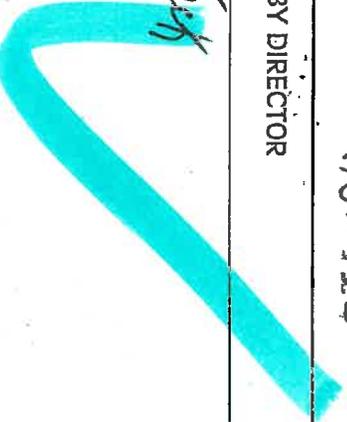


DEPARTMENT OF HEALTH AND HUMAN SERVICES
OFFICE OF DIRECTOR

ACTION REFERRAL

TO <i>Waldrop</i>	DATE <i>3-14-11</i>
----------------------	------------------------

DIRECTOR'S USE ONLY	ACTION REQUESTED
1. LOG NUMBER <i>1011411</i>	<input type="checkbox"/> Prepare reply for the Director's signature DATE DUE _____
2. DATE SIGNED BY DIRECTOR <i>Ci: Mr. Feist</i> 	<input checked="" type="checkbox"/> Prepare reply for appropriate signature DATE DUE <i>3-23-11</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.			

SOUTH CAROLINA VOICES for the Voiceless
A Statewide Grassroots Coalition of
Families & Advocates for Individuals with Disabilities & Special Needs of SC

We have enclosed a letter written to Dr. Beverly Buscemi, Executive Director of SC Department of Disabilities and Special Needs. For families and providers who are dependent on SCDDSN, there are issues that are of concern to us that we want to share with you. We are all very much aware of the challenges that these difficult financial times are presenting to all in SC. We appreciate the challenge you face in speaking to all needs but in your deliberations, there are issues involving the support that SC gives to it's most vulnerable citizens and their families that you should be addressed.

We very much appreciate your attention to our letter. We will make ourselves available should you have further questions.

RECEIVED

MAR 14 2011

Department of Health & Human Services
OFFICE OF THE DIRECTOR

Sincerely,



Carolyn C. Myers, Chairperson
SC Voices
106 Hunt Cup Lane
Camden, SC 29020-2140
803-432-0931
ccmyers@truvista.net

*P.S. Welcome to South Carolina for next week.
We need your expertise!*

South Carolina Voices for the Voiceless
106 Hunt Cup Lane
Camden, SC 29020

Beverly Buscemi, PHID
Executive Director
S.C. Department of Disabilities and Special Needs
PO Box 4706
Columbia, SC 29240

March 9, 2011

Dear Dr. Buscemi,

Approximately a year ago you invited Independent Advocacy Organizations to participate in an Advisory Group. South Carolina Voices for the Voiceless (SC Voices) is a grassroots organization with approximately 550 members. Our membership includes persons with disabilities, family members, providers, medical professionals and other interested parties. We advocate for people with disabilities living in their homes and other residential settings in the communities across SC. Our organization does not solicit or receive funding from DDSN or DHHS. Many other advocacy organizations who participate in your Advisory Group receive significant funding from DDSN. We believe receiving this funding hampers their independence and objectivity.

In the summer of 2009, had there been any established advocacy organization that had been advocating in support of families and individuals in our communities who were being threatened by cuts to the supports they depend on to keep their loved ones in their homes and community residences, SC Voices and other similar advocacy coalitions would have had no reason to organize. Families who have chosen the Home and Community Based Medicaid Waiver Option in place of institutional placement for their loved ones found themselves virtually alone in our need for understanding, help, and shared advocacy.

Families who are doing full time care taking of their loved ones are the least able to find time for advocacy but through much cooperation, mutual support and sharing of efforts, we have persisted. We were even portrayed as greedy by some when we

expressed our fears. We are not greedy! We are needy (of supports in caretaking)! If we were greedy we would have placed our children in the full time care of the State of SC. The truth is that these very families and individuals who are being cut have by their sacrifices and the loving home care saved the taxpayers of SC millions of dollars over their years of home care taking. It is common knowledge that home and community care is much less expensive than institutional care. It is also the most responsible care for those who are some of our state's most vulnerable citizens.

SC Voices now has three sister advocacy associations. They are Low Country Voices for Special Needs, A Place for Me and Voices of the Vulnerable of South Carolina/Upstate. In a February 18, 2011 letter, our three sister organizations expressed concerns and withdrew from your Advisory Group. With this letter, we wish to strongly endorse the concerns expressed in the letter by our sister organizations.

Family advocates were told by you that you hoped to have this group share ideas and solutions to the current budget crisis. You explained that our participation would help you better understand the needs of families in the communities. Family advocate's suggestions and input have had little if any impact in this group other than the assertion by one of DDSN's executive staff that our messages were negative. Family advocates suggested that furloughs, like most other state agencies have done, should be taken which was received with no comments from any. We suggested that large tracts of excess land belonging to DDSN Regional Centers, now less populated as a result of the Americans with Disabilities Act and the Supreme Court ruling *Olmstead vs. LC*, be sold. We were told that this was not an option. Later at the February 2011 DDSN Commission meeting, you announced that DDSN would be marketing this land as directed by the Budget and Control Board.

Much time in these meetings has been utilized to encourage Advisory Group members to turn out their families for Legislative Advocacy Day. When attempting to elicit a discussion about advocates helping to educate our Legislators to the fiscal benefits of the Home and Community Based Medicaid Waivers. I was told by a DDSN official, "Oh no! Don't mention the Home and Community Based Medicaid Waiver Options to Legislators. That will just confuse them! When we talk to them, we just call them "our programs". Just tell them your story on Legislative Advocacy Day and tell them how much you need "our programs". Is it to DDSN's benefit that Legislators not be educated concerning the important benefits of the Home and Community Based Medicaid Waivers to SC taxpayers? This was particularly distressing to me since over 20 years ago my husband (now deceased) and I took President Ronald Reagan's new conservative Medicaid waiver options to our legislators to help educate them to their benefits to SC families struggling with the challenge of supporting disabled children and adults and to the taxpayers. The

Legislators understood the benefits of this conservative Medicaid option, and they brought these money saving options to SC. Our severely challenged son was one of the first in the Midlands area to receive Medicaid services in his home. Perhaps knowing this will help you understand why these Waivers not being a priority with DDSN or SCDHHS and the recent weakening and dismantling of these supports is so distressing to us.

We are concerned about the civil rights of individuals with disabilities in SC. Home and community based waivers are supported by the Americans with Disabilities Act (ADA) and through the Supreme Court ruling Olmsted vs. LC. It has been our hope that DDSN and SCDHHS would more fully support the cost effective option of Home and Community Based Waivers promoted and begun by our most conservative President. We must question why fiscally conservative Home and Community Based Waivers have not been a priority.

Without proper oversight "DDSN" has free reign and control and can intimidate parents by the fear of having their services cut if they openly disagree with DDSN. Even in writing this letter there is fear among my fellow family advocates that they may suffer retaliation from DDSN if we speak of problems too openly. In sending e-mails for information to me, our members all request that if I send them on to others to please remove their identifying information. Services to our most vulnerable citizens and those who support them should not be hostage to the good graces of a few.

Family advocates support the following: (1) separating service coordination from service delivery as we believe this is a huge conflict of interest; (2) more choice of providers for Families in SC; (3) eliminating band funding; (4) direct billing to HHS by providers as is now done by the Autism Society and the CLTC (Community Long Term Care) program. Families in the CLTC program can follow their budgets by computer. Families with DDSN can't get a fix on their loved ones funding because it is delivered in a complicated banded manner, which has been eliminated in other states. We request health and safety concerns raised in the December 2008 IAC audit, and in prior audits (CMS, HHS, P&A, & DDSN) be addressed with clear transparency and accountability. DDSN says that they have been addressed but we believe the solutions have not been adequately addressed and need to be reviewed closely. We have concern in reference to the high salaries paid to DDSN executive employees and employees in the five district regional centers. We are especially concerned about recent significant raises to these same employees in a time of fiscal crisis. We are concerned that furloughs have not occurred at DDSN as have been taken in most other SC agencies.

Independent advocates pray for a mutually respectful relationship with DDSN staff,

and other DDSN funded advocacy organizations and the receptivity to collaborate on goals related to providing quality services for some of our state's most vulnerable citizens who are supported in their homes by some of our State's most responsible citizens. To date, this goal is not being accomplished through the Advisory Group. We would like to see an independent moderator or facilitator be brought in to help heal the fractures that exist in this group.

We thank you for your consideration of our concerns and experiences, and will be happy to further discuss this letter if that could prove constructive.

Sincerely,

A handwritten signature in cursive script, appearing to read 'Carolyn C. Myers'.

Carolyn Cooper Myers, Chairperson

SC Voices for the Voiceless

106 Hunt Cup Lane

Camden SC, 29020

cmymyers@truvista.net

803-432-0931



29202+8206

Director Anthony Keck,
Department of Health and Human Services
PO Box 8206
Columbia, SC 29202-8602

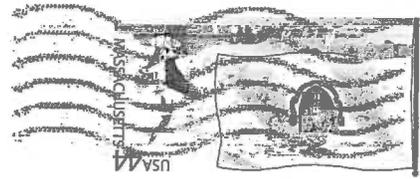
Department of Health & Human Services
OFFICE OF THE DIRECTOR

MAR 14 2011

RECEIVED

12 MAR 2011 PM 1:11

COLUMBIA SC 292



Mrs. Carolyn C. Myers
106 Hunt Cup Ln
Camden, SC 29020



197