Human Services
OFFICE OF THE DIRECTOR

Personal and Confidential

Mr. Tony Kack
Director's Office
Dept. Health & Human Services
P.O. Box 8206
Columbia, SC 29202-8206

#88
#52
#38

GREENVILLE SC 296
29 JAN 2011 PM 4 1



DEPARTMENT OF HEALTH AND HUMAN SERVICES
OFFICE OF DIRECTOR

ACTION REFERRAL

TO	DATE
Single for	8-24-10

DIRECTOR'S USE ONLY		ACTION REQUESTED	
1. LOG NUMBER	000088	<input checked="" type="checkbox"/> Prepare reply for the Director's signature	DATE DUE 9-2-10
2. DATE SIGNED BY DIRECTOR		<input type="checkbox"/> Prepare reply for appropriate signature	DATE DUE _____
CC: Ms. Foreman, Myers, Walbridge Ref log # 38, 45, 452- Attached closed 8/31/10, letter attached.			

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

Brenda James - Fwd: 1) Failure to Respond to Complaint; 2) Amendment to Complaint; 3) Early Resolution Prior To OCR Complaint

From: Emma Forkner
To: Felicity Myers; Sam waldrep
Date: 8/25/2010 7:13 PM
Subject: Fwd: 1) Failure to Respond to Complaint; 2) Amendment to Complaint; 3) Early Resolution Prior To OCR Complaint
CC: Brenda James; Deirdra Singleton

Brenda, please log this.

Felicity and Sam, Jennifer Campbell talked with Susan for an hour and had a good conversation. I assumed Ms Lait understood the Case Manager was organizing the effort to plan & coordinate the transition. I believe that is exactly what we communicated to Ms Lait in writing and by email.

I am certainly open to any thoughts that could facilitate this transition.

Emma

Emma Forkner
Director
Department of Health and Human Services
1801 Main Street
Columbia, South Carolina 29201
(803) 898-2504
(803) 255-8338 fax

RECEIVED
AUG 26 2010
Department of Health & Human Services
OFFICE OF THE DIRECTOR

>>> "Alan and Susan Lait" <asiscusa@directv.net> 8/25/2010 5:26 PM >>>
Date: August 25, 2010
Fourth Request

To: Dr. Beverly Buscemi, Executive Director Department of Disabilities & Special Needs
Ms. Emma Forkner, Director Health & Human Services

From: Susan and Alan Lait, Parents & Legal Guardians of Leah Elaine Lait
308 Turkey Run
Pickens, SC 29671

REF: Leah Elaine Lait - 1) Failure to Respond to Complaint; 2) Amendment To Complaint; 3) Early Resolution to OCR Complaint

It has been thirty-five (35) days since we submitted a 7/21/2010 formal complaint related to changes in our daughter's services as she turns age twenty-one. Our complaint has not been resolved.

On 7/21/2010, we sent a request to you as directors of South Carolina Department of Health and Human Services (DHHS) and Department of Disabilities and Special Needs (DDSN). Neither one of you provided a direct response nor did you direct us to DHHS or DDSN staff. Instead, in 7/26/2010 and 7/29/2010 letters, you simply referred us to our daughter's local service coordinator. Our daughter's service coordinator is employed by

a local, non-profit provider. The service coordinator is not an employee of DHHS or DDSN, and is not authorized to represent state agencies in responding to formal, written complaints.

On 8/5/2010, Kathy Lacy, DDSN employee, advised us via e-mail that rather than contact us directly, DHHS and DDSN held a teleconference with employees from the local non-profit. We were not advised of the teleconference in advance nor were we invited to attend the teleconference. Ms. Lacy advised us that she had been appointed to be the representative for both DDSN and DHHS by asking that we allow our service coordinator to assist us. On 8/11/2010, we met with the service coordinator, the case coordination supervisor and the executive director at our local non-profit provider. The non-profit provider very much wanted to assist us. Yet, they are not employees of DHHS or DDSN, and can not represent either agency by responding to formal, written complaints on behalf of a state agency.

Meanwhile, we have received conflicting verbal explanations as to changes in our daughter's services. We continue to encounter barriers to being informed as to how our daughter's services will change when she turns twenty-one. In five (5) days our daughter will turn age 21. In failing to respond as state agencies you have not allowed us the opportunity to properly plan for our daughter. We need assistance in the areas outlined in our original 7/21/2010 complaint. We would also like to submit an amendment to our original complaint.

Amendment To 7/21/2010 Formal Complaint - We are told that SC Medicaid is highly driven toward services for children and pregnant women rather than services for adults or adults with disabilities. We are concerned about ongoing therapy as our daughter with disabilities begins adult services. Prior to age 21, our daughter received speech, occupational and physical therapy through the Children's Division of Medicaid. Prior to changes in the MR/RD Medicaid Waiver which went into effect 1/1/2010, therapy was provided for adults with disabilities on the waiver. A 12/1/2009 DDSN memo stated that therapy services were being eliminated from the waiver since therapy services were provided through regular Medicaid. But effective 1/1/2010, the adult therapy services that had been previously provided through the waiver were not available through regular Medicaid as promised in the 12/1/2009 memo. The 12/1/2009 memo appears to be misleading based on the following:

One - It appears that there are severe restrictions as to "**choice**" and "**location**" of therapy. Private therapists or therapy groups in the community may **not** be reimbursed through Medicaid for therapy provided to "**adults**". Although, reimbursement **can** be provided to private therapists or groups for services provided to "**children**". Reimbursement for therapy provided to adults is **only** provided if billing is submitted directly by a hospital or physician who directly employs a therapist. I am told that in reference to adults, the Medicaid billing system has been programmed to kick out any claims submitted by private therapists or therapy groups even if there is an affiliation with a local hospital.

Two - Regular Medicaid currently provides only very restrictive conditions under which therapy can be provided. It appears that the conditions are so restrictive that an adult with disabilities may not access therapy to continue progress or maintain stability. Therapy is provided in an effort to avoid hospitalization following surgery or injury. We have not been advised of a manner in which our daughter many continue to receive therapy services.

Three - There are barriers to assistive technology. The three steps to acquiring assistive technology are **1) evaluation, 2) funding and 3) implementation**. A therapist completes the assistive technology evaluation. The therapist also provides implementation. Without appropriate access to therapists there is no access to evaluation or implementation.

Four - There are barriers to "**mode of communication**" - Our daughter has used assistive technology in reference to environmental controls over the years, yet her primary access to assistive technology is related to mode of communication. Leah uses assistive technology to access mode of communication. Restrictions to therapy create barriers to communication that prohibit communication related to basic wants, needs, help and safety.

Please consider this e-mail communication a fourth attempt in reference to our original complaint, an amendment to the original complaint and a request to document the policies in reference to changes in our daughter's services. It appears the manner in which DDSN and DHHS collaborated policies and changes in reference to the Medicaid MR/RD Waiver and regular Medicaid discriminate against our daughter based on **1) age, 2) disability, 3) mode of communication and 4) choice to reside in the community**.

Can you assist us in early resolution of these issues to avoid us meeting our responsibility as

parent/guardians in submitting a Civil Rights Complaint on behalf of our daughter.

Resolution - As resolution, we request the following:

- 1) DDSN and DHHS communicate directly with parent/guardians to assist in transition to adult services.
- 2) DDSN and DHHS provide appropriate documentation to assist in transition to adult services.
- 3) DDSN and DHHS assist in navigating access to ongoing speech, occupational and physical therapy services.
- 4) DDSN and DHHS assist in processing future requests related to Assistive Technology if barriers are encountered by the consumer.
- 5) DDSN and DHHS assist in providing access to the current 40 hours per week of PCA Personal Care Assistant (PCA) Services for the six weeks following the mother's 9/9/2010 surgery. At the close of the six weeks, it is the intention of the parent/guardians to utilize the adult CAP of 28 hours per week PCA Services.

We would appreciate direct assistance from DHHS and DDSN.

Sincerely,

Susan Lait for
Alan, Susan and Leah Lait
308 Turkey Run
Pickens, SC 29671
(864)878-4567

----- Original Message -----

From: Alan and Susan Lait
To: Emma Forkner ; Buscemi, Beverly
Cc: Alan and Susan Lait ; Sharon Steed ; Amy Zhu ; dale Thompson ; jking@ddsn.sc.gov
Sent: Wednesday, July 21, 2010 10:29 PM
Subject: Formal Complaint/Concerns

Date: July 21, 2010

To: Dr. Beverly Buscemi, Executive Director Department of Disabilities & Special Needs
Ms. Emma Forkner, Director Health & Human Services

From: Susan and Alan Lait, Parents & Legal Guardians of Leah Elaine Lait
308 Turkey Run
Pickens, SC 29671

REF: Leah Elaine Lait - Complaint/Concerns: 1) Request for Early Resolution; **2)** Request to be advised of Transition Changes from Children's to Adult Services in Writing; **3)** Request to be Advised of Appeal Process, Due Process and Legal Services Options in Writing; **4)** Request for response within ten (10) calendar days.

We enjoy the opportunity of our daughter, Leah, living at home with us and saving the State of South Carolina thousands of dollars each year. Our daughter will turn age twenty-one (21) in approximately six weeks. It is our understanding that on her 21st birthday, Leah's services will transition from children's to adult services. We are concerned that this transition may create barriers to medical and community based services.

Leah currently receives services through the Mental Retardation and Related Disabilities (MR/RD) Division of the South Carolina Department of Disabilities and Special Needs (SCDDSN). SCDDSN is the state agency created to oversee services for South Carolina citizens with disabilities and special needs. Leah

currently receives Medicaid through standard, fee-for-service Medicaid. In South Carolina, the State Medicaid Office is called the South Carolina Department of Health and Human Services (SCDHHS). Leah receives enhanced community based services through a Medicaid Waiver Plan called the MR/RD Waiver. The MR/RD Waiver provides Leah access to enhanced services which allow her to live at home, involved in her own community. The Anderson Disability and Special Needs Board (ADSNB), a local independent board, provides individual service coordination. Claims in reference to medical and community based services are processed through the SCDHHS (State Medicaid Office).

We are unsure where SCDDSN's responsibilities leave off and the SCDHHS's responsibilities begin. Therefore, we are sending requests to the directors of DDSN and DHHS. We would like to request DDSN and DHHS assist in Leah's transition from children's services to adult services. We request DDSN and DHHS to assist in collaborating early resolution to our concerns. If necessary, we request DDSN and DHHS to provide us information to access due process and/or formal resolution that may be available to us. We request to be advised in writing, in advance, of any changes in Leah's services. We request to be advised in writing of due process rights, responsibilities, legal service options and other state and/or federal agencies that may be requested to be involved in the formal resolution process. Should there be a need to submit an appeal, we request that Leah's services be continued during the appeals process. Please advise if DDSN or DHHS has professional staff assigned to issues concerning compliance with the American with Disabilities Act (ADA), Civil Rights or Olmstead.

In the past, we have enjoyed a supportive relationship with our local board, DDSN and DHHS. We hope to have similar support as we transition to adult services and address barriers to medical and community based services.

Our current areas of complaint/concern are as follows:

1) Medicaid and MR/RD Waiver as applied to Therapy - We have been advised that Leah is currently receiving Speech, Occupational and Physical Therapy Services through a Children's Services provision of Medicaid. We are concerned that Leah's current therapy services will be eliminated when she turns age twenty-one. Therapy services were previously included in the MR/RD Waiver as an adult service. On July 20, 2009, the DDSN Commission approved a renewal/amendment option that would amend the MR/RD Waiver. One of the services addressed was therapy. **DDSN Commissioners, consumers and providers were advised in a written summary document that therapy was to be eliminated from the waiver since therapy services were covered under regular Medicaid.** The summary document did not appear to be specific. The summary document did not establish a difference between children's therapy services, adult therapy services or define specific programs that might be effected. DDSN staff and DHHS staff assured consumers and providers that therapy could be eliminated from the waiver because therapy services were covered under regular Medicaid. The change of eliminating therapy as a waiver service was initiated with no specific information or documentation provided to consumers.

Four (4) months later, the Director of DHHS released written notice that the federal office of the Center for Medicaid Services (CMS) had approved the requested MR/RD Waiver changes including the elimination of therapy services. Following this notification, DHHS released a chart dated November 2009 in reference to therapy. This chart does not appear to represent similar levels of therapy that were previously provided for **"adults"** under the MR/RD Waiver. On January 1, 2010, the above mentioned changes in reference to therapy went into effect. Therapy was eliminated as a MR/RD Waiver Service effective January 1, 2010.

Leah continues to make documented progress with therapy. Leah's medical professionals have provided written recommendations that she continue to access speech, physical and occupational therapy. We are concerned as to barriers effecting **"medically necessary"** therapy recommended by physicians. We find the November 2009 Therapy Summary Chart difficult to understand. Is there a provision that will continue Leah's **current** therapy model as an adult? Please investigate and advise.

2) Primary Mode of Communication - Assistive Technology Access Through Therapy Access - Leah's primary mode of communication is Augmentative Communication with Assistive Technology (AT). For seventeen years, since the age of three, this has been Leah's **"primary mode of communication"**. This mode of communication has been documented to provide Leah access to communication at home, at school and in the community. In order to maintain access to Augmentative Communication through Assistive Technology Leah will need ongoing evaluation, therapy and training. Failure to provide access to therapists who are qualified, trained and experienced in the areas of augmentative communication and assistive technology will create

barriers to Leah's primary mode of communication. We request assistance to maintain therapy, equipment, supports and services that Leah needs to have access her primary mode of communication.

3) Personal Care Assistant (PCA) and Respite Services - Currently Leah receives forty (40) hours per week PCA services. We have been advised verbally that when Leah turns age twenty-one PCA hours will be reduced from 40 to 28 hours per week. We have been provided copies of a respite packet; a new policy with regard to respite providers as employees of the local board; the process to request an exception to achieve additional respite hours. We as a family and our potential respite providers are experiencing barriers to the process. These barriers do not appear to originate at the local board level. We request assistance from DDSN. Barriers appear to exist that inhibit the qualification process for the three exception categories that allow additional respite hours. Barriers also exist for the potential respite provider attempting to qualify as a respite provider.

4) Medicaid Plan Choices for Consumers on the MRRD Waiver - Leah is on the MRRD Waiver. We had been previously advised that Leah must remain on regular, fee-for-service Medicaid since she is on a waiver. Leah's annual review/anniversary date is September 1st. Healthy Connections Choices provided us a list of available Medicaid plan choices in our county. In addition to fee-for-service Medicaid there are five (5) choices for plans in our county. Yet, when we contacted fee-for-service Medicaid, we were advised that if our daughter was on the MRRD Waiver she had only one plan choice. We have received a copy of a 7/16/2010 Medicaid Bulletin. The bulletin seeks approval to expand Healthy Connections Choices effective October 1st. From the bulletin it appears that the changes require all Medicaid recipients, including fee-for-service Medicaid, to choose a Managed Care Organization or Medical Home Network Plan. Please confirm the plan options available to MRRD Waiver consumers in Pickens County. Is only one(1) out of the five (5) plan options available in Pickens County available to MRRD Waiver consumers? If this is the case, why do MRRD Waiver Consumers have only one plan choice? We are concerned that if an MRRD Waiver consumer, as an individual, is required to choose a plan, or a plan will be chosen for the consumer, but the consumer has only one plan choice, there is no choice. If the changes are effective October 1, 2010, will MRRD Waiver consumers be required to choose a plan or a plan will be chosen for them? Leah's anniversary date is September 1st...one month prior to the projected October 1, 2010 implementation date. If the changes are approved, since Leah's anniversary date occurs one month prior to the October 1st implementation date, may Leah remain on fee-for-service Medicaid until her next year's September 1st, 2011 anniversary date? We would like to request that DHHS delay submitting a request for expanding the Healthy Choices Program to provide consumers the opportunity to be involved and informed of potential changes.

We have been preparing for Leah's transition into adulthood since she was sixteen years old. Because of her disabilities, we must be both parents and legal guardians to Leah. We have arranged our lives in such a way that Leah can live with us in her own home as independent as her disabilities will allow. We approach the spending of Medicaid dollars as if we are spending our own funds by requesting only the services that Leah needs. With our family's approach to disability, we have the pleasure of Leah living with us and we have pride in saving the State of South Carolina thousands of dollars every year. It is our responsibility as parents and legal guardians to pursue the appropriate medical and community services that allow Leah to continue to live in her own home. We are seeking appropriate community based adult services and treatments. We request appropriate services recommended by Leah's medical professionals to address the risk of Leah being institutionalized. The U.S. Supreme Court in **Olmstead vs. LC** provides that care in the community can be flexible in order to remove barriers to full participation in the community. **Olmstead vs. LC** provides that state programs consider institutional bias and restrictions that act as barriers to services. We are requesting assistance in addressing barriers to medical and community based services. On a May 20, 2010, Cindy Mann, Director, Centers for Medicare & Medicaid Services (CMS), sent correspondence to State Medicaid Directors titled **"Community Living Initiative"**. CMS reaffirmed its commitment to policies identified in the **Olmstead Letters"**. According to Director Mann, CMS is offering tools and information to assist states in making greater strides in achieving the promise of the American with Disabilities Act (ADA) and Olmstead. We are requesting the promise of ADA and Olmstead on behalf of our daughter in the State of South Carolina.

We would sincerely appreciate a response from DDSN and DHHS within the next ten (10) calendar days in order that Leah continue to receive appropriate medical and community supports. We want to thank DDSN and DHHS in advance for your continued involvement.

Sincerely,

Susan and Alan Lait
Parents and Legal Guardians of Leah Elaine Lait
308 Turkey Run
Pickens, SC 29671

DEPARTMENT OF HEALTH AND HUMAN SERVICES
OFFICE OF DIRECTOR

ACTION REFERRAL

TO <i>Myers/Waldrep</i>	DATE <i>7-22-10</i>
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DIRECTOR'S USE ONLY	ACTION REQUESTED
1. LOG NUMBER <i>101038</i>	<input type="checkbox"/> I Prepare reply for the Director's signature DATE DUE _____
2. DATE SIGNED BY DIRECTOR <i>Cleared 8/18/10, letter attached.</i>	<input checked="" type="checkbox"/> Prepare reply for appropriate signature DATE DUE <i>8-2-10</i>
	<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.			

From: Jan Polatty
To: Brenda James
Date: 7/22/2010 11:52 AM
Subject: Fwd: Fw: Formal Complaint/Concerns
Attachments: Formal Complaint/Concerns

Please log to Felicity/Sam....thanks, Jan.

>>> Emma Forkner 7/22/2010 5:35 AM >>>
This will need to be logged.

RECEIVED

JUL 22 2010

Department of Health & Human Services
OFFICE OF THE DIRECTOR

Brenda James - Formal Complaint/Concerns

From: "Alan and Susan Lait" <asiscusa@directv.net>
To: "Emma Forkner" <FORKNER@scdhhs.gov>, "Buscemi, Beverly" <BBuscemi@ddsn.s...
Date: 7/21/2010 10:30 PM
Subject: Formal Complaint/Concerns
CC: "Alan and Susan Lait" <asiscusa@directv.net>, "Sharon Steed" <Sharon.Ste...>

Date: July 21, 2010

To: Dr. Beverly Buscemi, Executive Director Department of Disabilities & Special Needs
Ms. Emma Forkner, Director Health & Human Services

JUL 22 2010

RECEIVED

From: Susan and Alan Lait, Parents & Legal Guardians of Leah Elaine Lait
308 Turkey Run
Pickens, SC 29671

Department of Health & Human Services
OFFICE OF THE DIRECTOR

REF: Leah Elaine Lait - Complaint/Concerns: 1) Request for Early Resolution; 2) Request to be advised of Transition Changes from Children's to Adult Services in Writing; 3) Request to be Advised of Appeal Process, Due Process and Legal Services Options in Writing; 4) Request for response within ten (10) calendar days.

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3) Personal Care Assistant (PCA) and Respite Services - Currently Leah receives forty (40) hours per week PCA services. We have been advised verbally that when Leah turns age twenty-one PCA hours will be reduced from 40 to 28 hours per week. We have been provided copies of a respite packet; a new policy with regard to respite providers as employees of the local board; the process to request an exception to achieve additional respite hours. We as a family and our potential respite providers are experiencing barriers to the process. These barriers do not appear to originate at the local board level. We request assistance from DDSN. Barriers appear to exist that inhibit the qualification process for the three exception categories that allow additional respite hours. Barriers also exist for the potential respite provider attempting to qualify as a respite provider.

4) Medicaid Plan Choices for Consumers on the MR/RD Waiver - Leah is on the MR/RD Waiver. We had been previously advised that Leah must remain on regular, fee-for-service Medicaid since she is on a waiver. Leah's annual review/anniversary date is September 1st. Healthy Connections Choices provided us a list of available Medicaid plan choices in our county. In addition to fee-for-service Medicaid there are five (5) choices for plans in our county. Yet, when we contacted fee-for service Medicaid, we were advised that if our daughter was on the MR/RD Waiver she had only one plan choice. We have received a copy of a 7/16/2010 Medicaid Bulletin. The bulletin seeks approval to expand Healthy Connections Choices effective October 1st. From the bulletin it appears that the changes require all Medicaid recipients, including fee-for-service Medicaid, to choose a Managed Care Organization or Medical Home Network Plan. Please confirm the plan options available to MR/RD

Waiver consumers in Pickens County. Is only one (1) out of the five (5) plan options available in Pickens County available to MR/RD Waiver consumers? If this is the case, why do MR/RD Waiver Consumers have only one plan choice? We are concerned that if an MR/RD Waiver consumer, as an individual, is required to choose a plan, or a plan will be chosen for the consumer, but the consumer has only one plan choice, there is no choice. If the changes are effective October 1, 2010, will MR/RD Waiver consumers be required to choose a plan or a plan will be chosen for them? Leah's anniversary date is September 1st....one month prior to the projected October 1, 2010 implementation date. If the changes are approved, since Leah's anniversary date occurs one month prior to the October 1st implementation date, may Leah remain on fee-for-service Medicaid until her next year's September 1st, 2011 anniversary date? We would like to request that DHHS delay submitting a request for expanding the Healthy Choices Program to provide consumers the opportunity to be involved and informed of potential changes.

We have been preparing for Leah's transition into adulthood since she was sixteen years old. Because of her disabilities, we must be both parents and legal guardians to Leah. We have arranged our lives in such a way that Leah can live with us in her own home as independent as her disabilities will allow. We approach the spending of Medicaid dollars as if we are spending our own funds by requesting only the services that Leah needs. With our family's approach to disability, we have the pleasure of Leah living with us and we have pride in saving the State of South Carolina thousands of dollars every year. It is our responsibility as parents and legal guardians to pursue the appropriate medical and community services that allow Leah to continue to live in her own home. We are seeking appropriate community based adult services and treatments. We request appropriate services recommended by Leah's medical professionals to address the risk of Leah being institutionalized. The U.S. Supreme Court in **Olmstead vs. LC** provides that care in the community can be flexible in order to remove barriers to full participation in the community. **Olmstead vs. LC** provides that state programs consider institutional bias and restrictions that act as barriers to services. We are requesting assistance in addressing barriers to medical and community based services. On a May 20, 2010, Cindy Mann, Director, Centers for Medicare & Medicaid Services (CMS), sent correspondence to State Medicaid Directors titled "**Community Living Initiative**". CMS reaffirmed its commitment to policies identified in the **Olmstead Letters**". According to Director Mann, CMS is offering tools and information to assist states in making greater strides in achieving the promise of the American with Disabilities Act (ADA) and Olmstead. We are requesting the promise of ADA and Olmstead on behalf of our daughter in the State of South Carolina.

We would sincerely appreciate a response from DDSN and DHHS within the next ten (10) calendar days in order that Leah continue to receive appropriate medical and community supports. We want to thank DDSN and DHHS in advance for your continued involvement.

Sincerely,

Susan and Alan Lait
Parents and Legal Guardians of Leah Elaine Lait
308 Turkey Run
Pickens, SC 29671

DEPARTMENT OF HEALTH AND HUMAN SERVICES
OFFICE OF DIRECTOR

*Year copy
myrus*

ACTION REFERRAL

TO <i>Myers/Waldrep</i>	DATE <i>7-22-10</i>
----------------------------	------------------------

DIRECTOR'S USE ONLY	ACTION REQUESTED
1. LOG NUMBER <i>1011038</i>	<input type="checkbox"/> Prepare reply for the Director's signature DATE DUE _____
2. DATE SIGNED BY DIRECTOR _____	<input checked="" type="checkbox"/> Prepare reply for appropriate signature DATE DUE <i>8-2-10</i>
	<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.			

From: Jan Polatty
To: Brenda James
Date: 7/22/2010 11:52 AM
Subject: Fwd: Formal Complaint/Concerns
Attachments: Formal Complaint/Concerns

Please log to Felicity/Sam....thanks, Jan.

>>> Emma Forkner 7/22/2010 5:35 AM >>>
This will need to be logged.

RECEIVED

JUL 22 2010

Department of Health & Human Services
OFFICE OF THE DIRECTOR

Brenda James - Formal Complaint/Concerns

From: "Alan and Susan Lait" <aslscusa@directv.net>
To: "Emma Forkner" <FORKNER@scdhhs.gov>, "Buscemi, Beverly" <BBuscemi@ddsn.s...
Date: 7/21/2010 10:30 PM
Subject: Formal Complaint/Concerns
CC: "Alan and Susan Lait" <aslscusa@directv.net>, "Sharon Steed" <Sharon.Ste...

Date: July 21, 2010

To: Dr. Beverly Buscemi, Executive Director Department of Disabilities & Special Needs
Ms. Emma Forkner, Director Health & Human Services

JUL 22 2010

From: Susan and Alan Lait, Parents & Legal Guardians of Leah Elaine Lait
308 Turkey Run
Pickens, SC 29671

RECEIVED
Department of Health & Human Services
OFFICE OF THE DIRECTOR

REF: Leah Elaine Lait - Complaint/Concerns: 1) Request for Early Resolution; 2) Request to be advised of Transition Changes from Children's to Adult Services in Writing; 3) Request to be Advised of Appeal Process, Due Process and Legal Services Options in Writing; 4) Request for response within ten (10) calendar days.

We enjoy the opportunity of our daughter, Leah, living at home with us and saving the State of South Carolina thousands of dollars each year. Our daughter will turn age twenty-one (21) in approximately six weeks. It is our understanding that on her 21st birthday, Leah's services will transition from children's to adult services. We are concerned that this transition may create barriers to medical and community based services.

Leah currently receives services through the Mental Retardation and Related Disabilities (MR/RD) Division of the South Carolina Department of Disabilities and Special Needs (SCDDSN). SCDDSN is the state agency created to oversee services for South Carolina citizens with disabilities and special needs. Leah currently receives Medicaid through standard, fee-for-service Medicaid. In South Carolina, the State Medicaid Office is called the South Carolina Department of Health and Human Services (SCDHHS). Leah receives enhanced community based services through a Medicaid Waiver Plan called the MR/RD Waiver. The MR/RD Waiver provides Leah access to enhanced services which allow her to live at home, involved in her own community. The Anderson Disability and Special Needs Board (ADSNB), a local independent board, provides individual service coordination. Claims in reference to medical and community based services are processed through the SCDHHS (State Medicaid Office).

We are unsure where SCDDSN's responsibilities leave off and the SCDHHS's responsibilities begin. Therefore, we are sending requests to the directors of DDSN and DHHS. We would like to request DDSN and DHHS assist in Leah's transition from children's services to adult services. We request DDSN and DHHS to assist in collaborating early resolution to our concerns. If necessary, we request DDSN and DHHS to provide us information to access due process and/or formal resolution that may be available to us. We request to be advised in writing, in advance, of any changes in Leah's services. We request to be advised in writing of due process rights, responsibilities, legal service options and other state and/or federal agencies that may be requested to be involved in the formal resolution process. Should there be a need to submit an appeal, we request that Leah's services be continued during the appeals process. Please advise if DDSN or DHHS has professional staff assigned to issues concerning compliance with the American with Disabilities Act (ADA), Civil Rights or Olmstead.

In the past, we have enjoyed a supportive relationship with our local board, DDSN and DHHS. We hope to have similar support as we transition to adult services and address barriers to medical and community based services.

Our current areas of complaint/concern are as follows:

1) Medicaid and MR/RD Waiver as applied to Therapy - We have been advised that Leah is currently receiving Speech, Occupational and Physical Therapy Services through a Children's Services provision of Medicaid. We are concerned that Leah's current therapy services will be eliminated when she turns age twenty-one. Therapy services were previously included in the MR/RD Waiver as an adult service. On July 20, 2009, the DDSN Commission approved a renewal/amendment option that would amend the MR/RD Waiver. One of the services addressed was therapy. **DDSN Commissioners, consumers and providers were advised in a written summary document that therapy was to be eliminated from the waiver since therapy services were covered under regular Medicaid.** The summary document did not appear to be specific. The summary document did not establish a difference between children's therapy services, adult therapy services or define specific programs that might be effected. DDSN staff and DHHS staff assured consumers and providers that therapy could be eliminated from the waiver because therapy services were covered under regular Medicaid. The change of eliminating therapy as a waiver service was initiated with no specific information or documentation provided to consumers.

Four (4) months later, the Director of DHHS released written notice that the federal office of the Center for Medicaid Services (CMS) had approved the requested MR/RD Waiver changes including the elimination of therapy services. Following this notification, DHHS released a chart dated November 2009 in reference to therapy. This chart does not appear to represent similar levels of therapy that were previously provided for "adults" under the MR/RD Waiver. On January 1, 2010, the above mentioned changes in reference to therapy went into effect. Therapy was eliminated as a MR/RD Waiver Service effective January 1, 2010.

Leah continues to make documented progress with therapy. Leah's medical professionals have provided written recommendations that she continue to access speech, physical and occupational therapy. We are concerned as to barriers effecting "medically necessary" therapy recommended by physicians. We find the November 2009 Therapy Summary Chart difficult to understand, is there a provision that will continue Leah's current therapy model as an adult? Please investigate and advise.

2) Primary Mode of Communication - Assistive Technology Access Through Therapy Access - Leah's primary mode of communication is Augmentative Communication with Assistive Technology (AT). For seventeen years, since the age of three, this has been Leah's "primary mode of communication". This mode of communication has been documented to provide Leah access to communication at home, at school and in the community. In order to maintain access to Augmentative Communication through Assistive Technology Leah will need ongoing evaluation, therapy and training. Failure to provide access to therapists who are qualified, trained and experienced in the areas of augmentative communication and assistive technology will create barriers to Leah's primary mode of communication. We request assistance to maintain therapy, equipment, supports and services that Leah needs to have access her primary mode of communication.

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4) Medicaid Plan Choices for Consumers on the MR/RD Waiver - Leah is on the MR/RD Waiver. We had been previously advised that Leah must remain on regular, fee-for-service Medicaid since she is on a waiver. Leah's annual review/anniversary date is September 1st. Healthy Connections Choices provided us a list of available Medicaid plan choices in our county. In addition to fee-for-service Medicaid there are five (5) choices in our county. Yet, when we contacted fee-for service Medicaid, we were advised that if our daughter on the MR/RD Waiver she had only one plan choice. We have received a copy of a 7/16/2010 Medicaid F. The bulletin seeks approval to expand all Medicaid recipients, including fee-for-service Medicaid, to choose Managed Care Organization or Medical Home Network Plan. Please confirm the plan options avail-

Waiver consumers in Pickens County. Is only **one (1)** out of the five (5) plan options available in Pickens County available to MR/RD Waiver consumers? If this is the case, why do MR/RD Waiver Consumers have only **one** plan choice? We are concerned that if an MR/RD Waiver consumer, as an individual, is required to choose a plan, or a plan will be chosen for the consumer, but the consumer has only one plan choice, there is no choice. If the changes are effective October 1, 2010, will MR/RD Waiver consumers be required to choose a plan or a plan will be chosen for them? Leah's anniversary date is September 1st....one month prior to the projected October 1, 2010 implementation date. If the changes are approved, since Leah's anniversary date occurs one month prior to the October 1st implementation date, may Leah remain on fee-for-service Medicaid until her next year's September 1st, 2011 anniversary date? We would like to request that DHHS delay submitting a request for expanding the Healthy Choices Program to provide consumers the opportunity to be involved and informed of potential changes.

We have been preparing for Leah's transition into adulthood since she was sixteen years old. Because of her disabilities, we must be both parents and legal guardians to Leah. We have arranged our lives in such a way that Leah can live with us in her own home as independent as her disabilities will allow. We approach the spending of Medicaid dollars as if we are spending our own funds by requesting only the services that Leah needs. With our family's approach to disability, we have the pleasure of Leah living with us and we have pride in saving the State of South Carolina thousands of dollars every year. It is our responsibility as parents and legal guardians to pursue the appropriate medical and community services that allow Leah to continue to live in her own home. We are seeking appropriate community based adult services and treatments. We request appropriate services recommended by Leah's medical professionals to address the risk of Leah being institutionalized. The U.S. Supreme Court in **Olmstead vs. LC** provides that care in the community can be flexible in order to remove barriers to full participation in the community. **Olmstead vs. LC** provides that state programs consider institutional bias and restrictions that act as barriers to services. We are requesting assistance in addressing barriers to medical and community based services. On a May 20, 2010, Cindy Mann, Director, Centers for Medicare & Medicaid Services (CMS), sent correspondence to State Medicaid Directors titled **"Community Living Initiative"**. CMS reaffirmed its commitment to policies identified in the **Olmstead Letters"**. According to Director Mann, CMS is offering tools and information to assist states in making greater strides in achieving the promise of the American with Disabilities Act (ADA) and Olmstead. We are requesting the promise of ADA and Olmstead on behalf of our daughter in the State of South Carolina.

We would sincerely appreciate a response from DDSN and DHHS within the next ten (10) calendar days in order that Leah continue to receive appropriate medical and community supports. We want to thank DDSN and DHHS in advance for your continued involvement.

Sincerely,

Susan and Alan Lait
Parents and Legal Guardians of Leah Elaine Lait
308 Turkey Run
Pickens, SC 29671



Log # 00038
✓

State of South Carolina
Department of Health and Human Services

Mark Sanford
Governor

July 29, 2010

Emma Forkner
Director

Mr. & Mrs. Alan Lait
308 Turkey Run
Pickens, South Carolina 29671

Re: Leah Lait

Dear Mr. & Mrs. Lait:


The South Carolina Department of Health and Human Services (SCDHHS) received your recent email on July 22, 2010, regarding your daughter. We appreciate your efforts to anticipate issues that may accompany Leah as she becomes a young lady and transitions into adulthood. Although you may find the South Carolina Medicaid program offers more extensive services to those under the age of twenty-one (21), there are service options available for the adult population.

Additionally, we understand your daughter is fortunate to participate in the Mental Retardation/Related Disabilities Waiver. This waiver affords her many additional services and supports, based on South Carolina Department of Disabilities and Special Needs (SCDDSN) assessed need and within approved waiver limits, that are not available to the general Medicaid population.

My staff has contacted SCDDSN about Leah's situation. We were told by SCDDSN that your Service Coordinator, Amy Zhu from the Anderson Disabilities Board, is very capable and that she will be contacting you soon to discuss planning related to Leah's transition and your options.

We appreciate your efforts to obtain information on behalf of your daughter.

Sincerely,


Emma Forkner,
Director

EF/mwhj
cc. Dr. Buscemi, SCDDSN

Log #88



State of South Carolina
Department of Health and Human Services

Mark Sanford
Governor

Emma Forkner
Director

August 31, 2010

Alan and Susan Lait
308 Turkey Run
Pickens, South Carolina 29671

Dear Mr. and Mrs. Lait:

This is in response to your August 25, 2010 email to me regarding changes in your daughter's services as she turns twenty-one. As you are aware, the South Carolina Department of Health and Human Services (DHHS) is the single state agency responsible for the administration of the State Medical Assistance Plan (Medicaid). As such DHHS is responsible for policy development, provider qualification, recipient eligibility and claims processing. DHHS contracts with qualified providers, including other agencies and non-profit entities, to provide State Plan and Waiver services to eligible recipients and participants. The South Carolina Department of Disabilities and Special Needs(DDSN), by state law, coordinates services and programs with other state and local agencies for persons with mental retardation, related disabilities, head injuries, and spinal cord injuries. In this capacity, DDSN operates as both a provider of Medicaid services and as coordinator of Medicaid services rendered by other providers. All providers, directly or through subcontractors, are responsible for the delivery of services or items to recipients and participants in accordance with the policies established by DHHS.

As you may know, Waivers are intended to allow the State an opportunity to cover some services that otherwise might not be available. Waiver services are designed to supplement services available through other means, including support provided by the family. In the course of obtaining a Waiver, DHHS provides its planned policies to the Centers for Medicare and Medicaid Services (CMS) and CMS suggests changes or approves them as written. CMS approved the policies submitted with the MR/RD Waiver.

Alan and Susan Lait
August 31, 2010
Page 2

We regret that you find yourselves adversely affected by the State's transition to a more limited MR/RD Waiver and by the event of your daughter's 21st birthday. We would like to advise you that physical, occupational and speech therapy services are available to adults outside the MR/RD Waiver with limitations described at pages 177 & 178 of the Physicians Services Manual, accessible on the DHHS website at <http://www.scdhhs.gov/ResourceLibrary/manuals.asp>. The relevant pages are enclosed for your convenience.

Personal-care-type services, as you know, are limited to 28 hours per week. Up to 68 hours of Respite care is allowed per month based on the DDSN assessment of your family's situation. Additional Respite hours, up to 240 per month, may be authorized according to the following three (3) special needs circumstances:

1. The caregiver's hospitalization or need for medical treatments (necessitating absence from the participant);
2. The participant's need for constant hands-on/direct care and supervision due to a medically complex condition or severity/degree of disability; and
3. Seasonal relief for those over 12 who attend public school and whose parents work full time and care is needed during summer break from school.

The Respite criteria are contained in the approved Waiver document. All of our policies, Waiver and regular Medicaid, are designed and adopted to allow DHHS to provide the most appropriate and effective care for the Medicaid population in the state. Sometimes the application of these policies may not allow a recipient/participant to receive all the care they want in exactly the manner they desire. However, we believe that there are Waiver services and regular Medicaid services available that adequately and reasonably meet the needs of the Medicaid population. It is unfortunate that the combination of a more limited MR/RD Waiver and your daughter reaching age 21 have resulted in changes to her services from what she has been receiving as a child. We believe that your Service Coordinator is in the best position to determine which of the many services available to your daughter will provide her the best and most reasonable care within the policies established for the program.

We understand that your concerns about the State's transition to managed care, for most recipients, have been satisfactorily resolved during your conversations with Jennifer Campbell of the DHHS staff.

Alan and Susan Lait
August 31, 2010
Page 3

We cannot grant an exception to the established policies set forth above. Furthermore, we must decline to comply with your five (5) requests for the DHHS to directly intervene in your Service Plan by allowing the Service Coordinator to approve services outside the established policies.

Sincerely,

A handwritten signature in cursive script, appearing to read "Emma Forkner".

Emma Forkner
Director

EF/srb

Enclosure

DEPARTMENT OF HEALTH AND HUMAN SERVICES
OFFICE OF DIRECTOR

ACTION REFERRAL

TO <i>Myers</i>	DATE <i>8-2-10</i>
--------------------	-----------------------

DIRECTOR'S USE ONLY	ACTION REQUESTED
1. LOG NUMBER <i>1011052</i>	<input type="checkbox"/> Prepare reply for the Director's signature DATE DUE _____
2. DATE SIGNED BY DIRECTOR <i>cc: Ms. Forkner Ref: Log #45 + 38</i>	<input checked="" type="checkbox"/> Prepare reply for appropriate signature DATE DUE <i>8-11-10</i>
	<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.			

*Pls log
FCM
c: legal/emma*

From: Emma Forkner
To: Felicity Myers; George Maky; Sam waldrep
CC: Jan Polatty
Date: 8/2/2010 12:57 PM
Subject: Fwd: Third Request - 1) Request for Information; 2) Barriers to Obtaining Information;
3) Barriers to Due Process

fyi from Ms. Lait. Jan, please log.

Felicity, Sam and George, I am certainly open to your recommendations on responding.

Emma

Emma Forkner
Director
Department of Health and Human Services
1801 Main Street
Columbia, South Carolina 29201
(803) 898-2504
(803) 255-8338 fax

>>> "Alan and Susan Lait" <asiscusa@directv.net> 8/1/2010 11:30 AM >>>

August 1, 2010

Emma Forkner, Director
State of South Carolina
Department of Health and Human Services
Post Office Box 8206
Columbia, SC 29202-8206
(803)898-2504
Fax: (803)255-8235
FORKNER@scdhhs.gov

Alan & Susan Lait
Parents/Legal Co-guardians
308 Turkey Run
Pickens, SC 29671
(864)878-4567

REF: Leah Lait - 1) Third Request for Information; 2) Barriers To Obtaining Information; 3) Barriers to Due Process

Dear Ms. Forkner:

On 7/29/2010 you sent us the attached letter. Your letter did not provide responses to our questions or address our concerns. Should we assume that you are unable or unwilling to provide information? Are you expressing there is a state policy that prohibits communication with the general public or specific citizens? Or do you simply need more information from us? Based on our daughter's disabilities, it was

necessary that we become her legal co-guardians prior to the age of eighteen. A copy of our daughter's guardianship order is on file, but we would be happy to send you a personal copy.

Under the **Social Security Act**, as a result of disabilities since birth, on her eighteenth birthday, our daughter became eligible as a client for a federal program called **Social Security Income (SSI)**. As a result of being a client of SSI, she became eligible for regular, fee for service **Medicaid**. She also became eligible for **Medicaid Waiver Programs** that provide **Home Based Community Services (HBCS)** to people that would otherwise be institutionalized. Our daughter is a client on an HBCS Program called the **MR/RD Waiver Program**. Were you aware that with the assistance of HBCS Programs, families like ours save the State of South Carolina and our local communities dollars by allowing people with disabilities to live at home with their families?

This month our daughter will transition from **children's to adult services**. Our daughter will experience losses in services as a result of **1) turning age twenty-one, 2) changes in regular, fee for service Medicaid, 3) new Medicaid Plan options and 4) reductions and eliminations of services in the MR/RD Waiver Program**. In two previous requests, we have asked to be made aware of changes and to have the opportunity to plan for changes. You have denied us access to information and therefore, the ability to plan for our daughter's transition to adult services.

Our daughter receives local service coordination with an independent, organization called the **Anderson Disabilities and Special Needs Board (ADSNB)**. You have referred us to ADSNB for information. We noticed that in your 7/29/2010 letter you were not aware of the correct name of our local board. Staff at the ADSNB does not work for your office (State Medicaid office). The ADSNB is operated by an independent board of directors and calls themselves a local board. We know it's confusing. What you need to know is that our local board is unable to answer our questions in reference to Medicaid. The ADSNB referred us to your office.

We also made contact with another state agency before contacting you. Federal Medicaid dollars are directed from your office to a state agency that is both a "state agency" and a "provider" of services called the **South Carolina Department of Disabilities and Special Needs (SCDDSN)**. You mentioned SCDDSN in your 7/29/2010 letter. Beverly Buscemi, Director, SCDDS, Columbia, SC also referred us to the ADSNB. I regret to inform you that whomever you spoke to at SCDDSN misinformed you if you were informed that the local board (ADSNB) was able to answer our questions in reference to Medicaid.

We have made other attempts to obtain information before contacting you. We contacted **Medicaid Enrollment Counselors with South Carolina Healthy Connection Choices**. The counselors referred us to South Carolina Medicaid (your office) for information. We contacted the **South Carolina Medicaid Research Center**. We have also attempted to obtain information from the SCDHHS, SCDDSN and the SC Choices Web Pages.

We continue to experienced barriers in obtaining information that extend to your office and the office of the State Director of SCDDSN. We noticed that even your department stationary creates a barrier. Your stationary does not have contact information such as an address, telephone number, fax number or e-mail address to contact you. We obtained information to contact you from a private source.

As private citizens, we are not aware of nor are we obligated to your interagency chain-of-command. Even so, we have extended great effort and time to work through barriers progressing from our local board (ADSNB) to SCDDSN to your office. We have been persistent and patient. We are beginning the final weeks of our daughter's transition into adult services. We are facing **two (2) deadlines**. The **first** deadline is the actual date of our daughter's birthday when she transitions into adult services. The **second** deadline is her **Medicaid Anniversary Date** (yearly review) which we understand is the date by which a choice **must** be made with regard to a Medicaid Health Plan. There is also a third deadline which occurs following the above mentioned deadlines. This deadline is a Medicaid policy change that goes into effect **October 1st by which Medicaid recipients must choose a plan or one will be chosen for them**.

We are obligated as our daughter's legal co-guardians to pursue her government benefits, programs and services. We are concerned that by creating barriers to obtaining information, you are also creating barriers to due process. Please consider this correspondence a third request for assistance. Please refer to both our original 7/22/2010 e-mail and this correspondence. We request you provide us information directly rather than through a third party. Please do feel free to copy the ADSNB information you send us.

Please advise if we can be of assistance.

Sincerely,

Alan & Susan Lait for
Leah Elaine Lait

Note: Sent by electronic e-mail, electronic fax; U.S. Mail

Attach: 7/29/2010 Letter from Emma Forkner, Director, SCDHHS

Cc: Beverly Buscemi, Director, SCDDSN
Dale Thompson, Executive Director, ADSNB
Amy Zhu, Case Coordinator, ADSNB

The message is ready to be sent with the following file or link attachments:
Forkner7-26-2010LCscan0001.tif

Note: To protect against computer viruses, e-mail programs may prevent sending or receiving certain types of file attachments. Check your e-mail security settings to determine how attachments are handled.

DEPARTMENT OF HEALTH AND HUMAN SERVICES
OFFICE OF DIRECTOR

ACTION REFERRAL

TO <i>Myers</i>	DATE <i>7-28-10</i>
--------------------	------------------------

DIRECTOR'S USE ONLY	ACTION REQUESTED
1. LOG NUMBER <i>1011045</i>	<input type="checkbox"/> Prepare reply for the Director's signature DATE DUE _____
2. DATE SIGNED BY DIRECTOR <i>cc: Ms. Farther</i> <i>* Ref log #0038</i>	<input type="checkbox"/> Prepare reply for appropriate signature DATE DUE _____ <input type="checkbox"/> FOIA DATE DUE _____ <input checked="" 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.			

Beverly A. H. Buscemi, Ph.D.
State Director
David A. Goodell
Associate State Director
Operations
Kathi K. Lacy, Ph.D.
Associate State Director
Policy



3440 Harden Street Ext (29203)

P.O. Box 4706, Columbia, South Carolina 29240

V/TTY: 803/898-9600

Toll Free: 888/DSN-INFO

Website: www.ddsn.sc.gov

RECEIVED

JUL 28 2010

Department of Health & Human Services
OFFICE OF THE DIRECTOR

COMMISSION
Kelly Hanson Floyd
Chairman
Richard C. Huntress
Vice Chairman
Oris D. Speight, MD, MBA, CPE
Secretary
W. Robert Harrell
Nancy L. Barrow, M.Ed.
Deborah C. McPherson

Mr. and Mrs. Alan Lait
308 Turkey Run
Pickens, SC 29671

RE: Leah Lait

Dear Mr. and Mrs. Lait:

I am writing in response to your July 21, 2010 correspondence concerning your daughter Leah. As you indicated, Leah will soon be 21 years old. As with all Medicaid recipients, the transition from children's services to adult services can be challenging. Your Service Coordinator, Amy Zhu and the staff of Anderson County DSN Board have a great deal of experience and expertise in assisting families with this transition. I am confident that Ms. Zhu will be able to assist you with Leah's transition. In the event she has any questions regarding this process, the staff of South Carolina Department of Disabilities and Special Needs (SCDDSN) is available to assist Ms. Zhu and the Anderson DSN Board as needed.

As requested, I am enclosing the SCDDSN Reconsideration and South Carolina Department of Health and Human Services (SCDHHS) Medicaid Appeals Process. This document explains the process to be used by MR/RD Waiver participants to request reconsideration or appeal of adverse decision affecting MR/RD Waiver Services. It is our understanding that appeals of adverse decisions affecting Medicaid State Plan Services are to be made directly to the SCDHHS Division of Appeals and Hearings.

Regarding therapy services, as indicated on the "Therapy Summary Chart" you mentioned, Occupational, Speech and Physical Therapy Services are available to adult Medicaid recipients. Those services may be accessed as part of the Medicaid covered services of Home Health Services, Physician Services or Hospital Services. In all cases, these services must be prior authorized/ordered by a physician and typically are arranged by the physician or through his/her office.

The MR/RD Waiver covers Specialized Medicaid Equipment Supplies, and Assistive Technology which by definition includes devices, controls or appliances, specified in the Support Plan, which enable participants to increase their abilities to perform activities of daily living or to perceive, control or communicate with the environment in which they live. Therefore, should the need for an augmentative communication device be established, it could be covered through the waiver.

It is not clear from your letter what barriers are inhibiting the qualification process for Respite. However, we will be happy to work with Anderson DSN Board staff to clarify any policies that may be unclear in hopes of eliminating barriers to Leah receiving necessary Respite.

DISTRICT I

P.O. Box 239
Clinton, SC 29325-5328
Phone: (864) 938-3497

Midlands Center - Phone: 803/935-7500
Whitton Center - Phone: 864/833-2733

DISTRICT II

9995 Miles Jamison Road
Summerville, SC 29485
Phone: 843/832-5576

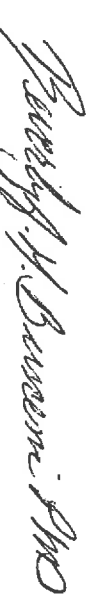
Coastal Center - Phone: 843/873-5750
Pee Dee Center - Phone: 843/664-2600
Salisbury Center - Phone: 843/332-4104

Mr. and Mrs. Lait
July 26, 2010
Page 2

It is our understanding that Medicaid recipients who are enrolled in a waiver may not choose a Managed Care Organization to provide their health care services. However, they may continue to receive services through the standard as fee – for – service system or choose the one Medical Homes Network (SC Solutions).

Thank you for the opportunity to respond. I hope you find this information helpful.

Sincerely,

A handwritten signature in cursive script, appearing to read "Beverly A.H. Buscemi".

Beverly A.H. Buscemi, Ph.D.
State Director

Enclosure

C: Emma Forkner, SCDHHS
Dale Thompson, Anderson DSN Board
Amy Zhu, Anderson DSN Board
Kathi K. Lacy, Ph.D., SCDDSN
John King, District I

SCDDSN RECONSIDERATION AND SCDHHS MEDICAID APPEALS PROCESS

The SC Department of Disabilities and Special Needs (SCDDSN) is responsible for the day-to-day operations of the Mental Retardation/Related Disabilities (MR/RD) Waiver, the Pervasive Developmental Disorder (PDD), the Community Supports Waiver (CSW) and the Head and Spinal Cord Injury (HASCI) Waiver. A request for reconsideration of an adverse decision must be sent in writing to the State Director at SCDDSN, P. O. Box 4706, Columbia, SC 29240. The SCDDSN reconsideration process must be completed in its entirety before appealing to the South Carolina Department of Health and Human Services (SCDHHS).

A formal request for reconsideration must be made in writing within thirty (30) calendar days of receipt of written notification of the adverse decision. The request must state the basis of the complaint, previous efforts to resolve the complaint and the relief sought. The reconsideration request must be dated and signed by the participant, the representative or the person assisting the participant in filing the request. If necessary, staff will assist the participant in filing a written reconsideration.

Note: In order for waiver benefits/services to continue during the reconsideration/appeal process, the participant/representative's request for reconsideration must be submitted within ten (10) calendar days of the written notification of the adverse decision. If the adverse action is upheld, the participant/representative may be required to repay waiver benefits received during the reconsideration/appeal process.

The State Director or designee shall issue a written decision within ten (10) working days of receipt of the written reconsideration request and shall communicate this decision to the participant/representative. If the State Director upholds the original adverse action/decision, the reason(s) shall be specifically identified in the written decision.

If the participant/representative fully completes the above reconsideration process and is dissatisfied with the results, the participant/representative has the right to appeal to the SCDHHS. The purpose of an administrative appeal is to prove error in fact or law. The participant/representative must submit a written request to the following address no later than thirty (30) calendar days from the receipt of the SCDDSN written reconsideration decision:

Division of Appeals and Hearings
SC Department of Health and Human Services
PO Box 8206
Columbia, SC 29202-8206

The participant/representative must attach a copy of the written reconsideration notification received from the SCDDSN regarding the specific matter that is the subject of the appeal. In the appeal request, the participant/representative must clearly state with specificity, which issue(s) the participant/representative wishes to appeal.

Unless the request is made to the above address within thirty (30) calendar days of the receipt of the SCDDSN written reconsideration decision, the SCDDSN decision will be final and binding. An appeal request is considered filed at the above address if postmarked by the thirtieth (30th) calendar day following receipt of the SCDDSN written reconsideration decision. The participant/representative shall be advised by the SCDHHS Division of Appeals and Hearings as to the status of the appeal request.

DEPARTMENT OF HEALTH AND HUMAN SERVICES
OFFICE OF DIRECTOR

ACTION REFERRAL

TO	DATE
Medical Services	2-1-11

DIRECTOR'S USE ONLY	ACTION REQUESTED
1. LOG NUMBER 1011330	<input type="checkbox"/> I Prepare reply for the Director's signature DATE DUE _____
2. DATE SIGNED BY DIRECTOR	<input checked="" type="checkbox"/> Prepare reply for appropriate signature DATE DUE 2-10-11
Ref logs # 38, 52, 88 log attached cc: Mr. Feek	<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.			

“What Happens When an Ineffective System and Deficit Collide?”

By Susan Lait

In 2005 our family’s personal story appeared in the South Carolina Partnership of Disability Organizations Program for Legislative Advocacy Day. I have attached a copy because it allows you to compare opportunities we had as a state six years ago compared to where we are today. It really is a case of opportunities lost. Our daughter Leah was 15 years old in 2005. Today Leah is twenty-one years old. Leah is unable to make decisions for herself. Prior to Leah turning eighteen, my husband and I appeared before our local Probate Court, to become in addition to her parents, our daughter’s legal guardians. At the probate hearing, the Judge addressed our responsibilities as guardians reminding us to pursue Leah’s rights concerning access to disability supports and services.

The American with Disabilities Act (ADA) and a U.S. Supreme Court Ruling, *Olunstead vs. LC*, provides that Leah have access to medical and community based services that allow her to live at home in her community. During the past two years, the agencies that serve citizens with disabilities have eliminated and/or reduced services creating vulnerability and a threat of institutionalization. We realize we save the State of South Carolina money remaining intact as a family and caring for Leah at home, but our primary reason for caring for our daughter is that we love our daughter. The fiscal challenge facing South Carolina is affecting the entire country. Yet, because we are facing a fiscal challenge as a state, we are not afforded the liberty of ignoring the basic rights and needs of people with disabilities. As a parent, I network with parents across the state. We have formed organizations to speak on behalf of children and adults with disabilities. In exhausting appeal options available on the state level, we are left with the next step in formal resolution which is to contact federal agencies. It is our Southern Tradition to do things on our own and to take care of our own. Yet, as parents and guardians we are obligated to pursue the promise of the **American with Disabilities Act (ADA)** and *Olunstead vs. LC* to access medical and community based services. We ask you to reflect on the responsibility South Carolina has when it comes to our citizens with disabilities.

I am happy to provide you additional information and insight as to the challenges we face as a family. Please do feel free to contact us.

Susan Lait

Susan Lait for
Alan, Susan & Leah Lait
308 Turkey Run
Pickens, SC 29671
(864)878-4567

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Department of Health & Human Services
OFFICE OF THE DIRECTOR

PERSONAL STORIES

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JAN 31 2011

Department of Health & Human Services
OFFICE OF THE DIRECTOR



Our daughter Leah is fifteen years old. She entered our lives with the help of an emergency "C" section, weighing 2 pounds, 11 ounces. It was during those first weeks in the hospital that we were introduced to the two faces of the disability system. The hospital staff instilled in us the confidence that we could care for our baby with special needs. But we heard a different message from a social worker: we would not be able to care for our baby without the involvement of the state system.

So we completed the state eligibility process and were told that Leah was eligible for services. Then we were told that due to funding constraints, services were not available. The only service offered was to place our newborn daughter in an institution. My husband and I stared at each other, confused. Like most Americans, we had assumed that there were resources to assist families and individuals facing disability.

We are in the final years of Leah's childhood. We have watched middle income families, like us, deplete family resources and become dependent on state and federal resources. We have prayed we won't be one of the families to go into crisis and need institutional placement. In having two faces, the state is sustaining an ineffective system, adding to the number of families needing help, increasing waiting lists and leading families to eventual crisis by operating as a system that primarily responds to crisis. So as legislators, the question becomes one of do we remain a "crisis system," or do we provide funding for less expensive community alternative services?

It will be the state legislature and the governor who will eliminate the two faces of the state system, by focusing on the needs of constituents, providing effective funding for community based services, and by realizing the crisis that faces us also faces the system.

Susan Lait
Pickens County

Personal and Confidential

Department of Health & Human Services
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Susan Lait
308 Turkey Run
Pickens, SC 29671-7816

GREENVILLE SC 296
29 JAN 2011 PM 4 L



Mr. Tony Kack
Director's Office
Dept. Health & Human Services
P.O. Box 8206
Columbia SC 29202-8206

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