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# ICF/MR BRANCH NEWSLETTER

NC Department of Health and Human Services  
Division of Facility Services  
Mental Health and Licensure Certification Section

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The purpose of this Newsletter is to provide information and updates on ICF/MR issues in North Carolina. We ask that you pass it on to the homes, facilities and organizations that serve your clients. Additionally if you have any questions, comments or suggestions do not hesitate to contact us at [Jay.Silva@ncmail.net](mailto:Jay.Silva@ncmail.net) or [Denise.Erwin@ncmail.net](mailto:Denise.Erwin@ncmail.net). You may also contact us by calling (919) 855-3795 and asking for an ICF/MR facility consultant or writing to:

ICF/MR Survey Team  
2718 Mail Service Center  
Raleigh, North Carolina 27699-2718

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## Comments from the Chief

Ladies and Gentlemen:

As much as I have enjoyed being the section chief of the Mental Health Licensure and Certification Section for nearly 4 years now, unfortunately, all good things must come to an end. Therefore, this will be the last newsletter in which the "Comments from the Chief" section will be coming from me. Effective December 1, 2003, I was named the section chief of the Licensure and Certification Section of DFS. With all this being said, I have thoroughly enjoyed working with all of you the past few years and appreciate your dedication and commitment in providing for some of our state's most vulnerable and challenged citizens. By the time the next newsletter comes out, a new section chief for Mental Health Licensure and Certification Section will have been chosen and I am certain the new chief will look forward to working with all of you as I have these past few years.

Jeff Horton, Chief  
DFS Mental Health Licensure and Certification  
Section.

## ICF/MR Surveys for North Carolina - Numbers for the 4<sup>th</sup> Quarter

October 1 through December 31, 2003

85 recertification surveys, 3 Follow-up surveys and 12 complaint surveys were conducted this quarter resulting in a total of 320 W tags cited. Specifically they included:

Standard Level citations:	312
Conditions cited:	
W 102 Governing Body	1
W 122 Client Protections:	3
W 195 Active Treatment:	3
W 266 Client Behavior and Facility Practices:	1
W 318 Health Care:	0

Additionally, conditions of participation resulted in 1 Immediate Jeopardy being cited and penalties being assessed as a result of a recertification survey. One Follow-Up Survey resulted in a COP being cited this quarter. Three COP's were cited due to 2 complaint surveys this quarter. The information listed does not include citations from life safety code surveys. Only those follow-ups resulting in citations are included above.

### *Most frequently cited deficiencies, 4<sup>th</sup> quarter:*

<i>TAGS</i>	<i>Total Times Cited</i>
<i>W-249</i>	<i>46</i>
<i>W-288</i>	<i>21</i>
<i>W-257</i>	<i>15</i>
<i>W-369</i>	<i>13</i>
<i>W-242</i>	<i>13</i>
<i>W-154</i>	<i>13</i>
<i>W-259</i>	<i>9</i>
<i>W-255</i>	<i>9</i>
<i>W-247</i>	<i>8</i>
<i>W153</i>	<i>8</i>

The information listed above does not include citations from life safety code surveys.

## *The following facilities had deficiency-free annual recertifications since October 2003:*

*Macon ICF/MR Group Home, Franklin, N.C. (We apologize for failing to identify this survey for June 2003.)*

*Mantle Court Group Home, Charlotte, N.C.*

*VOCA Oak Drive Group Home, Charlotte, N.C.*

*Hollingswood Group Home, Statesville, N.C.*

*Life, Inc. King Street Group Home, Halifax, N.C.*

*Life, Inc. Oakdale Home, New Bern, N.C.*

*Irene Wortham Residential Center – Azalea, Ashville, N.C.*

*Oakdale Group Home, Statesville, N.C.*

*VOCA Laurel Group Home, Charlotte, N.C.*

*Foothills ICF/MR Group Home, Granite Falls, N.C.*

*If you did receive a deficiency free annual survey (General and Life Safety) and we failed to identify your facility, please notify us at [Joseph.Milanese@ncmail.net](mailto:Joseph.Milanese@ncmail.net) and we will include it in the next edition of the newsletter.*

## **Center for Medicaid and Medicare Services (CMS) Notes**

CMS continues to update and improve its online web services. One of those services is “The CMS Quarterly Provider Update.” The “Update” is a national online source of information for Medicare Providers. The most current issue is January 2004 and covers current issues such as Medicare Prescription Drug, Improvement and Modernization Act of 2003. CMS also has an online list-server that will allow you to receive the most recent changes to both regulatory and non-regulatory issues regarding Medicare providers. For more information go to <http://cms.hhs.gov/providerupdate/>. There are additional links on this page for the listserver and email.

Specific additional information about ICF/MR programs can be found at the CMS ICF/MR Home Page: <http://cms.hhs.gov/medicaid/icfmr/default.asp>.

### **Update on “Look-Behind” Surveys:**

The Centers for Medicare & Medicaid Services (CMS) has had “look-behind” authority from the Federal government for ICF/MR facilities since the mid-1980’s. This was the result and response to reports and investigations of substandard care in the industry.

In September 2000 a contract was awarded to *The Council on Quality and Leadership in Supports for People with Disabilities* of Towson, Maryland to conduct the ICF/MR Federal Monitoring and Oversight project. The contract was for one year with additional one-year options available.

A recent report on the findings of the Federal Survey Teams (FST) has demonstrated that the “look-behind” surveys have met the mandate to identify problem areas in various State Agencies (SA). As a result CMS has accepted a recommendation to continue the “look-behind” surveys conducted by FST surveyors.

The bottom line is that North Carolina ICF/MR facilities will continue to have FST’s conducting look-behind surveys in close conjunction to routine annual recertifications by SA surveyors. The FST’s are also authorized and do conduct follow-up and complaint surveys.

For more information on the ICF/MR Federal Monitoring and Oversight project visit <http://www.cms.hhs.gov/medicaid/icfmr/icfcont.asp> online.

## Net Links:

We have identified a number of Net Links, which may be helpful to you in the care of your clients. If you know of others please let us know at [Joseph.Milanese@ncmail.net](mailto:Joseph.Milanese@ncmail.net) and we will add them for the benefit of others in the ICF/MR community. To use the list click on the link below or cut and paste it to the location (Netsite) field on your browser page.

## Federal

CMS has made major changes to their Web Pages so you may want to update your bookmarks.

Centers for Medicare & Medicaid Services <http://cms.hhs.gov/>

ICF/MR – <http://cms.hhs.gov/medicaid/icfmr/default.asp>

Medicare – <http://cms.hhs.gov/medicare/>

Medicaid – <http://cms.hhs.gov/medicaid/>

Laws and Regulations <http://www.hcfa.gov/regs/>

We routinely receive requests on how to access the ICF/MR regulations online. To get the regulations online go to [http://cms.hhs.gov/manuels/Pub\\_07.asp](http://cms.hhs.gov/manuels/Pub_07.asp) . This takes you to the CMS’s web page for the State Operations Manual (SOM), which includes the W tags (Appendix J).

Double click on Appendices for the Appendices from D to N. You will be required to save the file to your computer and it will arrive as a ZIP file, which you will then have to unzip and save as well. The regulations for Appendix J begin with the file “somap j 02,” (starts with W tag 100). They go through file “somap j 15,” (which ends with the final tag, W tag 488). File “somap j 01” tells how the survey process is done by the Survey Team. You can also access the regulations that govern identifying and correcting Immediate Jeopardies, also called Appendix Q, from this link.

## State

N.C. Government <http://www.ncgov.com/>

N.C. General Assembly <http://www.ncleg.net/homePage.pl>

North Carolina Department of Health and Human Services <http://www.dhhs.state.nc.us>

The Division of Facility Services <http://facility-servieces.state.nc.us/>

Nurse Aide I and Health Care Personnel Registry <http://www.ncnar.org/>

## ICF/MR Organizations and Information Sources

North Carolina Association of Community Based ICF/MR Providers  
<http://www.ncicfmr.org/>

National Association of QMRP <http://www.qmrp.org/>

American Association on Mental Retardation (AAMR) <http://www.aamr.org/>

The ARC <http://www.thearc.org>

Best Buddies (Information on MR) <http://www.bestbuddies.org/>

Research Center at UCLA <http://www.mrrc.npi.ucla.edu>

National Down Syndrome Society <http://www.ndss.org>

Special Olympics <http://www.specialolympics.org>

Council for Exceptional Children <http://www.cec.sped.org/>

The Association for the Severely Handicapped <http://www.tash.org/>

The ICF/MR branch has an extensive list of Internet sites to a variety of organizations in a variety of areas. We will be listing some of them here for your convenience in the months to come. This letter's groups covers Emotional Disturbances and Communication Disorders:

### Emotional Disturbance

Educational Management Techniques <http://interact.uoregon.edu/wrrc/Behavior.html>

Research and Training Center for Children's Mental Health

<http://lumpy.fmhi.usf.edu/CFSroot/rtc/rtchome.html>

Tourette Syndrome Association <http://www.tsa-usa.org/>

American Academy of Child and Adolescent Psychiatry <http://www.aacp.org/>

Anxiety Disorders Association of America <http://www.adaa.org>

American Institutes for Research <http://www.air-dc.org/web/aacap/>

Autism Society of America <http://www.autism-society.org>

Jay Lenches BD tips

[http://www.geocities.com/behaviordisorders/Behavior\\_Disor/Behavior\\_Disox.html](http://www.geocities.com/behaviordisorders/Behavior_Disor/Behavior_Disox.html)  
 Residential Summer Camp <http://www.campnuhop.org/>  
 CCBD of CEC <http://www.ccbd.net/>  
 Children and Adults of Attention Deficit/Hyperactive Disorder <http://www.chadd.org>  
 Public Schools of North Carolina <http://www.dpi.state.nc.us/>  
 US Office of Special Education Programs sponsored www sites  
<http://www.ed.gov/about/offices/list/osers/index.html?src=oc>  
 Potpourri of Mental Health and Children sites <http://www.fenichel.com/violence.shtml>  
 Center for Mental Health Services <http://www.mentalhealth.org/mhlinks/MHLINKS.HTM>  
 U.S. Office of Juvenile Justice <http://virlib.ncjrs.org/JuvenileJustice.asp>  
 National Depressive and Manic Depressive Association <http://www.ndmada.org>  
 National Institutes on Drug Abuse <http://www.nida.nih.gov/>  
 National Institutes of Mental Health <http://www.nimh.nih.gov/>  
 National Mental Health Association <http://www.nmha.org/>  
 Obsessive Compulsive Disorders <http://www.ocfoundation.org/>  
 Substance Abuse and Mental Health Services Administration <http://www.samhsa.gov/>  
 University of Kentucky Behavior Problem site  
<http://www.state.ky.us/agencies/behave/homepage.html>  
 Willie M. parents website <http://www.willieparents.com/whatis.html>  
 National Alliance for the Mentally Ill <http://www.nami.org/>

## Communication Disorder

American Speech, Language and Hearing Association <http://www.asha.org/>  
 Association of Young People who Stutter <http://friendswhostutter.org/>  
 National Stuttering Association <http://www.nsastutter.org>  
 Stuttering Foundation of America <http://www.stutterSFA.org>

We make every attempt to ensure web links are up to date, but they do change from time to time. If you should have problems accessing a link, simply send a message to [Joseph.Milanese@ncmail.net](mailto:Joseph.Milanese@ncmail.net) and identify the link so we can correct it within the Newsletter. Thank you in advance.

## Landau-Kleffner Syndrome (LKS)

The ICF/MR survey team is always looking for new information that may impact your clients and recently came across this information on LKS, which is often mistakenly diagnosed as developmental disability, autism, or mental retardation. Additional misdiagnoses include physical disorders such as deafness or other psychiatric disorders such as schizophrenia.

LKS also known as epileptiform aphasia is a rare neurological disorder that usually affects children between 3 and 8. The child suffers a loss of the ability to communicate through normal language, which may be

sudden in onset or gradual. They may not recognize their own name. They can also appear to be deaf failing to recognize sounds in the environment such as a telephone's ringing. Specifically, the speech and comprehension centers in the brain are affected and abnormal electro-encephalograms (EEG) are seen. It is not uncommon for the client to suffer seizures as well, although some do not.

Secondary to the loss of expressive language these children will exhibit a variety of behavioral problems. Attention deficits, depression, irritability and even autistic behaviors are routinely seen and can lead to the various misdiagnoses.

Other neurological symptoms can also occur such as loss of bowel and bladder control or visual disturbances.

Correct diagnosis is obtained through EEG's. Since the LKS pattern may not appear while the client is awake, "Sleeping" EEG's are recommended.

The treatment regime consists of anti-epileptic medications and steroids. Additional therapy would include speech and language therapy and special education.

You are invited to visit the web sites this information was found on:

They are the National Institute of Neurological Disorders and Stroke at [http://www.ninds.nih.gov/health\\_and\\_medical/disorders/landaukleffnersyndrome\\_doc.htm](http://www.ninds.nih.gov/health_and_medical/disorders/landaukleffnersyndrome_doc.htm),

Landau Kleffner Syndrome at <http://www.bobjanet.demon.co.uk/lks/home.html>

and "Folks-Friends of Landau-Kleffner Syndrome!" at <http://www.bobjanet.demon.co.uk/lks/fws.htm>.

We invite others who have questions or ideas for the Newsletter to please send them to us at [Joseph.Milanese@ncmail.net](mailto:Joseph.Milanese@ncmail.net).

***Final Notes: The ICF/MR Survey Team would like to take this opportunity to wish our boss, Jeff Horton, the best as he moves to a new job in the Division of Facility Services as the Chief for the Licensure and Certification Section. It has been very rewarding to work with him over the years and to have his valuable experience to guide us in our duties.***

**(We hope that you have found the information we have provided helpful and educational. The ICF/MR Branch has a common goal with the various ICF/MR facilities in North Carolina to ensure the clients have the best life experience available to them.)**

**ICF/MR SURVEY BRANCH**