# Gabriel Myers Workgroup Tampa, Florida July 24, 2009

Workgroup Members and Advisors Present: Jim Sewell, Chairman

Bill Janes Mike Haney Betty Busbee Robin Rosenberg Anne Wells Rajiv Tandon

#### **CALL TO ORDER**

The meeting was called to order at 9:10 a.m. Chairman Sewell welcomed those in attendance and introduced Ms. Jan Gregory, Suncoast Region Deputy Regional Director. Ms. Gregory welcomed attendees on behalf of Regional Director Nick Cox. She also shared a segment of a story written by a foster child. The story described the help and direction that the Department of Children and Families provides to foster children in the State of Florida. The foster child stated in her letter that, because of the Department of Children and Families, she and many other foster children are safe from the brutal and bitter life set before them. She said she came into foster care with no heart, soul, or confidence, but, with help, has become caring, loving, and competent.

#### WORKGROUP INTRODUCTIONS

Chairman Sewell asked the workgroup members and advisors to introduce themselves.

# CONFUSION AMONG PHYSICIANS REGARDING THE USE OF PSYCHOTROPIC MEDICATIONS IN CHILDREN WITHOUT BEHAVIOR MANAGEMENT ISSUES

Chairman Sewell introduced Dr. Joseph Chiaro, Deputy Secretary, Children's Medical Services, Florida Department of Health. Dr. Chiaro is a pediatrician, and he is board certified in pediatrics and in pediatric critical care. He has served as the Deputy Secretary for Children's Medical Services for the last 4-1/2 years.

Dr. Chiaro noted that he asked to speak to the workgroup because he oversees the Children's Medical Services offices throughout the state, wherein children with special needs are seen. He also oversees the Child Protection Team, which is charged under the law with seeing all children who have been reported to the Department of Children and Families who have certain kinds of serious injuries.

He added that some information that came out of one of his area offices was brought to his attention after the Gabriel Myers Workgroup was established which made it clear to him that there is a lot of confusion around the use of psychotropic medications. Dr. Chiaro advised that he would present his discussion in question form and provide some answers and recommendations for the workgroup's consideration.

## Question 1: What drugs are we talking about?

Dr. Chiaro provided the workgroup with copies of the list of medications in Florida Safe Families Network (FSFN) Psychotropic Medications Report dated June 5, 2009. He noted that this particular list should not be interpreted as an all inclusive list of psychotropic medications and added that it could be endless because it could include other medications not listed.

Dr. Chiaro also shared a list of psychotropic medications provided to him by the nursing director from the Children's Medical Services office that covers Okaloosa and Bay Counties. This list included all the same drugs as the FSFN list, plus additional medications. He added that he was told that WebMD is used as a reference in Escambia County. He noted that some of the medications on these lists are rarely ever used for children who have mood problems, behavioral problems, or psychotic problems. They are used for such conditions as seizure disorder, bed wetting and Tourette Syndrome. He added that he was not sure why some drugs were on the lists and some were not and suggested that if a medication list is necessary, perhaps a group of individuals should get together and decide what medications should be included. He noted that the group responsible for developing, modifying, and controlling this medication list should be a group of practitioners, but added that the ultimate responsibility should be placed with the Department of Children and Families.

#### **Question 2: What conditions are we treating?**

Dr. Chiaro shared information he received from Department of Children and Families staff that directed that, for purposes of determining the need to seek informed consent or a court order and guiding the input of information into FSFN, psychotropic medication is defined as any chemical substance prescribed with the primary intent to treat disturbances of reality testing, cognitive impairment, mood disorders and emotional dysregulations. He noted that the definition further states that the medications include, without limitation: antipsychotics; antidepressants; sedative hypnotics; lithium; stimulants; non-stimulant ADHD medications; anti-dementia medications and cognition enhancers; anticonvulsants and alpha-2 agonists; and any other medication used to stabilize or improve mood, mental status, behavior, or mental illness. He stated that his interpretation of "medications include, without limitations" those medications listed and possibly others. He added that the information he received also noted that psychotropic medication includes such medication when used for other medical purposes. Dr. Chiaro stated that a Children's Medical Services attorney reviewed the definition within the law for psychotropic medication and when the law was to be followed and opined that regardless of what a

child is being treated for, if the drug is on the list, the Department of Children and Families wants to track it.

Dr. Chiaro noted that some of the community based care programs within the Department of Children and Families have elected to write their own policies and procedures regarding psychotropic medications while others have deferred to the official Department policy and procedure. He provided the workgroup members with a copy of Big Bend Community Based Care's policy and procedure on Consent for Psychotropic Medication, which he feels tracks Section 39.407, Florida Statutes, closely. He added that what he found interesting is the form attached to the policy and procedure that relates to express and informed parental consent for the administration of psychotropic medication. He noted that by signing, the parent is saying he/she understands that a psychotropic medication means prescription medicines used for the treatment of mental disorders and includes, without limitation, antihypnotics, antipsychotics, antidepressants, anxiety agents, sedatives, psychomotor stimulants, and mood stabilizers. The form does not mention bedwetting, seizures or Tourette Syndrome. He also noted that by signing the parent is recognizing that their child has a mental disorder.

The other issue that Dr. Chiaro noted as important was the form for the Prescribing Physician's Medical Report which lists recognized side effects, risks, drug interaction precautions, possible side effects of stopping the medication, and contraindications of the medication. His concern was that the parent is acknowledging they have been informed, which means presumably the physician has taken the time to explain. He added that, just because the doctor signs a form stating he/she has explained everything and the parent signs saying he/she understands it all, does not prevent the child from having an adverse outcome. Dr. Chiaro suggested that one way to approach this issue would be to have the same expert panel he recommended earlier put together an understandable list for parents of the top side effects.

Dr. Chiaro continued that under the same question, "what conditions are we treating," some of the confusion comes from how one reads the law and what it is meant to say. He provided a direct quote from a judge, which stated, "If the child has a psychiatric/behavioral disorder/diagnosis and the medication is being used for psychotropic/behavioral modification purposes, the procedure for consent contained in the Florida statue is to be followed. If the child has a seizure disorder/epilepsy and is being treated with an anticonvulsant medication for control of seizures, it is not necessary to go through the process for psychotropic medication use even if the drug is on psychotropic medication list."

# Question 3: Who are we serving?

Dr. Chiaro stated that Florida Statute 39.407 is very clear on whom we are serving, "any child removed from the home and maintained in an out of home placement." He noted that he asked his colleagues in the Panhandle what is being done with these children. He said the response he got was children within Children's Medical Services who are in out-of-home care get the best care because they can rely on the Department of Children and

Families more than the natural parents. The problem with natural parents is they move and cannot always be found. When the child is within the DCF system, Children's Medical Services can monitor them and vigorously pursue any "no shows." Dr. Chiaro said that Children's Medical Services has begun to work in concert with the Department of Children and Families and the Agency for Health Care Administration to make life much better for children in foster care. He added that he believes all children in foster care are special needs children and noted that Children's Medical Services wants to work vigorously with other agencies to really begin to provide comprehensive care to these children.

Dr. Chiaro provided the workgroup with a draft document regarding medical homes for children in foster care. He explained that the cornerstones of the medical home model are primary care and family centered care. The suggested minimum criteria for operation of the medical home for foster care children are:

- 1. All foster care children receive a comprehensive medical assessment through the primary care provider within 72 hours of placement and a comprehensive behavioral assessment by a qualified professional within 96 hours of placement.
- 2. The primary care provider would maintain the comprehensive medical record, including treatment plan, medication list, medical supply list, allergies, and other important information that addresses the overall health status of the child and care of the child.
- 3. The care coordinator will assist with coordinating health care appointments and working with the DCF case manager.
- 4. If the child qualifies for the CMS Network based on a clinical screening, the family may be offered the choice of the CMS Network for the child's physical health care.
- 5. If the child qualifies for the Medical Foster Care Program, the operational procedures of the program will be applied.
- 6. Should the child's care be transferred to another primary care provider, the medical home team, in coordination with the DCF case manager, will be responsible for assuring that the medical information is complete and transferred quickly to another primary care provider.

In closing, Dr. Chiaro shared 5 recommendations:

- 1. Treat the child, not the chart.
- 2. Treat the condition and not the drug list.
- 3. Consider that less physician paperwork may lead to greater patient care.

- 4. Improve foster parent training and observation skills.
- 5. Remember the Chinese proverb Govern a family as you would cook a small fish, very gently.

# Questions/Comments/Discussion

1. Dr. Tandon asked Dr. Chiaro to explain how the medical home model differs from current practice.

Dr. Chiaro responded that in current practice a child may not see the same pediatrician after being moved from one placement to another and the records may not follow the child. He added that in a medical home there is a care coordinator for the children. He noted that continuity of care is one of the hallmarks of the medical home.

# **UPDATE ON QUALITY ASSURANCE REPORT, CHILDREN AGES 8-9**

Eleese Davis, Department of Children and Families Chief of Systems Performance Management, was introduced to provide an update on the Quality Assurance Review and an overview of the current quality assurance system.

# **Quality Assurance Review**

Ms. Davis advised that the review of the third cohort of children was conducted between June 24 and July 14, 2009 by the Department and community based care providers with ongoing consultation from Children's Legal Services. The population reviewed was children ages 8-9 in out of home care who are currently prescribed psychotropic medication. The purpose was to assess compliance with s. 39.407, Florida Statutes, and Chapter 65C-28.016, Florida Administrative Code, and determine the validity and reliability of the data contained in FSFN.

Ms. Davis provided a PowerPoint presentation which included a trend data chart reflecting a 1.9 percent decrease in children in out of home care and a 1.4 percent decrease in children on psychotropic medications between June 14 and July 19, 2009. The net result is an increase in the percentage of children on psychotropic medications because the out of home care population decreased more than the number of children on psychotropic medication.

Ms. Davis shared the key findings of the review:

- On the day the review began, there were 1,597 children ages 8-9 in out of home care.
- 373 of these children were prescribed a psychotropic medication, representing 23 percent of the total population of children in this age group who are in out of home care.
- 58 percent were white and 39 percent were black.

- 69 percent were males and 31 percent were females.
- 86 percent of the 373 children have a diagnosis of Attention Deficit Hyperactivity Disorder (ADHD).
- Parental rights were terminated in 168 (45 percent) of the cases.
- Of the 706 psychotropic medications prescribed, 469 (66 percent) were prescribed by a psychiatrist.
- 45 percent of the children were prescribed only one psychotropic medication and 32 percent were prescribed two psychotropic medications.
- 36 percent of the children were taking a psychotropic medication at the time of their most recent removal episode.
- There was no documentation that the case worker provided prior known medical information to the prescribing physician in 65 percent of the cases.
- 85 percent of the cases did not reflect that the case worker provided written information concerning the prescriptions to the parent or mailed the information to the parent's last known address.
- When express and informed consent could not be obtained, the case worker submitted a request for court authorization in 62 percent of the cases.
- There was no documentation that supervisors were discussing the behavioral health needs of these children in 270 (72 percent) of the cases.
- Informed consent or court order was absent for 194 of the 706 psychotropic medication prescriptions.
- Request for Action referrals were submitted for 855 identified issues related to missing parental consents, missing court orders, and FSFN data entry errors.

Ms. Davis continued with her presentation, sharing charts and graphs on the following:

- Number and percent of children age 8-9 on psychotropic medication by community based care lead agency
  - The chart reflected 1,597 children age 8-9 in out-of-home care
  - 373 of those children are prescribed 1 or more psychotropic medication
  - 23.4 percent of the children age 8-9 in out-of-home care are on psychotropic medication
- DSM IV-R Diagnosis for Children age 8-9
- Type of practitioner and board certification of the prescribing practitioners
- Age of the children prescribed a psychotropic medication compared to the total number of children age 0-9 in out-of-home care.
  - age 0-5: 1.25 percent (112) with psychotropic medication
  - age 6-7: 13.80 percent (268) with psychotropic medication
  - age 8-9: 23.36 percent (373) with psychotropic medication
- Race of children age 8-9 on psychotropic medication
  - 38.87 percent (145) black

- 54.69 percent (204) white
- 6.43 percent (24) other
- Gender of children age 8-9 on psychotropic medication
  - 30.56 percent (114) female
  - 69.44 percent (259) male
- Custody status of children age 8-9 prescribed a psychotropic medication
  - parental rights were terminated in 45 percent (168 cases) and not terminated in 55 percent (205 cases)
- Breakdown of the number of psychotropic medications children age 8-9 are prescribed
  - 45 percent (165) were prescribed one medication
  - 32 percent (121) were prescribed 2
  - 15 percent (57) were prescribed 3
  - 8 percent (30) were prescribed 4.
- Percentage of children age 8-9 on psychotropic medication upon removal
  - 36 percent (134) were on psychotropic medication on date of most recent removal
  - 64 percent (239) were not
- Providing medical history to prescribing practitioners (the record should reflect that specifics of all prior medical health information known to the agency were obtained by the agency worker and provided to the prescribing physician)
  - the case manager provided the medical information to the prescribing physician in 35 percent of the cases (131)
  - the case manager did not provide the medical information to the prescribing physician in 65 percent of the cases (242)
- Sending written information to parents (the agency worker ensured the parent or legal guardian received all written information concerning the prescription(s) or that written information was sent to the parent's last know address)
  - The case worker did provide or mail information regarding psychotropic medications to the parent/guardian 15 percent (32 cases) of the time
  - The case worker did not provide or mail information regarding psychotropic medications to the parent/guardian 85 percent (182 cases) of the time
- Facilitating contact between the parent/guardian and the prescribing practitioner (the agency worker made concerted efforts to facilitate contact between the parent or legal guardian and the prescribing practitioner in order for the parent or legal guardian to be as educated as possible regarding their consent for their child's use of psychotropic medication(s))

- in 19 percent of the cases (40), the case manager facilitated transportation arrangements and/or telephone calls between the parent/guardian and the prescribing practitioner
- in 81 percent of the cases (169), the case manager did not facilitate transportation arrangements and/or telephone calls between the parent/guardian and the prescribing practitioner
- Requesting court authorization (when express and informed consent could not be obtained from the child's parents, the agency worker submitted a request for court authorization to provide the psychotropic medications to Children's Legal Services)
  - This occurred in 62 percent (197) of the cases
  - This did not occur in 38 percent (122) of the cases
- Prescribing practitioner requirements to complete medical sections of the treatment plan
  - the prescribing practitioner completed the medical section of the treatment plan in 21 percent (77) of the cases
  - the prescribing practitioner did not complete the medical section of the treatment plan in 79 percent (296) of the cases
- Supervisory reviews of behavioral health needs (supervisors are required to minimally review all cases in their units once a quarter)
  - supervisory review and discussion of behavioral health were evident in 28 percent (103) of the cases
  - supervisory review was not documented in 72 percent (270) of the cases
- Number of Request for Action Referrals by type (855 for this age group)
  - 13 for child safety
  - 194 for missing informed consent or court order for any medication
  - 279 for missing psychotherapeutic medication treatment plan form for any medication
  - 269 for FSFN data entry errors
  - 73 for other
  - 27 required no Request For Action

Ms. Davis shared with the workgroup that the following action is underway:

- A Request for Action (RFA), the form used to alert management of necessary follow up, was completed for 855 concerns
- Cases identified without informed consent or a court order continue to be referred to Children's Legal Services
- On July 15, the special Quality Assurance Review was extended to children age 10-11 in out-of-home care who are prescribed psychotropic medications. This review includes 393 children and will be complete on August 3
- Weekly reporting to the Acting Assistant Secretary for Operations is being done to ensure corrective action is taken for each deficiency noted by quality assurance teams

- Training initiatives are being identified and coordinated out of both the Family Safety Program and Children's Legal Services, in partnership with community stakeholders. Focus of training efforts include:
  - Documentation and FSFN requirements
  - Issues related to express informed consent, and other policy and procedural requirements when psychotropic medications are prescribed for children
  - Best practices for improving child welfare casework and the coordination of child welfare, mental health, and other human services

# QUESTIONS/COMMENTS/DISCUSSION

1. Colonel Janes inquired if the lack of documentation is indicative of the remainder of the file or unique to the medication section, are case managers generally overloaded and not doing a good paperwork, is the volume of documentation for a case manager excessive, and are they not being trained or is the training provided excessive.

Kathy Newcomb, Quality Assurance Manager for the Suncoast Region, responded that documentation is an area that needs improvement across the board in all areas. She added that there are a lot of tools available to the worker to assist with documentation, but noted that the worker must be very organized and time based. She added that caseworkers will probably say they are overwhelmed with all the work they do and paperwork/documentation is probably the area that gets pushed aside.

Allen Abramowitz, Director of Family Safety, added that, compared to a few years ago, documentation has improved, but more improvement is needed especially where psychotropic medication is concerned.

2. Dr. Tandon commented that before the case manager submits a request to the court seeking authorization for use of psychotropic medication in a child there needs to be a completed medical section, and despite the clarity of the law in this regard, it has been found that this did not happen in 79 percent of all instances. He added that if they are submitting something to the court without this requirement, there is something missing in the process.

#### Regional Quality Assurance Model

Ms. Davis advised that, over the years, the Department has had three major quality assurance redesigns. The last redesign occurred when former Secretary Butterworth joined the agency and made the decision to decentralize and regionalize the entire quality assurance system (the regional quality assurance model was approved on March 11, 2008 for implementation on July 1, 2008). As a result, a set of minimum standards for case management and child protective investigations based upon the critical few was developed. The agency worked with national experts and an implementation and oversight team on these standards and tried to limit the focus to the core child welfare best practices issues. Seventy standards have been developed for case management and 50 for child protective investigations.

Ms. Davis continued that the Regional Quality Assurance model includes mandatory standardized quality assurance certification for all quality assurance professionals and standardized quality assurance training for supervisors. There are now standardized reporting systems. Ms. Davis added that the Administration for Children and Families identified the quality assurance process as one of the strengths in the Florida Children and Families System of Care during the Child and Family Services Review (CFSR).

Ms. Davis advised that the system was developed following the Chapin Hall model, which involves looking at 25 cases, 17 in a base review by community based care quality assurance and 8 as a side-by-side review by community based care and DCF regional quality assurance. Two cases are pulled for an in-depth review by DCF regional quality assurance.

Ms. Davis shared charts relating to the following:

- Assessment of Mental/Behavioral Health Needs
  - (86 percent conducted, 14 percent not conducted)
- Service Referrals Consistent with Identified Needs
  - (83 percent of service referrals were consistent with identified needs, 17 percent were not)
- Provision of Appropriate Services
  - (20 percent appropriate services were not provided, 80 percent appropriate services were provided)

#### QUESTIONS/COMMENTS/DISCUSSION

1. Dr. Tandon suggested that it might be useful to determine the reasons assessments were not completed on the 14 percent.

Ms. Davis responded that the hope of the quality assurance system is that leadership of the community based care agencies use the data to move forward with making changes.

## **COMMENTS FROM SECRETARY SHELDON**

Secretary Sheldon joined the meeting and was asked to share his comments.

Secretary Sheldon complimented the group on their work to date. He noted that the focus of the workgroup is not about adding another layer of bureaucracy and that case workers have to be empowered. He added that design of the system cannot be driven by risk management, and ultimately a system has to be designed that is simple and allows case managers to do their work. He noted that the Legislature is looking to the Department to solve this issue and members should not feel constricted by budget or statute.

Secretary Sheldon advised that he received a call from a lawyer in California who told him the remainder of the country is starting to look at what Florida is doing with regard to psychotherapeutic medication. He added that he thinks the attention on psychotherapeutic medication, both from the psychiatric community as well as the social service community, is having a huge impact in and of itself on getting people to rethink handling of the issue.

Secretary Sheldon added that he believes technology can make a huge difference. He noted that the Department will be rolling out, starting in Dade County, a mobile device which will have photo capability, GPS, date and time stamp, and the ability in the field to enter visitation forms and automatically upload the data. The device will be rolled out statewide during September and October.

Secretary Sheldon reiterated that a simple way has to be found to get the kind of documentation needed. He added that caseworkers should not be doing paperwork; they should be doing case work with a sufficient amount of documentation to ensure the process can be double checked.

He added that he was looking forward to the workgroup's findings.

# OUR KIDS EXPERIENCE: THE USE OF TECHNOLOGY TO ENSURE CHILDREN GET THE SERVICES THEY NEED

Dr. Gwen Wurm, Developmental Behavioral Pediatrician at the University of Miami and board member of Our Kids in Miami, was introduced to discuss activities of Our Kids. She shared a PowerPoint presentation on evidence based practice developed in part by the Connecticut Center for Effective Practice.

Dr. Wurm advised that, as a pediatrician doing developmental behavioral work, one of the issues she thought about was secondary prevention. She noted that Connecticut is about 3 or 4 years ahead of Florida in terms of a coordinated mental health system. They have started the Connecticut Center for Effective Practice and they look at evidence-based practice.

Dr. Wurm stated that Our Kids is heading in the direction of evidence-based practice and, along that line, they want to identify, adopt and implement those practices; research, evaluate and quality assure new and existing services; raise public awareness about evidenced based and best practices; and develop the infrastructure internally as to who we can disseminate these practices.

Dr. Wurm shared that the rationale for using evidence based practices is they are integrative in nature and combine practice, research, and theory; they use systemic clinical protocols; they incorporate models that have a strong science and research support; and they are clinically responsive and individualized to be unique to the client and family.

Dr. Wurm also shared the biases against evidence based practices, which include: some view them as too rigid; don't apply to real world problems; developed in some lab; overly simplistic; and just a band-aid.

Dr. Wurm advised that Connecticut has a Multidimensional Treatment Foster Care program and that Our Kids has a variation of that program. This particular program is for children that have serious health problems. Our Kids is working within all the domains of the child in an integrative system to deal with the problems.

Dr. Wurm shared the lessons learned in Connecticut, which included: 1) must invest in quality assurance and quality improvement of services; 2) must build capacity, invest in ongoing training of workforce, and provide ongoing technical assistance to providers; 3) fidelity to treatment models is key to successful outcomes; and 4) outcomes data should be shared with parents and stakeholders.

Dr. Wurm advised that Our Kids is monitoring psychotropic medications, but realizes that just limiting the psychotropic medications will not solve the problem. She added that one of the things that can be focused on in the future is how to prevent mental health problems in children who are already at risk and have already been traumatized.

With regard to prevention, Dr. Wurm referred to foster parents as a secret weapon and added that they need to be part of the solution, not just a bed for the foster child. She added that Our Kids wants to work on developing parent management training. She said there is evidence to support parent management training for oppositional behavior, conduct disorder, and some help with ADHD. She noted that a study completed this year in Oregon where parent management training has been used revealed decreased placements and increased parent satisfaction. Dr. Wurm advised that parent management training is not just parenting classes. She added that pilot programs of rigorous parent management training should be developed, through computer support in addition to telephonic support with therapists and ongoing classes as well as initial assessments where problem behaviors are identified that need to be worked on in any child entering care.

#### Questions/Comments/ Discussion

- 1. Colonel Janes asked if Connecticut is identifying their own evidence based practice or using those from the SAMHSA list of substance abuse/mental health evidence based practices.
- Dr. Wurm responded that she could not say, but recommended that Florida invest resources in collecting up what is available and build a menu based upon what has been already proven evidence.

Dr. Wurm introduced Pat Smith, Chief Information Officer for Our Kids, to share technology being used to help keep children safe.

Pat advised that Our Kids actually started to pilot the initiative mentioned by Secretary Sheldon for the state as well as a number of other programs last fall. She added that she wanted to show the workgroup that taking the technology the Department has made available one step further can make the jobs of case managers and supervisors easier.

Ms. Smith stated that Our Kids has transformed readily available information for quick decision making by scanning all the paperwork associated with a child's case file. This information is available to caseworkers and supervisors 24 hours a day, 7 days a week. Staff can connect through an internet connection and have this information at their fingertips anytime they need it. Our Kids, using information in the FSFN system, created a facebook profile for each child and created a Mindshare dashboard to quickly find exceptions for critical data. Mindshare is a management system that sits on top of FSFN and allows the user to see data in a more understandable way. She stated that this also gives management staff the ability to very quickly identify problems.

Ms. Smith stated that psychotherapeutic medication prescriptions can be tracked in Mindshare. She shared that, using an extract from the Agency for Health Care Administration (AHCA) of prescribed psychotherapeutic medications, Our Kids was able to compare their entries to Medicaid records. She advised that a working agreement is in the process to allow for AHCA to provide this information on a regular basis.

Ms. Smith shared a snapshot of an active medications report in Mindshare. She noted that this makes it easy for the caseworker, at a glance, to know which drugs the child is on. The screen will also show if paperwork is missing for this child. She said it is like a tickler file, it is an exception file, it is a management tool for the case worker, for Our Kids, for the Department, and access is provided depending on level of authority.

Ms. Smith continued that all this relevant medical data can be combined into a one-page medical passport so that, when a provider sees a child, he/she has the information needed readily at hand. She advised that a medical passport can be computerized, web based, follow the child in care, and it can be entered and accessed by health providers, case managers, foster parents, and judges under HIPAA compliant confidential protocols. She added that the technology is available and it has already been done by the state of Texas. She advised that Our Kids believes this can be done in Florida very quickly using off the shelf software.

In closing, Ms. Smith presented a summary of Our Kids' wish list and action items, which included: 1) the exchange of information with AHCA; 2) the exchange of information with Florida Shots database; 3) cultural change; 4) no regulatory or legislative restrictions to data sharing as long as appropriate security controls are in place; 5) pilot parent management training program that could rapidly be disseminated statewide; and 6) investigate other state mental health systems, particularly Connecticut.

#### Questions/Comments/Discussion

- 1. Dr. Wurm commented that one of the challenges in building the integrated passport is how you get that information in. She added that better care can be taken of these children with complete medical information, and noted that there is no excuse for not being able to have these integrated systems in place that will ensure the health and safety of these children.
- 2. Colonel Janes suggested working in collaboration with the state agency that has the lead for the state in electronic health records to find out if this can be a stimulus dollars project.

#### **PSYCHIATRIC TREATMENT REVIEW**

Dr. Michael Bengston, Associate Professor and Chief of Child and Adolescent Psychiatry, University of South Florida, was introduced.

Dr. Bengston advised that he was tasked with evaluating the psychiatric care of record for Gabriel Myers. He provided an overview of the information contained in the record. He noted that he believed Gabriel had behavioral problems that were challenging for people to manage. He stated that he found a couple of things that were concerning with the initial psychiatric assessments and the therapy assessments. He said he was also concerned somewhat with the fact that Gabriel ended up in the care of an older teen for part of his stay in one foster home because of the report of child-on-child sexual abuse in Ohio. He added that there were a lot of factors in his mind that contributed to the Gabriel's death besides the kinds of medications he might have been taking. Dr. Bengston said that possibly Gabriel did not get as much therapy at the front end as was needed. He also noted a lack of communication between the therapist and the psychiatrist.

## Questions/Comments/Discussion

1. Dr. Chiaro commented that it seemed that perhaps most or all of Gabriel's issues could have been allayed by a single stable foster parent placement.

Dr. Bengston responded that he didn't want to be predictive, but he thought it might have resulted in a better outcome. He added that typically when you see suicide in children this young, it is an impulsive act and that Gabriel certainly had some impulse control disorder issues.

# PROCESS FLOW CHART FOR CHILDREN IN THE DEPARTMENT'S CARE WHO ARE PRESCRIBED PSYCHOTROPIC MEDICATIONS

Alan Abramowitz, Family Safety Program Director, was introduced to discuss process flow charts relating to children on psychotropic medications.

Mr. Abramowitz advised that a draft operating procedure regarding psychotropic medications has been developed and is currently in the review process.

Mr. Abramowitz began his presentation by providing an orientation to process maps. Two process maps were reviewed and discussed. One process map related to children who are at the point of removal and may already be on psychotropic medication. The other represented children who are in out-of-home care and may need new or changed prescriptions for psychotropic medication. He provided an overview of each step of the process.

## Questions/Comments/Discussion

1. Comments and suggestions were offered on possible ways to enhance the process maps. Mr. Abramowitz will revise the maps based on the suggestions.

#### COMMUNITY BASED CARE ISSUES

Glen Casel, President, Community Based Care of Seminole, was introduced to address the work group. He stated that he had three particular items to share.

Mr. Casel's first item was his perspective of mental health service delivery to children involved in the dependency system in foster care. He reminded the workgroup that there has been a substantial challenge in trying to meet the atypical mental health needs of children involved in the dependency system. He added that there has been a substantial change in the way in which mental health services are delivered to children involved in the dependency system, specifically those under Medicaid. He noted that there now is a Medicaid specialty plan that includes management of community based care lead agencies. He added that some significant changes have occurred. For example, in every community based care lead agency across the state, there now are mental health professionals in the field talking about the mental health needs of children. This was discussed in the state for 20 or 25 years and could never be done. These mental health professionals are involved in staffings. They interact, not only about the way mental health issues facing a child matter in what is going on with them, but integrating them into the permanency plan of the direction the child's case is taking.

Mr. Casel noted that the comprehensive behavioral health assessment has been a requirement for a number of years, and Florida has been chronically unable to deliver. He noted that, while he does not believe the problem has been solved, he feels a substantial improvement has occurred. He added that the fact that Florida has started to integrate the mental health needs of children into the rest of their child welfare experience is significant.

Mr. Casel stated that his second item was from the perspective of a child welfare agency. He advised that all the child welfare agencies want to reflect their communities and the state well and, far more importantly than anything else, to serve children. He added that he is confident Florida will have the best review and accountability around the use of

medication for children in the child welfare system anywhere in the country and one of the best applications of meeting the mental health needs of children in foster care. He noted that he is convinced that Florida is on a path to be one of the best child welfare systems anywhere in this country. He advised that he felt it paramount in that evolution to say that Florida's lead agencies and service providers are ready to help. He asked that the work group engage the lead agencies and providers and talk them about what is being considered and how they can assist.

Mr. Casel advised that the last and most important perspective he wanted to share with the workgroup was his reason for doing the work he does. He stated that it is because he is an advocate for children and cares deeply about Florida's children and passionately about children who have been abused, neglected, or abandoned. He said he believes those who work in the child welfare system want to help children and are competent and caring. He feels they are buried in activities which need to be reduced and they need to be empowered to do the right thing. He added that you have to have basics and structure and expectations to be sure that the right things are happening and then you have to trust and believe that staff are capable and trained to make good decisions on behalf of children. He said the expectation that a case manager will know everything is never going to happen and that they have to be able to get the support and resource information they need.

#### Questions/Comments/Discussion

1. Ms. Rosenberg asked Mr. Casel to help the workgroup understand the child welfare prepaid mental health program and to include an overview of what percentage of children are covered under the plan and what parts of the state are not covered and what he sees as the challenges.

Mr. Casel responded that he would provide some basic information and follow up with additional information to the workgroup members later. He explained that legislation passed several years ago required the state to place the dependent care population into a managed care plan. He added that the idea of that was fine except that it essentially created two competing managed care arrangements because the child welfare service delivery system, via community based care, now is a managed care dynamic in the local community responsible for managing a child's child welfare case and their well being, and you could potentially have a separate entity responsible for managing their mental health needs. The community based care community made an argument that if they were going to put foster care children's Medicaid behavioral health into a managed health care plan, the community based care lead agencies had to be involved. The legislature responded to that and required that a plan to deliver the Medicaid behavioral health services include the lead agencies. There still had to be a managed care agency involved so the community based care lead agencies, in all areas except old AHCA area 6, which is some of the counties in and around Tampa, Ft Lauderdale, and old AHCA area 1, which is in and around Pensacola, went into a managed care plan for Medicaid mental health that included community based

care lead agencies. They partnered with Magellan Behavioral Health in order to be able to do that. Mr. Casel noted that some things that changed were dramatic and immediate.

Mr. Casel added that the behavioral health needs of children in foster care are acute and the presumption is as children come into the system, they will need mental health services by the nature of the path that brought them to foster care. The penetration rates for use of services in the child welfare prepaid mental heath program in any given month is over 40 percent, usually closer to 50, and, through the course of a year, around 65 percent. He added that nearly every child has some form of mental health service.

Mr. Casel advised that it is a very different plan and it illustrates the reason why an acute care plan is needed for this population. The biggest issue in Florida's social systems is funding. He added that, as the Medicaid budget has been constrained and challenged, the plan has been cut several times, and in an acute care plan that makes a substantial challenge.

# RED ITEM REPORT AND DISCUSSION OF NEW POLICY

Alan Abramowitz was recognized to speak about the Florida Statewide Advocacy Council 2003 Red Item Report. The Statewide Advisory Council was created as an independent monitor of state agencies providing services. The study was prompted by information on the widespread use of medication for foster care children in South Florida. He advised that the Council looked at 1,180 case files for review. The selection of the cases was based on whether or not a child was likely to be on psychotropic medication. The data under review were foster care worker's case records and HomeSafeNet data (HomeSafeNet is the precursor to FSFN).

Mr. Abramowitz advised that the systematic benefits of the study included: 1) it convened a multidisciplinary team comprising advocacy council members, including medical doctors and mental health professionals, nurses, social workers, law enforcement, attorneys and others; 2) it introduced a new approach to reviewing prescription and documentation practices for children; 3) it prompted executive leadership to analyze internal processes directly related to critical decision making and medical care; and 4) it initiated legislation that was very prescriptive on how to address the concerns of psychotropic medication.

Mr. Abramowitz continued that there were some limitations of the study that the statewide advisory committee pointed out. Many of the cases reviewed lacked accurate information to determine whether appropriate consent was obtained. They also recognized that the data did not meet the requirement of a statistically valid sample since they selected specific cases from a therapeutic group home so they would have the population of children on psychotropic medication, and many records had no psychiatric diagnosis or the diagnosis was so vague that it was not possible to validate justification for a prescription.

The *Red Item Report* included a number of recommendations. The first recommendation was to develop and implement a quality assurance program for monitoring the use of drugs and to ensure appropriate attempts at behavioral management were implemented and prescribing of drugs was a last resort. Mr. Abramowitz advised that former Secretary Butterworth changed the quality assurance tool used by the Department of Children and Families. He noted that the current quality assurance tool has 70 questions for case management and 50 for investigations. He added that questions have been added to get into some of the core issues without expanding too much to target psychotropic medication.

Mr. Abramowitz advised that the second recommendation was to develop a plan of care to include counseling for anger, self-esteem, positive reinforcement, dealing with fear and attitude, and character building traits. Not all foster children will need counseling, but it should be available. Mr. Abramowitz noted that all case plans include specific treatment plans for child therapeutic needs supervised by the judiciary. Also, both statute and administrative code were changed to require the normalcy provisions for the stigma associated with foster children so they can participate in activities such as cheerleading. to build self-esteem. He also shared many of the other councils and programs that have been created and developed to assist foster care children.

Mr. Abramowitz shared that the third recommendation was to ensure that appropriate standardized written informed consent is obtained prior to starting any new psychotropic medication. He shared that Children's Legal Services is becoming a more active player in this issue, including providing appropriate training and development of an operating procedure.

The fourth recommendation of the *Red Item Report* was to ensure that everyone who administers psychotropic medication to children in the foster care setting is trained to recognize the side effects of medication. Mr. Abramowitz advised that the Department now has an operating procedure that will hopefully address this recommendation.

Mr. Abramowitz advised that the fifth recommendation was to ensure pediatric psychiatrists perform medical examination prior to the implementation of the drugs. The next was to ensure foster care records on each child contain organized information and medical records are easily found. The final recommendation is to ensure the medical passports are current and made available to each physician. It was noted that the Department didn't implement or institutionalize most of the recommendations.

#### Questions/Comments/Discussion

1. With regard to the first recommendation of the *Red Item Report*, Colonel Janes raised the concern that a quality assurance process is in place but the Department is out of compliance with almost every aspect of the law on psychotropic medications.

Dr. Sewell commented that the recommendation was made in 2003 and there have since been at least 3 attempts at a quality assurance system. Two of those did not work. He expressed concern that the current system was implemented in the spring of 2008 and problems were recognized in October 2008 but were not addressed. He asked if the other part of the recommendation, which involved having a quality assurance system that looked at attempts at behavior management and prescribing the drugs as a last resort, was being included.

Ms. Davis responded that the standards are currently being revised.

Mr. Abramowitz added that when the standards were created, they were not just focused on psychotropic medication but more on the big picture and if the right thing is happening for the child.

2. With regard to recommendation 2, Colonel Janes noted that Mr. Abramowitz had shared examples of what was being done, but did not indicate if a specific plan is in place each year as recommended by the *Red Item Report*.

Mr. Abramowitz responded that the item is in the community based care contract and he believes each child has a plan. He added that Secretary Sheldon has made it a priority of the Department that these children feel normal and are empowered to become whatever they want.

3. Colonel Janes asked if the *Red Item Report* was ignored.

Mr. Abramowitz responded that he had found most people in the field were not aware of the report. He added that at the time of the report, the Department was litigating issues such as judges refusing to do court orders because they felt the department had the authority to sign court orders without court approval.

Ms. Rosenberg added that part of the official response from the Department at the time was that the *Red Item Report* was inadequate and unscientific.

Mr. Abramowitz added that in 2003 there were probably over 20, 000 backlog cases that had not been investigated in the state, along with other issues involving child safety, and there were cases in boxes that had not been investigated.

Dr. Sewell commented that the Secretary has said several times that the Department has a good habit of developing action plans and recommendations, but a lousy record of follow through. He added that that is why the whole issue becomes institutionalizing quality assurance so that we are not dealing with the same issues three year from now.

## CHILDREN ON PSYCHOTROPIC MEDICATION

Dr. David Moore, Medical Director for Florida Health Partners and for North Florida Behavioral Health Partnership and for ValueOptions Tampa Service Center, presented a PowerPoint presentation on considerations for Systematic Care of Children Using Rational Psychopharmacology as Part of an Overall Treatment Strategy.

Dr. Moore advised that, in 2004, Tampa Regional Service Center looked at the use of atypical antipsychotics in children under the age of 14. That was a time prior to Medicaid pharmacy putting psychotropic medications on the preferred drug list. What they saw was an increase in the prescribing of atypicals from January 2002 through March 2004. The reason they chose the atypicals to look at were: 1) there were no indications in children for prescribing atypicals; 2) there was a lot of prescribing of atypicals; 3) in doing chart reviews they did not find much diagnostic justification for those atypicals.

Dr. Moore noted that to conduct the study, a population of 478 children under the age of 14 was identified as having filled a prescription for an atypical antipsychotic and having a medication management visit at a Regional Care Center within 60 days of the fill date. He added that a sample of 234 treatment record audits that were very thorough was used to establish a 95 percent confidence level. An automated tool was developed to capture the treatment record data on the defined sample.

Dr. Moore advised that a primary diagnosis was found in 233 of the 234 charts, and the top diagnosis for boys and girls of all races was ADHD. This raised the question of why atypicals were being prescribed for ADHD. In looking at secondary Axis I diagnoses, it was found that 27 percent were disruptive behavior disorders and for those who did not have ADHD as a primary diagnosis, 20 percent had that as their secondary diagnosis. The next most common was "other mental disorder." Again, the concern was that the majority of these children were being prescribed atypicals with the diagnosis of some kind of disruptive behavior disorder.

He noted that, in looking at the Axis II conditions, mental retardation and developmental disabilities made up 16 percent of those that had an Axis II diagnosis. He added that that co-morbidity is significant when you think about certain medical conditions.

Dr. Moore advised that the study only found documentation of medical conditions in 107 of the 234 charts, but of those, 35 percent of those children were diagnosed with asthma and 8 percent with seizure disorders. He added that they saw more major chronic medical disorders than expected.

Dr. Moore continued that Axis IV issues were only found in 140 charts. Sixty-five percent were having problems with their primary support group and 51 percent were having problems in school. So you've got kids in the school and kids in their home environment that were having significant problems.

Dr. Moore noted that a secondary reason for doing the study is that prescribing atypicals may add to the incidence of diabetes and cardiovascular disease and shorten the life of those children who will become adults by as much as 25 years. In looking for those at risk for diabetes and/or cardiovascular disease, documentation of diabetes was found in 53 children, and where the question was answered, 28 percent had relatives with diabetes. Of the 45 children where there was actually a question asked about a history of heart disease, 27 percent had a family history. He added that what is relevant about these findings is the questions were not being asked.

Dr. Moore advised that a lot of different classes of medications were tried in these children, but antipsychotics made up 44 percent of the original medications tried, which was concerning because psychosis was not among any of the diagnoses. He noted that antipsychotics were as frequently tried as primarily as the stimulants, giving a 44 percent chance of starting out on an antipsychotic and a 44 percent chance of starting out on a stimulant.

Dr. Moore said that the study also looked at ethnicity of these children, types of services by ethnicity grouping, and then the total population. What was found was there was a lot more medication management, outpatient therapy, and individual and family therapy for the children not prescribed the atypicals. He noted that this was disconcerting if you think medication should be prescribed after trying other things.

Dr. Moore advised that when you look at the target symptoms when they were documented, and they were documented in 208 of the 234 charts, 46 percent were severe aggressive behavior, and when you combine severe aggressive behavior, anger, moody and impulsivity, you've got a large part of this population. He added that these are angry, unstable, impulsive children and that is why they were prescribed the atypical antipsychotics.

Dr. Moore continued that in 82 of the cases, there was no documentation of the parent/guardian receiving information about the illness or target symptoms for which the medication was prescribed. Seventy percent showed some discussion of the potential side effects, but that is only part of informed consent. Fifteen percent had discussions about stopping medication without talking with the doctor, and in 8 percent there was documentation of partial or non-compliance.

Dr. Moore advised that what becomes more concerning is documentation of important physical findings. Only 38 percent of the charts included height and/or weight. Almost half of those who had a height and weight were ranked in the 85<sup>th</sup> percentile or higher for BMI. This is a very significant risk for diabetes and metabolic syndrome, especially for African Americans and females. So not only should they have been looking for it, but when they found it, there should have been some coordination of care with the primary care doctor.

Dr. Moore continued that the items on the Children's Functional Assessment Rating Scale (CFARS) were put into 4 different domains in a global domain and found that

basically the children in the sample in all of the groups generally had higher CFARS mean scores. CFARS goes from 1-7; 1-3 is mild. 4-6 is moderate.

Dr. Moore said that, based on the information learned, the clinical committee recommended that there should be in the chart, a form that will list the medication that is being prescribed, the dosage, the frequency, the target symptoms for which it is being prescribed, who is prescribing it, when do you stop, height, weight, abdominal girth or BMI, blood pressure, and heart rate, for all children on atypicals.

Dr. Moore noted that if you want to make a difference in how psychotropic medications are being prescribed, you have to change the culture both in your prescribers and your child welfare system and in your foster parents and in your natural parents.

Dr. Moore shared current data for the past 6 months for children 0-5 and 6-13. The most concerning data in the 0-5 age group was the number of antipsychotics and stimulants prescribed. In the 6-13 age group; 10,113 children (average of 10) were prescribed psycho stimulants.

Dr. Moore concluded with the following recommendations:

- Focus efforts on the appropriate use of medications for the clinically meaningful target symptoms as clearly defined by the child and the legal guardian. Do not have someone bringing the child to a medication management appointment that does not have the authority to give express and informed consent.
- Have a thorough assessment (to include the comprehensive assessments if done) available prior to/at the time of medication evaluations
- At every medication management visit, the adult guardian (with authority to sign for treatment) must be present and an active member of the treatment team for the child.
- Develop educational trainings for the prescribers, case managers, and other treatment team members on the Florida Guidelines for Psychopharmacological Treatment of Children.
- Encourage the use of non-pharmacological treatments that are recognized as effective and are paid for by payors.
- Assist the Legislature, judges, parents, schools, agencies, and all others that approved
  of off-label prescribing of psychotropic medications should be at the end of the line
  for treatment of children and not at the front whenever possible.
- Poisons in/Poisons out it should be the responsibility of all concerned when we are prescribing these medications to children.

• Documentation from everyone with coordination being the responsibility of everyone involved with the child.

#### Questions/Comments/Discussion

1. Ms. Rosenberg commented, with regard to recommendation 3, that the caregiver and the person that has legal capacity to consent is not always the same person. She noted that the problem is that these children for the most part do not have a legal guardian who is capable of attending that appointment and signing the document. Either parental rights have been terminated, so it is the state, or the parent has continued legal right but may or may not be involved.

Dr. Moore responded that perhaps the workgroup should consider getting the law changed and that children should not be the victims of prescriptions of psychotropic drugs without express and informed consent.

# **ADJOURNMENT**

The next meeting of the work group is scheduled for August 5, 2009.

Adjourned at 4:30 p.m.