

**Erie County Safety Net
for Youth**

Dual Diagnosis System

Transformation Task Force

**Report January 15, 2008 to Erie County Community
Coordinating Council
on Children and Families**

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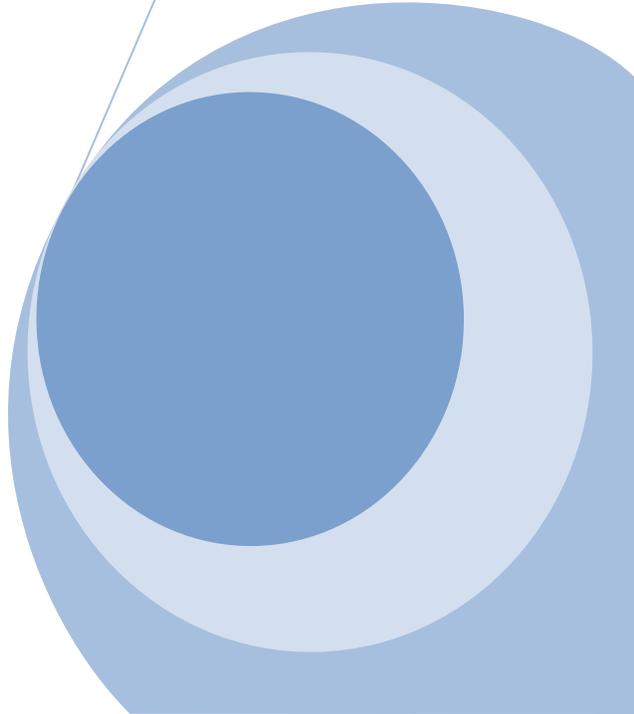


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I. Introduction and Statement of Problem

Over the last 10 to 15 years, there has been an unprecedented influx of youth with *dual diagnoses*,¹ or have multiple diagnoses requiring assistance and services from the New York State Office of Mental Health (OMH) and the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD). OMH serves adults and youth with severe mental illnesses. Also, OMRDD serves adults and youth with developmental disabilities and mental retardation. Both agencies provide and oversee an array of services provided to individuals that meet specific diagnostic or inclusion criteria. The current problem includes the operation of the two agencies as separate entities with little collaboration across the offices. Youth with dual diagnoses are often faced with the dilemma of receiving services from only one of these two systems. When a youth is diagnosed with a mental illness as the primary problem, he/she is allowed to OMH services and is denied access to OMRDD. Alternatively, if a youth is diagnosed with developmental disabilities as the primary problem, he/she is given access to OMRDD services and denied OMH. With a dual diagnosis, a youth would require access to both systems. When access to one system is denied so is the funding for the agency that could provide the needed care. Throughout Western New York, consistent and clear protocols for providing services across both systems have not been established. A significant void has been created in providing effective treatment and services to individuals with dual diagnoses. Without access to care across both agencies, the potential will exist for even greater costs by taxpayers to care for youths that are only partially treated. Added to the dilemma is how OMH and OMRDD are to serve youth with dual diagnosis in collaboration with services from the New York State Office of Children and Family Services in the dual role of the Community Multi Service Office (formerly known as the Division for Youth) and as the State oversight body for all local Districts of Social Services, New York State Office of Alcohol and Substance Abuse Services, and the State Education Department.

Erie County currently faces an increase number of youth with dual diagnoses that are being treated inadequately. December 2006, the Erie County Safety Net for Youth Task Force was assembled. This task force centers on identifying barriers and system issues that impede the care and treatment of youths who are dually diagnosed and make recommendations on how to eliminate these barriers. The following report includes a historical account of New York's treatment of youths, case studies illuminating the state of care, effective care of youths in Erie County, the delineation of barriers that exist, and data on needs and costs the present systems of care. Finally, this Task Force will conclude with specific recommendations on how to best serve youths with dual diagnoses.

¹ The term dual diagnosis refers to those individuals who have been diagnosed with a mental illness and a developmental disability and/or mental retardation.

II. History and Background

In 1972, the abuse of individuals with mental illness and developmental disabilities at the Willowbrook State School began a series of events that changed New York State's approach to individuals diagnosed with various challenges. At that time, mental health problems and mental retardation were considered severely limiting disabilities that required institutionalization for those affected. In response to documented abuse in state institutions and New York State's desire to improve the quality of life for individuals with disabilities as well as their families, New York State formed two agencies. The two agencies that identify and provide services are the Office of Mental Health (OMH) and Office of Mental Retardation and Developmental Disabilities (OMRDD). In addition, the other state agencies that provide care to this population of children and youth is the NYS Department of Education (SED), the NYS Office of Child and Family Services (OCFS), which includes the juvenile justice system and oversees the Erie County Department of Social Services, and the New York State Office of Substance Abuse and Alcohol Services (OASAS). Thirty-five years later, New York State clearly provides numerous services and supports to individuals with mental health problems and their families. However, families and youth face serious challenges in working across the systems when accessing services and supports. Specifically, each service system has its own mandates, regulations, and terminology. While these parameters seek to protect youths in respective systems, the complexities create barriers for families and youths who access the appropriate services within and among systems.

NYS Governor Spitzer launched the *People First Community Forums* on April 26, 2007. He asked "What does the child need and what helps the family manage their child at home? What supports help stabilize a family and enable them to deal with the possible long term challenges in a more effective manner? How can we overcome the barriers?" In this effort, the state agencies seek to improve coordination of all services. Governor Eliot Spitzer announced that Commissioner Richard F. Daines, M.D., of the Department of Health (DOH), Commissioner Karen M. Carpenter-Palumbo of the Office of Alcoholism and Substance Abuse Services (OASAS), Commissioner Michael F. Hogan, Ph.D., of the Office of Mental Health (OMH), and Commissioner Diana Jones Ritter of the Office of Mental Retardation and Developmental Disabilities (OMRDD) will conduct a series of Coordinated Care Listening Forums (CCLF). The Governor directed the commissioners to travel the state, listen to health care needs of New Yorkers, and provide recommendations to improve and coordinate support for people across the four systems.

"For far too long in this state, individuals with multiple needs had to navigate through a complex myriad of state and local bureaucracies before they begin to receive the care they need, which is why patient-centered system in New York is necessary.

Improved collaboration at all levels of government will be essential in moving our systems of care forward in the twenty-first century,” Governor Spitzer stated.

The People First Coordinated Care Listening Forums are a starting point for new collaborative initiatives aimed at better serving New York’s residents. The forums are designed to listen to people who require services across various systems, to better understand their needs with the goal of obtaining insight on how to improve quality and outcomes, as well as coordinate supports for individuals. Based on Governor Spitzer’s clear identification of these children and families need, our task force has been motivated to make a difference in Erie County. Too many children and adolescents have been negatively affected by the lack of coordination and system silos.

Historically, in Erie County, efforts have been made to address the growing needs of this county’s family and children. The Erie County Community Coordinating Council on Children and Families (ECCCCCF) was developed in 1988. The Council’s duties as defined by the legislation include:

- Fostering cooperation among local government and public or private agencies.
- Eliminating duplication of services.
- Stressing meaningful accountability by service providers.
- Improving methods of ascertaining community needs and setting program goals
- Identifying problems or deficiencies in existing services.
- Recommending correction action when appropriate.

(See the Council’s report at <http://www.erie.gov/health/mentalhealth/ecccccfcf.asp>.)

In 1998, Erie County developed a subcommittee of the ECCCCCF, called the Safety Net for Youth Committee (SNFYC) to address youth that do not have adequate supports and are in dire need of services. The multi-disciplinary group meets monthly to review the situations about referred children. Governmental and private agencies refer to this committee when all other avenues are exhausted. The greater numbers of referred youth are dually diagnosed and require services across two or more systems. In December 2006, due to the increasing number and complexity of the referrals, the SNFY Committee decided to form a Task Force to develop this report. The task force is a result of a didactic and collaborative effort of various system representatives, which are listed in the appendix. There are efforts in the works to coordinate the results with Region II Cross Systems Leadership Team. *See Appendix for these reports.*

III. Case Studies

In order to help make this significant issue more personal, our task force had several real life case studies presented. While each story is different, there are common themes that underlie each situation. The Safety Net for Youth receives cases on a regular basis and desires to recommend changes in the current system. Other powerful case studies are provided as part of the appendix. *See Appendix A and C.*

Case Study 1: Anne a ten-year-old child with developmental delays experienced mental health issues and exhibited severe behaviors. Removed from her family and ten subsequent foster families that could not manage her multiple disabilities, due to the current system barriers the families were denied access and funds necessary to stabilize Anne. Anne’s developmental disability was not documented to satisfy OMRDD eligibility criteria. Her education was fragmented due to multiple foster care settings in various school districts. Child and adolescent psychiatric services and behavioral psychologist resources in the WNY area are extremely limited. Despite attempts and collaboration among agencies, the Department of Social Services (DSS) was ultimately forced to remove Anne from the WNY area and place her in a costly institution in Florida. A feasible discharge plan remains unclear, further alienating this child from her family and her WNY home. At a tremendous financial cost to the region, the system has failed Anne for a number of reasons. Especially, because upfront intensive cross-systems resources were not offered early enough for Anne and her foster family at the time could have benefitted. In addition, there was a shortage of child, adolescent psychiatrists and behavioral psychologists. As a result, she was without the right evaluation and supports, she became out of control exhibiting antisocial behaviors. She became difficult to treat.

Case Study 2: In November 2007, a mother of a 12-year-old dually diagnosed youth, raised concerns about her son (See Alex’s story, appendix A). She encountered roadblock after roadblock trying to get appropriate educational services for her son in a suburban district. She attempted to get him into a day school, but was told that they had a waiting list of 29 (19 of these students were confirmed by NYSED). Frustrated but determined, she made contacts with a state senator. Her son received an appropriate placement and she brought local and state agencies to the table with the state senator to look at this issue and analyze what can be done. It was determined by the NYSED that there were 19 students on the waiting list for this particular agency. At the meeting, NYSED requested the agency to expand programming and they agreed. However, it was unclear how to prevent this from happening in the future. NYSED states local need for out of district placements is determined by the school districts, BOCES, and private educational programs. There is apparently no central list that is maintained by NYSED. Under the Individuals with Disabilities Education Act 2004, there are laws that strongly encourage education for students with disabilities in the least restrictive placement with their non-disabled peers. Therefore, NYSED looks to the districts, then BOCES to be the first rings of support to provide free appropriate public education for youth with disabilities. With students on the autism spectrum or dually diagnosed, the districts

develop programs to support these youth or gain BOCES help to build education plans. If this does not work, they will approve day school, day treatment variances, or program expansions where each student can be served appropriately.

Tragically, these are not isolated cases. In response to the challenge of raising a child with multiple needs, families lack the knowledge or have fear of seeking help. They develop a sense of being overwhelmed and often perceive themselves as unable to manage. Dangerous events in a child's life can quickly develop as the situation can become intense and volatile. Typically, DSS is contacted and the challenge of obtaining services begins. Eligibility for access to the systems is often the first lengthy barrier impeding the delivery of necessary supports. Once eligible for one system, the necessary supports funded by other systems are rendered unavailable. Within the present WNY service delivery paradigm, crossing the systems effectively becomes extremely difficult, and too often necessitates out of home and out of state residential or institutional placements that is costly to the county and the state. While there are certainly circumstances where youth may need temporary out of home treatment, more options need to be available to families and foster parents earlier on.

IV. System Strengths

Erie County continues to build on its strengths to ensure optimal service delivery to families, children, and youth. A progressive shift to a Family-Driven model allows for a partnership, which builds a system with flexibility and spirit of cooperation among all parts of a very complicated system.

The Safety Net for Youth Committee itself demonstrates the collaboration and partnership of multiple agencies. It is through this group's continued efforts that service needs are identified, especially issues related to the dually diagnosed group of children and adolescents and their families. The strength of SNFYC is finding creative ways of service provision to individuals. The next step is finding creative ways for systemic transformation.

The Western New York Developmental Disabilities Service Office (WNYDDSO) and Erie County of Mental Health (ECDMH) are working together to develop a comprehensive crisis system. The New York State Office of Mental Retardation and Developmental Disabilities released a RFP in November 2007. The State has allocated funding for development of crisis services for individuals with a cognitive impairment and severe behavioral disorder. The WNYDDSO, in planning for a possible move from the current West Seneca campus, is in the process of identifying various funding mechanisms that will be used to complement the current RFP. In addition, the ECDMH is currently working through Family Voices Network (FVN) to include the capacity to serve a subset of the target population through the wraparound process.

IV. System Barriers to Effective Care

Within Erie County's systems of care, the collaboration between system occur because individual relationships of members in various provider systems, which is time consuming and costly. There is no standardized protocol for how agencies should collaborate. Factors prohibiting a standardized protocol for cross system service delivery include:

1. **Cross System Information and Training Needs:** System knowledge, including eligibility requirements and linkage protocol is lacking for both families and professionals. Targeted, empirically based training programs for direct care level providers are also needed.
 - a. Publications, such as the Family Support Directory compiled by the WNY Family Support Coalition may be under utilized due to lack of awareness.
 - b. Assessments completed within one service system may not address the issues required for admission or care in another service system, yielding costly duplication of assessment services and overtaxing of limited evaluation resources.
 - c. Availability of behavioral health trained staff capable of providing critical support services to families is highly limited.
 - d. College and medical school training regarding identification and treatment of children with co-existing developmental disabilities and mental health disorders is extremely limited.
 - e. Ongoing training opportunities for primary care physicians and pediatricians in relation to appropriate assessments are crucial in determining type, level of services, supports required by the child or adolescent and the family.
 - f. Providers and families lack a clear understanding of service coordinator and care manager roles.
 - g. Lack of uniform, transferable paperwork system to facilitate linkage, service delivery within and across systems.
 - h. There is limited availability of psychiatric and psychological care within the WNY community. Some psychiatrics are not comfortable treating dually diagnosed kids or they work in settings where such children are generally not accepted for services. Women's and Children's Hospital of Buffalo get many referrals for youth who have been turned down by other OMH-licensed clinics because they do not take children with IQ's below 70. Dually diagnosed kids often have Medicaid, as their only insurance or as secondary insurance. This severely limits where they can go for services, even if they should be as fortunate as to discover a psychiatrist who would otherwise see their child. In order to get psychiatric services, they pretty much have to be seen in an OMH-licensed clinic or in a DDSO clinic, like the one in West Seneca.

- i. OMH does allow Women’s and Children’s Hospital of Buffalo to evaluate and treat youth who are dually diagnosed, but it is reportedly becoming more difficult. The regulations are clear, they are allowed to; however, they face some problems. As reported, OMH has told WCHOB they cannot develop a diagnostic evaluation program for young children suspected of having autism. Their rationale is WCHOB is not supposed to evaluate anyone except to determine if he/she is appropriate for admission to their clinic treatment program. They are not to provide a diagnosis so a child can get needed services elsewhere, such as in the schools. Due to regulations, there continues to be pressure from OMH, for WCHOB not to complete autism evaluations or see children with autism in their clinic. Some other OMH-licensed clinics seem to believe that they are not allowed to, but according to the regulations, they can if there is a primary mental health diagnosis. These other clinics do not have nearly as much psychiatric time as WCHOB and they really have to use it to see children who are concurrently receiving therapy in their clinic. So where do the dually diagnosed youth go who need only medication and cannot benefit from any sort of therapy? Because WCHOB seems to be just about the only place in the area for this, it really limits where evaluations can be done and they can easily be inundated with referrals. There needs to be a way to create greater flexibility for evaluating youth that have features that cross both OMH and OMRDD systems without being limiting.
2. **Crisis Services Needs:** There is currently no comprehensive multi-disciplinary assessment or treatment program to assist families in preventing and controlling crises within the child or youth’s naturally occurring environment. Current NYS mandates such as Clinic Plus and SED place limits on local school districts to maintain youth within the state system because this will potentially increase the need for crisis intervention services within Erie County.
3. **Cross Systems Processes:** Philosophical orientations within each system may hinder collaboration across systems.
 - a. Programmatic funding guidelines, including current Medicaid regulations make it difficult to provide cross system services.
 - b. Agency guidelines, funding, acceptance guidelines for services may prohibit a family (vs. client) model of care.
 - c. Lack of capacity due to a variety of privacy/confidentiality issues, to share important client and family specific information between systems.
 - d. There is no “step down” process between levels of care (e.g. Residential Treatment Facility to home; acute hospitalization to home) to build on the youth’s success in the least restrictive environment.
 - e. School districts are inappropriately asked to pursue residential school placements in lieu of IRA or RTC settings due to lack of availability.

- f. Enrollment capacity place limits on agency based day schools and preclude educational placements for needy students, regardless of the agency's ability to expand its program to accommodate the waitlists. This suggests that the severity of the waitlist for agency based day school placements is unknown at critical administrative and decision making levels.
 - g. Instate residential educational services for students with significant and or multiple needs are limited. Out of state placements limits important family involvement.
 - h. The number of psychiatrists treating children and adolescents is extremely limited in the WNY area.
4. **Family Advocacy Concerns:** Sometimes, there is a "bridge" between families, service providers, and others. Other times, there is an adversarial relationship, where sides are drawn (this can be barrier or strength depending on the advocate).
- Examples are:
- a. There is often a stigma attached to receiving services.
 - b. Families may sometimes not provide all the necessary, relevant information due to concerns such as stigma, potential out of home placement, and financial entitlements, etc.
 - c. There is often not a functional family to provide services to (i.e. foster care, congregate care).
 - d. Lack of respect for the family voice.
 - e. Professional distance on the part of service providers and/or inability to provide cultural competence.
 - f. Lack of trust as "sides" develop.
 - g. Families do not provide important information or due to low literacy, they do not understand information given to them.
 - h. Some of the youth come from families that cannot or will not support their healthy growth. Therefore, a major focus for these children needs to be finding a permanent home. The longer these youth drift without permanent roots, the more difficult it becomes to find an appropriate family situation. In addition, residential placements for some youth and family are the healthiest option available.
5. **Educational Concerns:** Erie County face barriers in a number of areas such as Buffalo Schools and surrounding areas. These are also more universal and affect the county as well as nationally:
- a. The waiting lists for area day school specializing in educational programming for specific groups of students remains very large.
 - 1) A number of students who have autism have trouble finding placements (because specialized agency school programs are reportedly capped by the State Education Department). These

students are receiving home instruction, currently are not in the appropriate setting, and are on long waiting lists.

- 2) Students who have Juvenile Delinquency problems and behaviors are on waiting lists for Gateway-Longview, Falk, New Directions, Hopevale, and Baker Victory Services, et al. This population carries an extremely high need of management and supervision which even the day schools are currently having a difficult time providing. Waiting periods have been longer than a year in some instances.
 - b. There is currently a county initiative to reduce the number and length of stay of youngsters in residential placements. This mandate often dictates that students re-enter their local school during the middle of a semester, causing educational difficulties for the student as well as the teaching staff.
 - 1) Continuity of instructional text books series, specific order of content presentation, methods and techniques are usually disrupted, leaving the child fragmented in the educational setting.
 - 2) All too often, students end up repeating a grade at the elementary and junior high school levels due to the timing of school re-entry. Discharges between spring recess and the end of the school year very often carry educational complications and setbacks.
 - c. Unplanned discharges through the court system, as well as emergency systems, prove the foster care system can present challenges to the school district in terms of making appropriate educational placements in a timely manner.
 - 1) Lack of required paperwork (e.g. signed consent forms) delays entry.
6. **Costs to Society:** In every instance, home will be the least expensive route while maintaining the family system. However, this requires a creative use of fiscal resources.
- a. Incarceration costs more than delivering services to the family in the home. Services also impact the quality of life.
 - b. Out of state residential facility costs more. How can we bring our children home?
 - c. An out of state facility costs the County airfare, telephone calls, as well as local services to the family and puts an emotional strain on the families.
 - d. Not identifying the appropriate in-home services cost more while trying to determine what works and does not work. This is an additional problem when there is an inability to access the appropriate services.
 - e. The lack of cross system communication has each child and the family starting over and duplicating unnecessary assessments when entering into a new service system.

- f. Once SAMSHA dollars are no longer available, the sustainability of programs may be costly. Funding to support families at the front end may alleviate some costs.
 - g. Multiple agency and placement moves are costly. It requires many service providers and staff resources.
 - h. Wraparound for foster parents would reduce costs for youth who are placed in Residential Treatment Centers. The current regulations limit wraparound services to foster parents.
7. **Unclear delineation of who is responsible for youth with dual diagnosis by OMRDD/OMH/SED/OCFS/ and OASAS:** This causes uncertainty especially when placement and/or services are not working in one of the systems.

V. Data and Scope of Issue in Erie County

Erie County has a reported population of 921,390 according to a 2006 estimate. The number of persons with a disability, age 5 and above is reportedly 168,549, or better than 18.3% of the total population. The percentage of persons that are under 18 years old is 22.6% (see <http://quickfacts.census.gov/qfd/states/36/36029.html>). As these numbers have continued to increase, the county’s tax payer base has continued to decline. Youth that have developmental disabilities or are seriously emotionally disturbed generally can get served adequately in the respective systems designed to meet their needs as previously mentioned. However, when there are co-occurring issues the systems typically break down.

Historically, youth with dual diagnosis were the system’s “hot potatoes.” They were getting passed back and forth between the various mental health, social services and educational systems. The Erie County Department of Social Services was usually the agency of last resort for trying to find services and/or placement. The Safety Net for Youth was formed initially to help alleviate this major community concern. Some examples of data collected are as follows:

Example of Anne: Aforementioned, the ECDSS provided a case example for our process. This case showed how one youth presented complex and challenging problems over an extended period. It provided the Task Force a way to open up the dialogue about how services were provided and what could have been done differently.

These are a few of the monthly rates for Anne over the last few years:

New Directions Diagnostic	\$6971.90
Hopevale Therapeutic	\$1516.60
Catholic Charities Regular FC	\$274.02
Devereux-Florida RTC	\$6165.00

1. There are complicating factors whenever youth are placed. One factor is the lack of a family perspective and youth guided system (such as in the Families CAN philosophy). Another factor is that some of the youth come from families that cannot or will not support their healthy growth. In addition, residential placements for some youth and family are the healthiest option.
2. **Autistic Services Waitlist:** Veronica Federiconi, Executive Director at Autistic Services, shows example of local problem dealing with youth referred to them and NYSED cap on expansion of day school services according to her. *See Appendix B.*

Waiting List as of 6/1/07

- We currently have twenty-three (23) students on our waiting list that meets all above mentioned criteria.
- Two (2) of those students are in crisis and are on home teaching.
- We will probably receive about 5-7 more requests before the end of the 2006-2007 school year.

We also maintain a list of students who requested placement but were removed from our waiting list because we were unable to place them in a timely manner and they had to seek placement elsewhere. There are currently twenty-two additional (22) students on that list.”

3. **Baker Victory Services Studies of Multiple Diagnosed Youth:** See Two Reports from Baker Victory Services from 2003 and 2006.They show the prevalence of needs for local youth who are dually diagnosed over two time periods. This identifies some of the numbers and needs over time (excerpt from report). *See Appendix C.*

Survey of Special Needs: Data Summary for March, 2002 through April, 2003

Agency/ Source	Multiple Diagnosis		Sexually Aggressive Youth		Sexually Aggressive Youth w/Multiple Diagnosis		Total Youth	
	N =	% for agency / source	N =	% for agency/ source	N =	% for agency/ source	N =	% of cum. total
Cattaraugus Co. DSS	2	50%	2	50%	0	0%	4	1.9%
Chautauqua Co. DSS	1*	17%	0	0%	5*	83%	6	2.8%
Erie Co. DSS	10*	53%	2*	10%	7*	37%	19	9.0%
Genesee Co. DSS	1	10%	8*	80%	1	10%	10	4.7%
Monroe Co. DSS	6	75%	0	0%	2	25%	8	3.8%
Wyoming Co. DSS	1*	14%	0	0%	6*	86%	7	3.3%
Erie Co. Community								

Coordinating Council on Child & Families	3	27%	7	64%	1	9%	11	5.2%
Erie County Detention	4*	50%	2	25%	2	25%	8	3.8%
WNY DDSO	4*	44%	0	0%	5	56%	9	4.2%
Erie Co. BOCES 1	0	0%	1	100%	0	0%	1	0.5%
Erie Co. BOCES 2	3*	100%	0	0%	0	0%	3	1.4%
WNY Children's Psychiatric Center	0	0%	11	92%	1	8%	12	5.7%
Child and Adolescent Treatment Services	0	0%	6	100%	0	0%	6	2.8%
Baker Victory Services	17	38%	19	42%	9	20%	45	21.2%
Child & Family Services	0	0%	0	0%	1	100%	1	0.5%
Gateway Longview	24	65%	7	19%	6	16%	37	17.5%
Gustavus Adolphus	2	22%	6	67%	1	11%	9	4.2%
Randolph	6	67%	3	33%	0	0%	9	4.2%
Wyndham Lawn	0	0%	7	100%	0	0%	7	3.3%
CUMMULATIVE TOTAL	84*	39.6%	81*	38.2%	47*	22.2%	212	100%

* Potential services which might alleviate the need for specialized placement were noted as follows:

Source	Multiple Dx	Sexually Aggressive	Both	Services Noted
Chautaugua DSS	1		1	Both Multiple systemic therapy
Erie DSS	1	1	4	All waiver/Respect
Genesee DSS		7		2 intensive counseling/supervision; 5 structured setting/family support
Wyoming DSS	1		2	Greater OMRDD services and support (respite) RAD intensive tx for family; Intensive in-home services & specialized sexually aggressive youth program
Erie Co. Detention	1			Common sense parenting/day treatment
WNY DDSO	1			Intensive arson treatment
Erie Co. BOCES 2	1			Intensive case management
TOTAL	6	8	7	-----

qi1:h:\survey of special needs

**Survey of Special Needs:
Data Summary for 2005 by AGENCY/SOURCE**

Agency/ Source	Multiple Diagnosis		Sexually Aggressive Youth		Sexually Aggressive Youth w/Multiple Diagnosis		Total Youth	
	N =	% for agency / source	N =	% for agency/ source	N =	% for agency/ source	N =	% of cum. total
Allegany Co. DSS	2	40%	0	0%	3	60%	5	3.2%
Allegany Co. Probation	2	100%	0	0%	0	0%	2	1.3%
Cattaraugus Co. DSS	1	33.3%	1	33.3%	1	33.3%	3	1.9%
Erie Co. DSS	6	50%	5	42%	1	8%	12	7.7%
Erie Co. Family Court	15*	60%	5*	20%	5	20%	25	16.1%
Genesee Co. DSS	1	100%	0	0%	0	0%	1	0.6%
Niagara Co DSS	5	100%	0	0%	0	0%	5	3.2%
Wyoming Co DSS	7*	88%	1	12%	0	0%	8	5.2%
Wyoming Co Probation	12	80%	1*	7%	2*	13.3%	15	9.7%
Genesee/Livingston/ Steuben/Wyoming BOCES	1	100%	0	0%	0	0%	1	0.6%
Care Management Coalition of WNY: <i>Baker Victory Services Child & Family Services Gateway Longview Gustavus Adolphus Randolph Wyndham Lawn</i>	24	31%	41	52%	13	17%	78	50.3%
CUMMULATIVE TOTAL	76	49.0%	54	34.8%	25	16.1%	155	99.8%

* Potential services which might alleviate the need for specialized placement were noted as follows:

Source	Multi Dx	Sexually Aggressive	Both	Services Noted
Erie Co Family Court	1	1		aggression program, sexual aggressive program
Wyoming Co Probation		1	2	sexual offender counseling program (3)
Wyoming Co DSS	2			pre-adoptive counseling, attachment counseling
TOTAL	3	2	2	-----

4. **OMH Report of Dually Diagnosed Youth:** The raw numbers here begin to show the significant scope of what we are facing. It is important to note that because there youth are identified as dually diagnosed, does not mean they are without appropriate services since most are receiving effective services. *See Appendix K.*
5. **People in WNY DDSO counties who are under 22 years of age and whose DDP2 indicates they have a psychiatric diagnosis:**

The New York State Office of Mental Retardation and Developmental Disabilities (OMRDD) utilize a number of tools to identify and capture the service needs of individuals receiving services. The TABS system documents the specific services on individuals as well as service histories. The Developmental Disabilities Abilities Profile (DDP-2) documents some clinical diagnoses as well as skills and abilities.

Data current to October, 2007 indicates that **2281** individuals under the age of 22 residing in Erie County were receiving services through an OMRDD (state or voluntary) provider.

Total having a Development Disabilities Profile (DDP-2 completed)	1193	
Psychiatric diagnosis	127	11% of total
Autism	373	16% of total

6. **Financial Data:** The following is an example of the cost of wraparound services and residential care for these youth (institutional placement vs. wraparound services).
 - a. Economic Benefits of Wraparound Services: Per Capita costs for a family in Wraparound in Erie County is approximately \$21,000 a year: \$11,000 of flex funds (buying services from a vendor or buying discretionary supports) and \$10,000 administrative infrastructure (staff, rent, utilities). The average cost for an Erie County child or adolescent to receive services from an RTC is \$121,000 a year. So every child and adolescent that you can de-institutionalize, hypothetically creates six wrap slots according to an EC representative.

- b. Obviously, the currently funded six year SAMHSA Grant is a tremendous asset for Erie County. The key challenge is ensuring that in all that we do we create and support sustainability of those efforts after the funding ends. Creating a system which prevents or reduces out-of-home placements is paramount. By example, mathematically for every child that you prevent or return from a Residential Treatment Center placement, on a yearly basis, you generate enough funding for six community based Wrap Around families.
- c. An OMH representative reported that the OMH waiver program can run anywhere from a budget of \$38,000 up to \$52,000 per year. But there is a mathematical calculation that goes on over how many slots you have, so there is an overall cap depending upon what the slots are. They try to keep it somewhere between \$42,000 and \$46,000, and that includes skill building, respite, crisis respite, medication, hospitalization.
- d. These costs do not include what it costs a family to stay connected to their child. For example, there are youth from Erie County placed in Rochester and further. The cost of gas for the family to get to Rochester to stay connected is expensive, too. It is conceded that some youth will need various levels of residential programming; however, efforts need to be made to keep youth close to family where possible and allow opportunities for youth to “step down” to less restrictive levels of care when clinically indicated and supported by families.

VI. Summary:

The building blocks for dual diagnosis system transformation include leadership from government agencies, private agencies and family support groups which all believe in solution and family focused principles. The collaboration of these agencies must be community based, strengths based, and outcome based forming the backbone for multiple agencies and natural supports to work together with families. The goal is a cross system wraparound model with an integrated crisis network. It must be dynamic allowing for blended funding and regulatory support in Erie County.

Principles for Change:

- **Family and Youth Driven:** Partnering with families is the base for developing services, regulations, and a network to ensure maximum benefits of service provision. By delivering services in our home community, resources can be consolidated and be more cost effective.
- **Blended Funding:** Funding across systems with timely distribution of funds reduces costs of service per event and per child.
- **Regulatory Support:** Strict regulations about who can be serviced can result in children and families not getting necessary services. A coordinated system with flexibility in regulations decreases the band-aid solutions and increases private/county/state cooperation.

- **Prevention and Early Identification:** Proactive assessment using research-based evaluation methods allows for early treatment and greater quality and cost measures. Family integrity is maintained in lieu of more dramatic measures such as placement out of the home.
- **Cross System Wraparound Process:** Pooling services across agencies for children, youth and families necessitates flexibility in regulatory standards to provide simultaneous services in multiple systems.
- **Education and Training:** Information is crucial about early identification, the wraparound process and family driven care, special needs of children, and skills development. Cross training between agencies and involvement with local universities, Family Court personnel, general practice pediatricians and physicians are necessary to improve care.

The discussions about principles of change resulted in three broad-based recommendations and action steps. The representative agencies agree that on an individual case by case basis we collectively can problem solve together to formulate a service and treatment plan for individuals. However, this is not optimal. A systemic transformation is a commitment to create a process, which ensures critical pieces are not overlooked in a system transformation.

VII. Recommendations

Establish a cross system wraparound model of care, which addresses the provision of the bio-psychosocial needs for children and youth with dual diagnosis. Such a system requires that mental health and developmental needs are addressed while ensuring there are home services, appropriate educational programs, and support services in place. This comprehensive model can be developed as a pilot program in which represented agencies pool their talents and skills while at the same time, administrative liaisons collaborate on adjusting regulatory standards, practices, and processes. This model also requires a need to evaluate early identification and prevention for the pilot group with processes in place to provide wraparound services early on rather than await a crisis situation. The model also necessitates a subgroup of professionals working in concert with the university on education and cross training of professionals, families, school personnel, social services, family court, general practice pediatricians and family practice physicians. Parent training must also be integral to support children and youth in the home. The cross system wraparound model builds on family and youth's strengths.

To orchestrate a true cross system wraparound model, blended funding across agencies is crucial in identifying and providing services and eliminating regulatory barriers. Funding streams for children and youth with dual diagnoses requires a review of regulatory changes and waivers that can be used for quicker accessibility to needed services. Regulatory change includes recognition of the changing demographics of Erie County, such as the increase in Autism Spectrum Disorders, the changing resource needs

of our workforce, and the prioritization of this special group. The first step is the identification that reallocation of funds is important for servicing this group without concern for regulatory limits. This includes the development of a seamless cross-systems process allowing for continuity of care. It would be optimal for individuals to move across systems (e.g. in-home providers, schools, OMRDD services, mental health services) utilizing a Passport system that increases efficiency in obtaining services. The proposed Passport system is founded on the principle that these children and families require services across systems necessitating open and timely communication, mutual problem-solving, shared responsibility of service delivery and regulatory flexibility. Another example is early identification in the cross system wraparound process identifies a need for a specialty classroom, portioned funds from multiple agencies within the Passport system could be used to fund the program.

A specialized crisis services network addresses the complex needs of dually diagnosed youth and their families is in its infancy stages in identifying mechanisms. There is a critical need for more psychiatric services for evaluation and treatment. Through one of the funding streams (OMRDD/OMH) that will be used to supplement the Request for Proposal. A comprehensive system with clearly defined processes will improve the quality of services as well as ensure the safety of children, families and the community. A specialized and comprehensive crisis services network needs to be created building on the existing crisis system. This network requires the funding stream and the support of all stakeholders in this community.

As a result of identifying barriers and potential solutions, it is imperative that the above three recommendations be seriously considered as a step in changing the current system of services. The implementation of a cross systems wraparound model including a crisis network can best be achieved with a blended funding stream for a pilot project in Erie County. Not only may it benefit our children, youth and families, but it may serve as a model program nationally. With an initial focus of five children in a pilot Passport program, we propose an action plan to provide services in a cost effective and timely manner for children who do not fit in one clear service category.

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Appendix A

Additional Case Studies: Chris Hoff's comments:

I have just a few questions for today's group. Imagine for a moment that you have just been told that your child has an autistic spectrum disorder.

Would you know how to recognize it in a young child?

Would you know where to go for a competent treatment?

Would you know how to be a competent, loving, parent?

Imagine being told this and then finding no help or support anywhere.

You might have been told in the past that your child has ADHD, OCD, ODD, Pediatric bipolar or any number of other related disorders. Now some Professional adds on autism. But don't worry it's only mild.

They might call it Asperger's, PDD-NOS, High functioning autism, or non-verbal learning disorder.

Would you know how to discipline your child?

Imagine telling your family – parents, aunts, uncles.

They tell you there's nothing wrong with your child that some strong discipline won't fix.

When you bring this information to school they tell you - well his IQ is within normal range

He does not qualify.

When you tell family friends they shun you and your child.

Here is a quote from one of our moms- "A few weeks ago a neighbors child had a very serious fall which resulted in a head injury. Everyone rallied around the family and showed tremendous support. They had a benefit, made food, sent cards. My child received a diagnosis of Asperger's syndrome. There is no support.

There is isolation or disbelief. Your judgment as a parent is called into question."

One of our moms is a nurse. She has been told by teachers: "I can't learn about your child's disability. Do you know how many children I have to take care of?"

She replied: "I am a nurse I cannot tell my patients I cannot learn about your child's sickness I have too many other patients to care for. I would get fired and lose my license."

I have had the privilege to facilitate an Asperger's, PDD-NOS, high functioning autism & nonverbal learning disorder parent group. During this past year parents have come or called or emailed me looking for help. Hoping I had answers. I could offer support and advice but there are not the programs or info they are looking for. Very often they have gone many places to find help and are traumatized by what happens. Parents go to school looking for help because usually a report from a professional gives recommendations that are school based. Schools are frustrated because parents think school will fix their child. The rate for suicide attempt or threat in these children once they are middle school age is nearly 100% - this was by an informal question I would ask of parents after several parents reporting this at one of our meetings. You would not know this if we did not have a group. This was approximately 30 - 10-16 yr olds. I was astounded by the numbers once I had the courage to ask. They want to know how to tell their children but they do not totally understand themselves and are worried they will cause more stress. Or they think not telling them is the answer. Many times there is a history of some other genetic condition in the family history. This needs further investigation.

The needs of our families stem from public & professional misinformation & misunderstanding.

1. Parents need to be competently educated about their child's disability. It can be very hard to figure out what behavior is normal, what is the disability and what is a mental health issue and how to handle these issues.
2. How to discipline effectively using a Positive approach. Many times parents are over disciplining, under disciplining or not disciplining. This is because standard methods of disciplining are not effective. The ASD child does not relate the punishment to the behavior.
3. There should be a specific certification for professionals so parents know they are taking their child to a professional who is knowledgeable about ASD.
4. Support is needed for the whole family!! There are unique sibling issues that need to be dealt with professionally. Parents need support in many ways. There are probably a lot of dads with ASD that are not recognized. This creates a family dynamic that is very hard on the mom. Competent respite is needed. Moms can become part of the ASD child's routine. Very often mom has anxiety herself.
5. A whole child approach is needed.
 - a. complete medical history including family history
 - b. emotional evaluation
 - c. neurological evaluation
 - d. educational evaluation
 - e. psychiatric evaluation
 - f. genetic evaluation

When a true team approach is taken then we will see positive results.

Care needs to be delivered in the families' community. Under one roof would be preferable.

Finally, please try to focus on some of the positive aspects of ASD. People need to realize teaching and learning can work both ways. ASD children and adults have a lot to offer if we can accept them for who they are and look for their unique gifts. Many of my families would not want to cure their children. Some parents know ASD is a part of who their children are. They are looking for acceptance, understanding and an opportunity for their children to have a normal as possible life.

There are many issues, but creating a standard of care and education are very important. Parents need help & places to seek treatment that understand their clientele. Parents need to understand this is a developmental disability and a mental health disability. They need to get their child into counseling. To help with the anxiety at an early age. Their child is not crazy and they are not bad parents. They do need to learn how to be the parent of an ASD child.

_____ Hi Chris!

It is been awhile since I have been in touch with you; please forgive me. Thank you, though, for keeping in touch and sending me the information that you do on Asperger's and High Functioning Autism Spectrum Disorders. I really appreciate your thinking of me. I almost have mixed feelings about the following over the summer (2007), my daughter Justine (who will be 12 in March '08), was tested by Dr. Santa Maria who said based on what she scored, and his interview with her, she does not in fact have any form of autism and/or a learning disorder. At the time, I didn't present her abilities very well on the test either as it was confusing. He said I made it look as if she were mentally retarded. Needless, to say I was embarrassed. I think I answered the questions based on what she would not do for herself, was still trying and her resistance to some activities. I didn't mean that she could not do certain things for herself. Anyway, his diagnosis of her was that she has major depressive disorder, obsessive compulsive disorder and this made it appear as if she has a learning disorder. At this time, Justine is doing much better in school. Her grades are better and it is not a struggle to get her to school on time. Justine's current Psychiatrist that she sees for medicine is Dr. Martin and he diagnosed her as having just OCD and anxiety. However, she is on Prozac and I believe that has helped to motivate her more and get her to have more stamina mentally. I am not sure why Dr. Martin did not diagnose Justine as having Major Depressive Disorder as Dr. Santa Maria did. I do believe she has that. She still is a difficult child and I am not sure if I should just take Dr. SM's diagnosis as the end or do more research. I am happy that she does not have a learning disorder. I am concerned that some of her actions in the past were very confusing and I am wondering if some things she has not just outgrown. Her balance and gait were awkward. She had a lot of

occupational therapy (O.T.) and physical therapy (P.T.) issues and she has just learned to ride a bike at the end of summer. Her rigid thinking is quite the challenge. I could go on. I am going to start attending mental health support groups again. Somehow, I feel like I was almost a phony saying she had a learning disorder. When there are parents who struggle every day with their own child who actually has Asperger's and/or some kind of learning disorder.

I hope I have made sense to you. Thank you for your time and have a Happy New Year!

Denise Panzarella----- Original Message -----

Chris,

Here is a reply to what we talked about. Hope this helps.

There are three general areas that need attention in the Asperger person's life that are sorely neglected such as information and support for family, up to date medical support in all areas, and proper educational support.

The parents seem to be hungry for information and tend to become experts in their child's disorder, reading every study and book they can get their hands on and going to every seminar they can afford. What I am talking about is lack of support from extended family. It is sad when these boys grow up in cultures where the mom has to constantly shield them from comments from aunts, uncles, grandmas, grandpas, great aunts, etc. that go like this: "Give me just two weeks with him and I will straighten him out." "What he needs is a good slap on the butt is all." "All he needs is some good old fashioned discipline." "If he were mine he would not be allowed to get away with that under my roof."

No amount of self-education from the parents has stopped this thinking, and it is seen in many families. The parents are seen as "babying" the boy, thus this style of parenting has caused the boy to act differently than his sibling. It has become the parents' fault in the eyes of family and friends. The family is then cast aside because they are different and not seen as being skilled as parents. Maybe if someone from the outside was brought in at different stages of the child's life to educate the family then more acceptance would take place within the family and that would filter outward towards the friends of the parents.

Up to date medical support in all areas means that not only do we need our boys to have the latest diagnostic testing available for Asperger's, and the latest interventions an early age but we need ALL medical professionals to have a great understanding of what Asperger's is. What I mean is that ALL medical personnel should be required to have taken course work on what Autism and Asperger Syndrome is and should have at practical experience working with Autistic and Asperger people before getting their medical license.

We have gone to many, many very highly specialized doctors such as dentists, orthopedic surgeons (my son has titanium rods in his back), neurologists, nurses, etc. who have done a very good job in their specialized field and treated my son for his problem he came to see them for, but they looked at him strangely and had no idea why he was freaking out over a needle, or a dentist drill (we had to leave her) or just could not stop talking about Star Wars. They could not deal with the Asperger part of him because they did not know what they were up against and had no experience in it. Whenever we go to a doctor I constantly have to act as a buffer for my son and educate office staff, nurse, doctor, etc. Shame on them! Open your eyes and start educating yourselves!

The educational system is the worst because we have to deal with it every day. I cannot wait until my son graduates and goes to college and can choose which school, teacher and courses he wants. Each year is another Asperger tutorial then we sit back and wait to see who was not paying attention. Also, they will punish him for acting like an Asperger person, then we invite them to one of our little meetings where I try to spell things out like the teacher is in first grade - Do you get this now? I am at my wits end with teachers who think this kid is doing this on purpose. I am just burned out about people not getting it.

One of the biggest drawbacks is that during middle school and high school an Asperger student is not allowed to keep the same Resource Room Teacher. It takes so long for the Asperger person to mesh personalities and for the teacher to learn how to deal with his quirks, that this is really the biggest shame that New York State is overlooking in educating these kids. There is no continuity for them. It is traumatic in September all over again for them. There are no familiar faces for them from 6th grade through 12th grade.

Socialization is also a huge problem. The educational system has nothing set up in the lunchroom, in the hallway when the kids change classes, in homeroom, etc. during those "free" , roaming times when the other kids are socializing our kids are just lost or getting picked on. A buddy system would be great.

Hey New York State when are you going to wake up and realize that not every person in this state is college material? You are losing all of your plumbers, carpenters, electricians, etc. Do you know how much these people get per hour now? Not every one is regent's material. I am lucky that my son has been passing the regents with flying colors, but many, many Asperger's kids have very specific talents. However, other kids may not be able to pass the regents tests. We need to now close our eyes to these very talented and smart people. Asperger people need us as much as we need them.

Arlene Biehler

Appendix B

Autistic Services, Inc.

Data related to expansion of ASI School Program

Capacity

Our current capacity is for 42 students.

Description of Eligibility to be placed on our waiting list

We maintain an annual waiting list for students between the ages of 5-20 for entrance into our school program. In order to be placed on our waiting list, the provider School District Committee on Special Education chairperson or Superintendent must submit a formal letter of request to Autistic Services. The letter must also have an attachment of the student's current Individualized Education Program (IEP) and recent psychological evaluation. Either the psychological evaluation must have a diagnosis of an Autism Spectrum Disorder or the IEP must designate the student disability as Autism.

Waiting List as of 6/1/07

We currently have twenty-three (23) students on our waiting list that meets all above mentioned criteria. Two (2) of those students are in crisis and are on home teaching. We will probably receive about 5-7 more requests before the end of the 2006-2007 school year.

We also maintain a list of students who requested placement, but were removed from our waiting list because we were unable to place them in a timely manner and they had to seek placement elsewhere. There are currently twenty-two additional (22) students on that list.

Tours of our school

Since January 2007, we have provided 29 scheduled tours of our school. Most parents/Districts will follow up with a request for placement and others look elsewhere because of length of wait time before their child will be considered for placement.

Appendix C

Alex's Story

My son Alex is 12 years old. He has Fragile X Syndrome, ADHD, and is also severely bipolar. He has always marched to his own drum. He is always been the odd man out. He is the kid who does not even seem to hear the same music as everyone else. Somehow, he made it through elementary school with adequate success for his ability. When I would go to school events and see him with his classmates, I was always somewhat startled by how different he was than the rest of his class yet again, he seemed to get by.

This year Alex moved on to middle school and in addition, his class size increased from a 12-1-1 to a 15-1-1. It was a disaster from the start. On the second day of school, I received a telephone call from the principal informing me that my son was on the floor, his pants were halfway down, his shoes were on the other side of the room and he was refusing to get on the bus. I replied "And???" To which she said, "Well, what do you want me to do?" I knew then that this was going to be a bad year. By this time, the bus had already left, so Alex essentially got detention the second day of school because the principal did not know how to properly handle my son. Anyone who works with kids like Alex knows that this is not an uncommon problem. Yet, it was one that clearly the school was unprepared to handle.

Over the summer, my son came home from BOCES with terrible bruises on his arms. There were perfectly round deep purple bruises on the insides of his arm where clearly he had been pinched. In addition, finger shaped bruises appeared up both of his arms. Obviously, everyone was very concerned because those round bruises appeared to be malicious and were not caused by another student. The second week of school at Hoover Middle, my son came home with large dark bruises on the right side of his chest below the clavicle and on his back and arm. Clearly, someone had grabbed him by the shoulder with excessive force.

Things continued to deteriorate rapidly, resulting in Alex being placed in a room alone with a one on one teacher. He has not been included in field trips even though he has his own male teacher who could certainly handle Alex physically, if necessary. He had very little, if any, educational structure this year. The school began calling daily to tell me how disruptive Alex was and how we needed to change his placement. The school very clearly wanted my son out. They were not subtle about that! The only problem was, where would he go? There seemed to be only one school that could really meet Alex's needs due to the nature of his disabilities and his anxiety level. The problem was the right school had a 27 child wait list.

The more I looked into Alex's options, the more upset and hopeless the situation became. I could leave him where he is; however, he is clearly not wanted, not receiving

an education, not interacting with other people and getting physically hurt. Another option for Alex was another inappropriate placement. Transitions are extremely difficult on my son. When he switched schools a few years back he had nightmares for three months. I knew that once I moved him it had to be for good. I could not put him through this more than once.

In talking to people, I heard more and more stories about how these special programs want to expand and are not being allowed to do this. Integration is wonderful, if your child can benefit. But for kids like mine, where the noise and sensory input is too great, you might as well poke him with a stick all day long because that is what school has become for him. A place where he does not fit in, is not welcome, is not thriving and is constantly in sensory overload. It is my feeling that although well intentioned, the people limiting these programs are missing the very special and unique needs of some of our children. There is no one size fits all when it comes to children with disabilities and putting a parent in a position to have to put their child in an inappropriate place, sometimes with risk to their safety, is appalling.

In all honestly, I cannot blame the school district. They were clearly unable to deal with a child like mine with serious needs. In fairness, they cannot be all things to all children. They were as helpless as I, to find an alternative placement, which is why my son ended up segregated in a room with a one on one teacher.

Things will not change or improve until people realize that there is an urgent need for some of these specialized programs. Integration is an excellent concept, but it is not the answer for all of our children.

Appendix D

2005

Interim Report (excerpt from report)

Statewide Comprehensive Plan for Mental Health Services

Out-of-State Placement APPROVED for Children in Residential Chapter 392 L. of 2005

Care “Billy’s Law”

S.5810-An Effective: October 31, 2005

This legislation is intended to strengthen the oversight, control, and accountability concerning the placement of children with disabilities in out-of-state residential facilities. It creates an Out-of-State Placement Committee, comprised of the State Commissioners of OCFS, OMH, OMRDD, SED, OASAS, DOH, and the Director of the Division of Probation and Correctional Alternatives (DPCA). This Committee is required to develop core requirements for a “registry” of approved residential programs for future Out of- State Placements. The Committee is responsible for assuring that all out-of-state residential facilities placed on the registry meet minimum requirements, including current licensure with an appropriate state agency in its home state; existence of regulations in the home state to ensure prompt investigations of any abuse or neglect report; prompt notification to the New York State placing agency when enforcement actions are taken against the facility, and compliance with applicable laws and regulations. One agency member of the Committee is required to conduct a site visit within a time frame to be established by the Committee. The Committee must also establish recommended contract parameters for future contracts with out-of-state schools, designed to assure a high quality of service by registered agencies. The Committee also must establish “model processes for placement” of a child in an out-of-state program or school, including review of alternative service options to avoid an out-of-home placement and review of all viable and least restrictive options for placing the child **within the State.**”

Appendix E

CHILDREN IN BROOME COUNTY WITH COOCCURRING MENTAL HEALTH AND DEVELOPMENTAL DISABILITY CONDITIONS (excerpt)

NUMBERS AND SERVICE GAPS

Recommendations

Based on the findings and conclusions of this study, CGR offers the following suggestions and recommendations for state and local consideration and action:

- This report should be forwarded to the Commissioners and other key state and regional officials in OHM and OMRDD, as well as to the NYS Conference of Local Mental Hygiene Directors. Broome County officials, service providers and advocates should follow-up with meetings with those officials to present suggestions and action plans to be developed locally in response to the report.
- An action plan process should be convened by the Broome County Mental Health Commissioner, include representatives from the County Children's Mental Health Task Force and high level officials from the county's MH and MRDD service providers and advocacy groups, to develop specific short-term and longer-term action and implement plans in response to the report.
- Concentrated efforts should be undertaken to work with service providers to formally identify the roughly 300 children and adolescents estimated to have co-occurring MH and DD conditions and unmet needs in one or more service systems— and begin to determine how to best address their short-term and longer-term needs. It should be possible to begin to have each agency identify names of those they serve who they consider to have co-occurring conditions, so that a master list can be developed. Parental approval may be needed to make such names available to create such a central register. There is currently no central register of these individuals, and no way of carefully defining their needs or even evaluating and diagnosing them on a consistent, and professional basis. Once a formal process can be established for the identification of such individuals, beyond a one-shot survey process such as used in this study, it should become possible to begin to more carefully define their needs and processes for addressing them.
- A key step in defining this group of children and adolescents and their needs more precisely is to establish a consistent process based on access to licensed trained professionals (e.g., psychologists, MSWs, etc.) conducting comprehensive diagnoses and needs assessments of youth identified by service providers as likely to have co-occurring MH and DD conditions. Such assessments should be focused on determining diagnoses and establishing service and treatment needs.
- Consistent with the previous recommendation, emphasis should be placed in the community on expanding the capacity for conducting *psychological* assessments of troubled youth in the community as a realistic alternative to expanding the

- number of child psychiatrists. More focus is needed on obtaining sound psychological testing and assessments of children considered as likely to have co-occurring MH and DD conditions. Such testing is important for arriving at diagnoses; identifying individuals' strengths, weaknesses and treatment goals; and determining eligibility for various services. To supplement the efforts of psychologists and social workers, clinical trainees with Masters Degrees at SUNY Binghamton could perhaps be used to help in the diagnostic process.
- Once such a diagnosis process is in place, individuals with co-occurring conditions should be able to access services through a single point of entry. This could either mean (a) making revisions in the existing county SPOA to incorporate children with co-occurring conditions, (b) creating a new but similar process to expedite the review and service access process for such persons, or (c) potentially building on the existing processes involved with the county's Coordinated Children's Services Initiative (CCSI). Particular consideration should be given to blending features of the SPOA within the context of the CCSI process.
 - In the meantime, MRDD representatives should be explicitly invited to, and expected to become active participants in, the SPOA and/or CCSI processes in order to begin to ensure that broad cross-systems perspectives are represented in the discussion of individuals who have, or may have, co-occurring conditions. Eligibility for services across systems needs to be explicitly addressed.
 - Ultimately an effective database and management system should be established to record the characteristics, diagnoses and service needs of children with co-occurring conditions; to track services they are receiving; and to monitor their progress and outcomes across service systems over time.
 - Efforts should be initiated to "demystify" services for both parents of children with co-occurring conditions and youth and family service providers. Ways should be explored of better educating providers and parents concerning better understanding of what services are available, and the eligibility requirements of each. Available services and admission criteria should be publicized more effectively through a variety of approaches, including building on existing service guides, creative use of the Internet, etc.
 - Task forces should be established to determine what can and should be done to respond to the following needs and service gaps identified in the study for children with co-occurring conditions: (a) child and adolescent psychiatric and psychological evaluations and testing, including the need in particular for more comprehensive professional psychological diagnoses and assessments prior to, and perhaps even avoiding in many cases the need for, any involvement with a psychiatrist; (b) counseling services for children and parents; (c) emergency and ongoing respite care for children and families; (d) crisis intervention (including the potential for an MRDD expert at CPEP); and (e) medication management. Other needs and gaps should be added to this list as appropriate. Any expansion or modification of services should be done consistent with the "best practices" recommendations in the report.

- More efforts are needed to develop cross-training of service provider staff in both the MH and MRDD service systems. Increasingly, staff will be needed with cross-specialty skill sets that can assess needs and serve children with co-occurring conditions, and their families, in a holistic manner.
- More effective linkages should be explored between community-based service providers and school district special education programs. Such linkages should include representation on SPOA or related processes for accessing services, and should include discussions of the extent of need for cross-referrals between school, MH and MRDD systems to ensure that information is shared across systems where appropriate, and that service and treatment needs are met appropriately, efficiently and cost-effectively.
- Consideration should be given to exploring ways of putting together cross-agency, cross-systems recruiting packages to help share the costs of bringing needed specialists to Broome County who may not otherwise be attracted to the community without more financial resources than individual agencies could afford. Combined funding packages, and planned sharing of staff time across agencies, may create options for attracting high-caliber professionals not otherwise likely to consider coming to the area.
- The State should be approached for cross-systems funding to establish a pilot project in the county to develop implementation plans, strategies and staffing to address specific actions that are developed by the action planning team recommended above.
- Ideally State funding should be available to help with such a comprehensive pilot approach, including contributing to the afore-mentioned recruit-funding package. The State should be a willing contributor to Broome's efforts to break down funding and service system barriers, as those efforts could become a model for other areas across the state.
- The next step in the process, as suggested above, should include making arrangements as soon as possible for a strategic planning "visioning day" with key stakeholders to prioritize and expand on these recommendations, establish goals and action plans, and determine subsequent actions and timelines. Elected local officials should be briefed, key State officials should be informed, and plans should be developed for a pilot project, which should be proposed to State officials as soon as possible for their support.

Appendix F

Devereux Florida Intensive Residential Services THE VIERA CAMPUS

The Devereux Florida Viera Campus is located on 55 acres in central Brevard County on the East Coast of Florida. Programs offered at this site include the Intensive Residential Treatment Program for children and adolescents, a Dual Diagnosis Center for children and adolescents with symptoms of both mental illness and mental retardation, and an on-site accredited school. A large lake for paddle boating and fishing, playing fields, a swimming pool, a large playground, and plenty of palm trees highlight the serene setting.

Intensive Residential Treatment/Specialty Hospital

The Intensive Residential Treatment Center (IRTC) provides a secure setting for the treatment of severely emotionally, behaviorally, and psychiatrically disturbed youth from ages 5 through 17. This program is comprised of 75 beds situated across three units, entitled the Discovery, Explorer and Endeavor Units. Treatment occurs in small groups of children accompanied by a team of trained staff including Direct Care Professionals, Shift Supervisors, Nurses, Activity Therapist, Speech Therapist, Administrative/Case Manager, Psychotherapist, Certified Behavior Analyst, and Child and Adolescent Psychiatrist. A PhD Psychologist is available for consultation and testing. A therapeutic living environment is created in which teamwork is paramount, where problems are seen as opportunities for learning, and where privilege and responsibility go hand in hand. The discharge planner who arranges for placement at the time of discharge provides aftercare coordination. Individual, group and family therapy occur on a regular basis. Groups are developed to meet client need and include dealing with psychosexual issues, substance abuse, anger management, social skill development, diversity, and grief/loss issues. Nurses provide groups dealing with medication and related health topics. Two full time psychiatrists oversee treatment for each child and coordinate treatment planning.

Dual Diagnosis Center

The Dual Diagnosis Center (DDC) provides treatment for children and adolescents, ages 5 through 17, with the co-existence of symptoms of both mental illness and mental retardation. This program is comprised of 51 beds across two units, entitled the Pioneer and Voyager Units. In addition to being identified with mild to moderate retardation with an IQ range of 40-75, the candidates must also have been diagnosed

with a psychiatric disturbance, as identified on Axis I. Through a positive skill-training approach, the DDC utilizes the empirical and validated procedures of Applied Behavior Analysis along with various clinical therapies to encourage residents to engage in appropriate behaviors. The efforts of the DDC Programs are aimed at providing these children with the supports, training and skills essential in attaining a successful discharge into a less restrictive setting. The individuals admitted to the program display clear deficits in adaptive and social functioning as well as a wide range of challenging behaviors including aggression, property destruction, severe tantrum behavior, self-injurious behavior, run away problems, and the difficulty to follow directions reliably. Treatment teams are comprised of an inter-disciplinary approach which may include Psychiatry, Applied Behavior Analysis, Education, Individual Therapy, Group or Family Therapy, Speech/Language Services, Nursing, Activity Therapy, and other therapies as need is determined. The development of the Individual Plan of Care is based on assessments, direct observation and interviews with the child and family.

Diabetes Management Program

Devereux Florida has earned the reputation for being able to establish success working with youngsters with psychiatric issues, as well as diabetes. A youngster with diabetes may exhibit irritability, depression, anxiety, anger and fear, resulting in non-compliance with managing their diabetes. Devereux Florida's Diabetes Management Program teaches children how to take control of their illness. This is accomplished working one on one with a nurse and dietician, with individualized instruction on the importance of a healthy diet and maintaining good nutrition. Behavioral staff assists in monitoring and encouraging compliance toward diabetic health. Oversight of this program is provided by John A. Duncan, M.D., a nationally recognized Board Certified General Pediatrician and Board Certified Pediatric Endocrinologist.

Devereux School

Children participating in the IRTC and DDC programs attend the Devereux School, an educational program (K-12) located on the Viera Campus property. Unlike most residential treatment centers, the Devereux School is dually accredited by the Southern Association of Colleges and Schools and the Florida Council of Independent Schools. The school also includes an excellent Vocational Education and Training component. The Devereux School firmly believes that all students have the ability to achieve academic success. Having each child engaged in the educational process is essential with experiences of success paramount. The program addresses a wide range of children's needs including learning disabilities, truancy, academic weakness, job skill development, speech and language therapy, art, teen pregnancy prevention and athletic programming. The Vocational Education and Training program is designed to

provide students, ages 14 or older, with a positive training experience by combining elements of a traditional work environment with the skills needs to become productive and valuable members of society.

Appendix G

Families Together

2007 Policy Agenda for Improving Children's Mental Health in New York State

There are over half a million children and youth in New York State who has a mental or addictive disorder associated with significant functional impairment. New York State's public mental health system serves approximately 140,000 children and adolescents each year leaving thousands without necessary treatment or in inappropriate or more expensive settings. Studies and real life experience show that prompt access to appropriate mental health services saves money and can improve the quality of life for children and families in addition to ensure that children grow into healthy, productive adults.

Principles for developing children's mental health services:

- 1 All children, youth and their families must have timely, affordable access to appropriate mental health services within their community.
- 2 Children and youth must receive an appropriate education in the least restrictive environment.
- 3 Families and youth must be full participants in planning services for their family and in ALL levels of planning, delivering and monitoring services for children.
- 4 Families should NEVER have to relinquish custody of their children to receive needed mental health services.

Priorities for the 2007/08 New Your State Budget:

Children in need of mental health services can be found in multiple systems including the education, child welfare, developmental disabilities, substance abuse and juvenile justice systems. When mental health services in all these systems are viewed as a whole, it is clear that coordinating services can only improve access for children and families along with improve the efficiency of service delivery.

- **Fund, develop and support a community-based system of care for children and youth with social, emotional and behavioral disabilities.** We support the governor's budget proposal to continue the expansion of enhanced children's services through increases in the Home and Community Based Waiver and through the continuation of Child and Family Clinic Plus and the COLA for workforce retention. We support the \$500,000 for transition services for children leaving State Education Department placement and ask for an additional \$500,000 for demonstration programs for peer support for youth. This expansion must include family support, respite, and transition services which are essential for our system of care. Services must be coordinated across systems, culturally competent and youth as well as family-centered.
- **Bring kids home and keep them home.** Currently New York State sends children to out of state facilities to receive treatment that is not available in this state. We must bring our children home by increasing the capacity of high-end services.
- **Provide health insurance for all children and ensure that this coverage includes the full range of health needs including mental health and substance abuse.** We support the proposed expansion of Child Health Plus and call for the inclusion of a full range of

mental health services. Timothy's Law must be expanded to cover trauma, substance abuse services and be required for small employers.

Together in New York State ☐ 888-326-8644 ☐ 518-432-0333 ☐ www.ftnys.org

Appendix H

New York State
Conference of



Local Mental Hygiene Directors, Inc.

Integrated Systems of Care for Children's Mental Health: A Technical Assistance Resource Book

Meridian
Consulting Services Inc.

Prepared by:
October 1999 (Excerpt from Report)

Core Elements of an Integrated System of Care for Children and Families with Complex Needs Introduction

In communities across New York State, there are children with severe emotional and behavioral problems also their families service needs are very complex. While many of these children and families are well known to county departments, providers, schools, communities are confounded in their attempts to serve them. The coordination, flexibility, and creativity is essential to helping families of children with serious emotional disturbances is difficult to achieve in the current service structure. The existing system is fragmented, with rigid program requirements established through narrow categorical funding streams and bureaucracies designed to address a single problem or need. One major result is an over reliance on residential services, with too many children being served away from their homes, schools, and communities. A deep-seated frustration with the current system of care is the driving force behind a call for better ways to serve children with emotional and behavioral problems as well as their families. In response, the New York State Conference of Local Mental Hygiene Directors, Inc. has taken a proactive role to improve service delivery for children with serious emotional disturbances and their families. As part of its Technical Assistance Project, the Conference selected Meridian Consulting Services, Inc. to review county models of integrated systems of care and provide New York State's County Directors with information on best practices needed to advance system improvements. This document, *Integrated Systems of Care for Children's Mental Health: A Technical Assistance Resource Book*, is the outcome of Meridian's work. This *Resource Book* includes a description of core elements of an integrated system of care; (pages); profiles of seven

state and national models (sections 2-8); family perspectives about these models (section 9); and, an assessment tool to help communities take stock and make improvements in their approaches to serving children and families with complex needs (section 10).

Meridian’s Process

Meridian’s model selection and research identify core elements guided by a Steering Committee, composed of staff from the Conference of Local Mental Hygiene Directors; Phil Endress, Oneida County Mental Health Commissioner; Dr. David Gottesman, former Albany County Mental Health Commissioner and Medical Director for Kids Oneida; Joan Valery, Families United Network; and Agnes Rivera, Mental Health Association of New York City. To identify national sites, Meridian interviewed experts in children’s mental health for suggested models. Experts included: Beth Stroul and Ira Lourie, MD, two well known authors in this field; Barbara Huff, Executive Director of the Federation for Children’s Mental Health; and Pat Sokol, former Director of the Robert Wood Johnson Foundation’s Mental Health Services Program for Youth Initiative. New York State models were identified with the aid of the Steering Committee and with input from staff at the New York State Office of Mental Health involved with the implementation of the Coordinated Children’s Services Initiative (CCSI)

Appendix I

SYNOPSIS OF A CHILD IN FOSTER CARE

Anne experienced a chaotic family life from her earliest days. Born to a mother with multiple psychiatric diagnoses in addition to borderline cognitive abilities and a father with developmental challenges, parenting and routine care were inconsistent at best. Following a hospitalization at seventeen months old for failure to thrive, Anne entered foster care. Her challenging behaviors included aggression, tantrums and limit testing. Eight months later, these behaviors necessitated a move to another foster home.

Anne returned home not quite three years old. Within a year, allegations arose regarding sexual abuse. Following a lengthy investigation, CPS placed this child in a therapeutic foster home. Over the course of a year, Anne was diagnosed with Reactive Attachment Disorder, Oppositional Defiant Disorder and Expressive/Receptive Language Disorder. Post Traumatic Stress Disorder was a concern. Multiple attempts to locate an appropriate education program are only partially successful. Those that address her cognitive challenges fail to fully meet her emotional needs.

Three therapeutic homes later, at age six, Anne's therapist recommended a higher level of care. OMH community residence declines admission – Anne requires a higher level of care. No Residential Treatment Facility in WNY area will accept a child as young as six. Six months later, Anne's therapist notes this child cannot be maintained in therapeutic foster care. Testing indicates Anne is moderately developmentally delayed as well as mentally ill. Three months later, an application for SPOA services is denied recommending a referral to RTF. Unfortunately, there are no RTF beds for females in the WNY area.

Three additional therapeutic foster homes later, Anne is accepted into a diagnostic program. The diagnostic program recommends discharge to a therapeutic foster care program however; all area TFC programs express concerns about accepting Anne. Five Residential Treatment Centers also decline admission. RTFs decline placement due to age, gender or cognitive functioning. Now eight years old, OMRDD indicates Anne is not appropriate for their services. (They will later reconsider but they do not have an appropriate bed.)

Anne was discharged to a very experience foster family that was caring for three of her siblings. Wrap Around Services are added to secure the placement. Four months later, following multiple episodes of physical and sexual aggression, this placement failed. Anne was placed in a therapeutic foster home on an emergency basis. Following an assault on another student with a pencil, Anne was taken to the hospital for psychiatric assessment. She was not admitted.

Anne's diagnoses have not changed much over the years. Once again, various programs are contacted. OMH Community residence, Hillside Dual Diagnosis Program, WNY Children's Psychiatric Center, RTCs and RTFs all decline because of their own criteria. A few months prior to her tenth birthday, Anne moved to a dual diagnosis facility in Florida. She had exhausted all her options in New York State.

Appendix J

JOINT PLANNING AGREEMENTS IN REGION 2

JANUARY 1, 1998 (Excerpt of Report)

“The Joint Planning Committee has come to the following agreements which lay the groundwork for reintegration planning and services:

1. Reintegration services are those community based services provided to the child and his or her family following a placement in residential care. Services will be customized to the individual family’s strengths and needs and environmental supports and challenges to ensure successful transition from placement to the family and community.
2. In order to create a reduced length of stay for children in residential level care, reintegration planning will be prompt and thorough.
3. Reintegration planning will be initiated upon agreement of placement among the family, the placing agency and placement agency at which time the following issues will be determined:
 - A. Projected discharge date
 - B. Permanency planning goal
 - C. Discharge resource options:
 1. to whom the child will be discharged:
 - a. Family of origin
 - b. Other family resources
 - c. Adoptive family
 - d. Lower Level of Care
 2. Independent Living
 - D. Visitation/Respite Resources
 - E. School placement upon discharge
 - F. Anticipated continuing needs
4. Reintegration planning is to be included as a standard item of discussion when developing and reviewing service plans.
5. The case manager is responsible for coordinating the participation of relevant parties necessary for the successful implementation of service plans. Relevant parties may include:
 - A. Family
 - B. Local district representatives
 - C. Voluntary agency representatives
 - D. School personnel
 - E. Judiciary
 1. Law Guardian
 2. Judges
 3. Service Providers
 4. Health

5. Mental Health
 6. Chemical Dependency
 7. Developmental disabilities
 8. Other
6. Local school districts play a significant role in ensuring the successful transition of the child to the family, the school, and the community. Therefore:
 - A. The local school district will be included in service planning at the time of and throughout placement, as well as in planning for reintegration.
 - B. Discharge will occur when most appropriate for the child, which may not be coterminous with the school year.
 7. Reintegration planning requires collaboration to maximize available resources to meet individual needs of children and families, and to reduce identified barriers to successful transition of the child to home and community. The reintegration plan will include specificity regarding the roles and responsibilities of the family, the local district staff, and the voluntary agency staff. Reintegration planning will be mindful of safety issues for the child and the community.”

CROSS-SYSTEMS KIDS:

A CALL TO ACTION (2000) – Excerpt of Report

“SUMMARY OF ISSUES CREATED BY CURRENT SYSTEMS DESIGN”

- Each service system has separate and clearly defined criteria for service eligibility. For children who require services from multiple systems, the entry requirements are complicated and block access. In some cases, regulation blocks children in one service system from receiving services in another service system.
- Families are particularly frustrated by our separate service systems. They want to be provided with family support/advocacy by trained parents who will assist the family in working with the service system professionals.
- The existing service array does not contain sufficient specialty services to directly meet the needs of cross-systems children and their families. Mixing complicated populations of youth into generic programs not only places children at risk, it also does not offer the specific treatment that many of these children and families require.
- Educational issues present substantial concerns, as each school district is individually responsible for each of their children. Particularly when an out-of-home placement is involved, the sheer number of school districts makes cross-systems planning a challenge.
- In attempting to address systemic issues one child and family at a time, considerable professional hours are expended on frequently fruitless efforts to

figure out how to make our complicated service system respond to the cross-systems needs of our children and youth.

- Children and youth frequently receive costly services that are not helpful. A yearlong placement in a 30-day emergency bed is not good for the child, and is a poor use of fiscal resources.
- Rapid response to crises is often essential with cross-system children to prevent them from regressing or from being victimized, however, a lack of cooperative resources often forces placement of children into inadequate situations.
- Cross-systems needs frequently emerge when a crisis occurs and a placement is requested immediately. Cross-systems work needs to be done far earlier to prevent the crisis from developing. Early identification of cross-systems children should result in the provision of a cross-systems assessment and service response in order for children and their families to be effectively helped.

SOLUTIONS

Many solutions for cross-systems children can be created through strong collaboration at the local level. Development of common principles and a commitment to shared responsibility have produced positive outcomes for many children in Region II. However, our desire to serve these children and their families effectively can only be achieved if the barriers embedded in the current infrastructure of service delivery are addressed. Stakeholders at the state and local level will need to create new policies, practices, legislation, regulations, and funding mechanisms in order to care for these most vulnerable children.

The Region II Joint Planning Committee, therefore, believes that a state Task Force should be created to examine the barriers to serving cross-system kids and to propose solutions that will allow this needy group of youth and their families to access the right service at the right time. The Region II Joint Planning Committee wants to participate in the membership of the Task Force, to share our experiences and the lessons that we have learned in our five years together. The Task Force should consider the issues and principles laid out in this paper as well as those issues encountered by this group of children and youth in the rest of the state. In particular, any solution proposed should be grounded in:

- sharing of responsibility across service systems for responding to the needs of cross-systems children and their families,
- involvement of families in planning for their children, and
- the strengths, needs of individual children and their families should drive the service delivery system.

Our children and families need your leadership to create a statewide Task Force. We therefore urge you to step forward to make this Task Force a reality.”

Appendix K

OMH Report of Dually Diagnosed Youth: the raw numbers here begin to show the significant scope of what we are facing. It is important to note that because youth are identified as dually diagnosed, does not mean they are without appropriate services since most are receiving effective services:

Erie Dually Diagnosed Info 2007-MAY.htm

DOB	Axis1Prime	Guardian	Gender	Full Scale IQ
08/23/89	Psychotic DO, NOS	Parent	F	48
08/23/89	Psychotic DO, NOS	Parent	F	48
03/09/97	Post-Traumatic Stress DO	DSS	F	57
03/09/97	Post-Traumatic Stress DO	DSS	F	57
12/12/84	ADHD	Parents	M	62
06/09/85	Dysthymic DO	DSS	M	62
01/29/91	Psychotic DO, NOS	Parent	M	63
12/08/93	ADHD	DSS	F	64
01/15/85	PTSD	DSS	F	66
08/15/91	Post-Traumatic Stress DO	DSS	M	66
01/15/91	Impulse Control DO	Parent	F	66
01/08/93	Bipolar DO, NOS	DSS	M	67
07/30/90	Post-Traumatic Stress DO, 309.81	Parent	F	68
10/05/87	Parent Child Relational Problems	Mother	M	68
11/19/93	Oppositional Defiant DO	DSS	F	69
11/15/88	Mood DO	Parent	F	69
11/15/88	Reactive Attachment DO	Parent	F	69
12/18/90	Depression, NOS	Parent	F	69
12/18/90	Post-Traumatic Stress DO, 309.81	Parent	F	69
11/14/91	ADHD	Mother	F	70
02/08/88	Attention Deficit Hyperactivity DO	Parent	M	70
08/27/87	Oppositional Defiant DO	Parent	F	70
05/04/91	Conduct DO Early Onset	Parent	M	70
01/06/89	Post-Traumatic Stress Disorder (PTSD)	DSS	F	70
07/03/90	Oppositional Defiant	DSS	F	71
02/23/92	PTSD	DSS	F	71
02/19/94	Attention Deficit Hyperactivity DO	Relative	F	71
02/19/94	Attention Deficit Hyperactivity DO	Relative	F	71
02/19/94	Attention Deficit Hyperactivity DO	Relative	F	71
10/27/89	Psychosis, NOS	DSS	M	71
10/27/89	Schizoaffective DO, 295.70	Relative	M	71
10/05/91	Oppositional Defiant DO	Parent	F	71
10/27/89	Schizoaffective DO, 295.70	Relative	M	71

10/27/89	Schizoaffective DO, 295.70	Relative	M	71
10/27/89	r/o Schizophrenia vs Schizoaffective do	DSS	M	71
10/27/89	Schizoaffective DO, 295.70	Relative	M	71
04/05/92	Schizophrenia, undifferentiated type with violent and sexual obsessions	Parent	M	71
01/15/91	Psychotic DO	Parent	F	73
01/29/91	Psychotic DO, NOS	Parent	M	73
07/25/90	Conduct DO Childhood Onset Type	Parent	F	73
01/25/91	Post-Traumatic Stress DO	Parent	F	73
05/22/92	Attachment DO nos	DSS	M	73
01/25/91	Reactive Attachment DO	Parent	F	73
07/25/90	Conduct DO Childhood Onset Type	Mother	F	73
11/26/96	Post-Traumatic Stress DO	DSS	M	74
12/24/90	Post-Traumatic Stress DO, 309.81	DSS	F	74
11/26/96	Post-Traumatic Stress DO	DSS	M	74
11/19/93	Oppositional Defiant DO	DSS	F	75
07/28/91	Psychotic DO, NOS, 298.9	Parent	M	75
02/19/94	Oppositional Defiant DO	Relative	F	76
07/02/95	Attention Deficit Hyperactivity DO Combined Type by Hx	Parent	M	76
10/07/95	Attention Deficit Hyperactivity DO	DSS	M	76
01/15/91	Post-Traumatic Stress DO, 309.81	Parent	F	77
07/10/89	PTSD	Parents	M	77
07/10/89	PTSD, Chronic	Parent & OCFS	M	77
01/30/94	Attention Deficit Hyperactivity DO, 314.01	Parent	M	77
02/02/88	Attention Deficit Hyperactivity DO	Parent	F	78
08/23/89	Psychotic DO, NOS; Specified , by hx.	Parent	F	78
04/06/93	Post-Traumatic Stress DO, 309.81	DSS	M	78
07/23/91	Conduct DO Childhood Onset	Parent	M	78
07/23/91	Conduct DO Childhood Onset	Parent	M	78
01/06/89	Attention Deficit Hyperactivity DO, 314.01	DSS	F	78
02/02/88	Conduct DO Childhood Onset	Parent	F	78
02/02/88	Conduct DO Childhood Onset	Parent	F	78
07/09/89	Bipolar DO, NOS	Parent	M	79
08/28/90	Major Depression with psychotic features	Parent	F	79
08/28/90	Depressive DO NOS, 311.00	Parent	F	79
04/02/87	Pervasive Develop DO	Mother	F	80
08/28/90	Reactive Attachment DO	Parent	F	80
10/18/88		Parent	M	80
02/18/88	Mood DO, NOS	Parent	F	80
02/02/95	Post-Traumatic Stress Disorder (PTSD)	DSS	M	81

08/17/87	Depressive DO NOS	Parent	F	81
07/23/91	Conduct DO Childhood Onset	Parent	M	81
08/17/87	Bipolar DO, 296.76	Parent	F	81
05/21/90	ADHD	Adopted Mother	M	82
05/17/91	Intermittent Explosive DO	DSS	F	82
11/21/86	Cyclothymia	Mother	M	83
05/06/95	Oppositional Defiant DO, 313.81	Parent	M	83
02/26/88	Intermittent Explosive DO	DSS	F	83
08/25/95	Oppositional Defiant DO, 313.81	Relative	M	83
11/01/89	Attention Deficit Hyperactivity DO	DSS	M	83
03/06/93	ADHD	Parents	M	84
05/26/89	ADHD	Mother	M	84
04/21/88	Pervasive Developmental DO, NOS	Parent	M	84
04/21/88	Pervasive Developmental DO, NOS	Parent	M	84
01/06/93	Bipolar DO Mixed	Parent	M	84
04/21/88	Pervasive Developmental DO, NOS	Parent	M	84
01/06/93	Attention Deficit Hyperactivity DO, Combined Type	Parent	M	84
04/06/93	Attention Deficit Hyperactivity DO	DSS	M	84
04/06/93	Attention Deficit Hyperactivity DO	DSS	M	84
02/02/91	Generalized Anxiety DO, NOS	Other	M	85
09/25/91	Bipolar DO, NOS	Parent	M	85
09/25/91	r/o Mood DO, NOS	Parent	M	85
01/24/97	Mood DO, NOS	Parent	F	85
12/19/88	Impulse Control DO	DSS	M	85
10/30/86	PTSD	DSS	M	86
11/23/99	Post-Traumatic Stress DO, 309.81	DSS	M	86
05/23/97	Attention Deficit Hyperactivity DO	Parent	M	87
05/23/97	Attention Deficit Hyperactivity DO	Parent	M	87
12/08/94	Conduct DO Childhood Onset	DSS	M	87
09/27/92	Bipolar DO, 296.76	Parent	M	87
12/08/94	Mood DO, NOS, 296.90	DSS	M	87
02/20/93	Attention Deficit Hyperactivity DO (ADHD)	DSS	M	87
03/27/95	Attention Deficit Hyperactivity DO	Parent	M	88
04/07/87	Depressive DO NOS	Relative	M	88
03/18/90	Psychosis, NOS	Parent	M	88
11/29/92	R/O Reactive Attachment do	Parent	M	88
04/07/87	Oppositional Defiant DO Severe	Relative	M	88
08/16/87	Post-Traumatic Stress Disorder (PTSD)	DSS	F	88
03/24/91	Psychotic DO, NOS, 298.9	Parent	M	89
08/24/93	Reactive Attachment DO	Parent	F	90

11/28/93	ADHD	Grandmother	F	91
11/12/85	Psychotic DO	Mother	F	91
11/21/94	Psychotic DO, NOS, 298.9	Parent	F	91
01/01/94	Anxiety DO, NOS	DSS	F	91
11/20/87	Bipolar Do, Depressed w/o psychosis	Parent	F	91
08/12/86	Major Depression, recurrent, without psychotic features	DSS	F	91
07/06/91	Mood DO, NOS	Parent	M	91
01/01/94	Conduct DO Childhood Onset, 312.81	DSS	F	91
02/26/85	Mood DO	Parents	M	92
12/18/87	Bipolar DO	Mother	M	92
10/20/95	Disruptive Behavior DO	Parent	F	92
07/21/90	Post-Traumatic Stress Disorder (PTSD) Improved	DSS	F	92
07/21/90	Post-Traumatic Stress Disorder (PTSD) Improved	DSS	F	92
11/23/88	Attention Deficit Hyperactivity DO Combined Type	Parents	F	92
11/23/88	Mood DO, NOS	Parent	F	92
11/02/92	Attention Deficit Hyperactivity DO- Combined Type	DSS	M	92
07/21/90	Post-Traumatic Stress Disorder (PTSD) Improved	DSS	F	93
10/11/87	Bipolar DO, TYPE I	Parent	M	94
04/17/89	Bipolar DO	Father	F	95
06/16/91	Mood DO, NOS	Parent	M	95
06/16/91	Mood DO, NOS	Parent	M	95
10/23/91	Major Depression, second episode, severe w/o psychotic features	Parent	F	95
10/23/91	Post-Traumatic Stress DO	Parent	F	95
10/23/91	Major Depression Recurrent Type with Psychotic Features	Parent	F	95
10/23/91	Major Depression, recurrent, severe, with Psychotic Features	Parent	F	95
10/20/95	Parent Child Relational Problems	Parent	F	95
07/05/93	Post-Traumatic Stress DO	DSS	F	96
04/02/88	Bipolar DO, most recent episode hypomanic/manic	Parent	F	96
08/29/94	Bipolar DO, mixed state	Parent	M	96
10/18/87	Oppositional Defiant DO, Severe	Parent	F	96
07/05/93	Reactive Attachment DO	DSS	F	96
03/19/94	PTSD	DSS	M	97
02/14/88	Psychotic DO, NOS	Parent	M	97
02/22/92	Generalized Anxiety DO	Parent	F	97
08/25/89	Bipolar DO, NOS	Parent	F	98

07/21/93	Conduct DO Childhood Onset	Parent	M	98
07/21/93	Generalized Anxiety DO by history	Parent	M	98
12/01/92	Psychotic DO	Mother	M	99
07/05/90	Reactive Attachment DO	DSS	M	99
11/09/91	Hx of Attention Deficit Hyperactivity DO, Combined Type	DSS	F	99
12/05/90	Major Depression, in Partial Remission	Parent	F	99
07/05/90	Conduct DO, by hx	DSS	M	99
07/05/90	Reactive Attachment DO	DSS	M	99
08/15/95		Parent	F	100
06/11/87	Post-Traumatic Stress Disorder (PTSD)	Parent	F	100
12/08/90	Oppositional Defiant DO	Parent	M	100
12/08/90	Oppositional Defiant DO	Parent	M	100
06/01/89	Post-Traumatic Stress DO	Relative	F	101
01/27/97	Disruptive Behavior DO	Parent	M	101
01/09/90	Major Depressive DO, Recurrent with psychotic Features	Parent	F	101
07/07/90	Aspergers Syndrome	Parent	M	101
06/01/89	Post-Traumatic Stress DO	Relative	F	101
07/28/86	Obsessive-Compulsive DO (principle)	Parent	M	103
04/21/88	Psychotic DO	Father	M	103
04/21/88	Psychotic DO	Father	M	103
10/29/89	ADHD	Mother	M	104
10/02/88	Bipolar DO	Mother	M	104
11/22/87	Bipolar DO NOS		M	104
10/29/89	Attention Deficit Hyperactivity DO, Combined Type	DSS	M	104
10/29/89	Attention Deficit Hyperactivity DO, Combined Type	DSS	M	104
10/29/89	Severe child/Parent Problem	DSS	M	104
07/26/89	Post-Traumatic Stress DO		F	104
12/05/90	Major Depression, 296.21	Parent	F	105
12/05/90	Major Depression, 296.21	Parent	F	105
05/23/84	ADHD	Father	F	107
01/26/87	PTSD	Mother	M	107
02/14/88	R/O Schizophrenia	Parent	M	107
08/12/86	Cyclothymia	Parent	F	108
09/06/87	Aspergers	Mother	M	109
01/21/93	Post-Traumatic Stress DO	Parent	M	109
06/09/94	ADHD-Combined	Parent	M	109
03/17/88	Post-Traumatic Stress DO	Parent	F	109
01/29/91	Major Depressive DO-recurrent	Parent	M	109

09/28/98	Oppositional Defiant DO	Parent	F	111
10/26/93	Most likely Bipolar DO, nos	Parent	F	111
10/26/93	Bipolar DO, nos	Parent	F	111
10/25/92	Psychosis, NOS	Parent	M	111
10/25/92	Bipolar DO, 296.76	Parent	M	111
09/28/98	Reactive Attachment DO	Family Court	F	111
10/25/92	Psychosis, NOS	Parent	M	111
09/16/89	Post-Traumatic Stress DO	Parent	F	113
09/30/94	ADHD	Parents	M	114
07/10/89	Bipolar DO	Parent	F	115
11/07/90	Conduct DO Childhood Onset	Parent	F	118
05/24/93	Oppositional Defiant DO	Parent	M	122
11/12/87	Dysthymia with past episode of Major Depression	DSS	M	123
06/14/85	Impulse Control	Mother	M	125
02/15/89	ADHD	Parents	M	Avg
12/15/84	Delusional/Paranoid	Mother	M	Avg
05/07/85	Intermittent Explosive DO	Mother	M	Avg
06/01/86	Depression NOS	Father	F	Avg
10/01/87	Anorexia Nervosa, Restricting Type	Parent	M	Missing
07/09/91	Attention Deficit Hyperactivity DO	DSS	M	Unknown
07/06/91	Bipolar DO nos	Parent	M	Unknown

Appendix L

OMRDD Data on Dual Diagnoses (October 2007)

The New York State Office of Mental Retardation and Developmental Disabilities (OMRDD) utilize a number of tools to identify and capture the service needs of individuals receiving services. The TABS system documents the specific services an individual is receiving as well as service histories. The Developmental Disabilities Abilities Profile (DDP-2) documents some clinical diagnoses as well as skills and abilities.

Data current to October, 2007 indicates that 2281 individuals under the age of 22 residing in Erie County were receiving services through an OMRDD (state or voluntary) provider.

Of these individuals, 1193 have a Developmental Disabilities Abilities Profile (DDP-2) completed. 127 individuals (11%) indicate the person has a psychiatric diagnosis. 373 of these individuals (16%) have a diagnosis of autism indicated in TABS.

Appendix M

11-3-06

Residential Care in New York State 2006 and Beyond (Excerpt from Report)

Draft Paper Developed by:
The NYS Child and Family Service Review Workgroup - Safety and Well-Being in
Residential Care Steering Committee

The charge to stakeholders

In summary, as articulated by this paper, the steering committee envisions a residential care system that:

- Is fully committed to the outcomes of safety, permanency, and well-being.
- Demonstrates in its daily actions the value of family in addition to community; is family-focused, child-centered, and strength-based.
- Serves children and youth whose safety as well as treatment needs can only be met in a structured, consistent, predictable environment, and their families.
- Is chosen in a strategically, therapeutically purposeful manner and does not require prior demonstrated placement failures.
- Is a highly specialized service intervention that makes a unique contribution to local systems of care?
- Provides a safe environment that breaks the cycle of trauma.
- Offers individualized services based on a comprehensive assessment of the needs of the child and family.
- Creates an effective transition from residential care to home and community.
- Partners with others in the community to identify and support permanency.

Unfortunately, not all of these characteristics exist in all residential settings in New York State today, nor are all of the resources in place to achieve some of the stated goals. We will achieve better outcomes for children along with families and improve the system

overall, when these are both realized. Purchasers and providers will be more confident that they are using resources effectively as well as efficiently, and investors will be more inclined to make additional investments in needed services.

We realize that it is one thing to describe a preferred alternative and quite another to achieve it. A great deal of work must be done to seriously pursue this agenda. Progress can only be achieved through an effective collaboration of all stakeholder groups. Although it is ultimately government's role to develop a policy foundation and a vehicle for financing the system, much of the discussion, in addition to the development work require significant investments locally and regionally.

The following are the areas of actions that are necessary to further develop residential care, which can only be accomplished through cooperative efforts of all stakeholders. Although initiatives have already begun in some of these areas, all must be further improved to achieve the envisioned system of care.

- **Workforce development:** *A highly trained and specialized workforce is required to meet the needs of these children and youth in providing sophisticated, individualized treatment.* At the core of a successful program, described in this paper, is the relationship between the direct care staff and residents. Those workers need the requisite skills and longevity in the job to develop the expertise required. The stakeholders need to commit to the recruitment, retention, and development of a highly skilled workforce and to compensate accordingly.
- **Quality of child, youth, and family assessment:** *To enable the appropriate and strategic use of residential care, assessments of strengths as well as needs of the child, youth, and family must be complete, accurate, and holistic.* Currently, assessments are limited by system perspective and service availability. This can result in the failure to place a child in residential care when needed or, conversely, to place a child in such care who does not need its intense level of structure and service. Incomplete assessments can also prolong lengths of stay, as time is wasted in targeting service needs inappropriately.
- **Clear criteria for placement in residential level of care:** *Referrals for residential placement can be appropriately made only according to clearly established criteria.* Purchasers, providers, and oversight agencies must have a common understanding of the decision-making process for placement. Such a process needs to be measurable and routinely monitored. The purchasers/case managers must understand the contribution they are asking the residential care provider to make, including expected outcomes from placement. Other states, such as California, have been successful in establishing a well-understood, statewide decision-making criterion for placement of children and youth in

residential care (California Alliance of Child and Family Services, 2006). Surely, this is a feasible goal for New York State.

- **Services development:** *Local systems of care must develop a capacity for whatever service is necessary, as determined by the needs of the youth and family.* Individualized service plans tend to be limited to services that are regularly available. Service plans should be flexible, responding to the changing needs of the child, youth, and family. Only then will services truly become individualized.
- **Role of residential care in the local system:** *Children and families with complex needs require a comprehensive approach by the local system of care.* To be effective, the role of each provider must be understood and valued for its unique contribution to that system. All stakeholders have a contributing role to play in supporting a comprehensive care plan. In some localities the Coordinated Children's Services Initiative (CCSI) or the Single Point of Access (SPOA) are beginning to meet this need.
- **Performance-based system:** *All stakeholders are accountable to one another and to the local system of care.* Providers are responsible for clearly identifying, measuring, monitoring successful outcomes for children, youth, and families. Critical and objective methods that measure specific outcomes and treatment progress in essential domains need to be developed and agreed upon. Funders and regulators are responsible for supporting performance-based activities through provision of adequate resources.
- **Effective and promising practices:** *New models, new methods, and new approaches to working with these young people and their families must be sought, found, tested, and distributed widely throughout the field.* We should use and share the data we have gathered, especially concerning the needs of our current population as well as successful treatment interventions. Approaches must be more about collaboration, partnership, child, youth, family development and less about controlling behavior.
- **Transition planning:** *Residential treatment providers must work cohesively with local districts and other service providers, to create and support well-established community in addition to home-based services.* Regardless of how successful a residential care intervention is, gains achieved during the placement may be challenged when the environment in which the youth lives after discharge is less predictable and less consistent. These services should assist the youth not only in the transition out of care, but also in the transition into adulthood, including access to an education and job development, as many of the young people served in residential care are adolescents. Services and supports need to be planned, prepared, and put in place well in advance of the youth's discharge.

- **Permanency for children and youth**—*Connections with the child’s birth family should be protected and developed.* Concurrently, providers need to identify an alternative significant adult resource that can be integrated into the child’s life when the birth family is not a viable resource. This effort is a shared responsibility of the members of the local system of care. It is an essential part of what gives children and youth hope for self-sufficiency and a positive future.

Throughout the development of this paper, workgroup participants and colleagues have embraced the notion that, as a part of a sound system of services, residential care can and should be a viable treatment alternative. Although the art and science of this form of treatment may be well understood by providers and certain stakeholders, without a clear delineation of desired outcomes, residential care will always be a “last resort” for those seeking help for children.

Clearly, re-envisioning residential care will be a significant undertaking. Recognizing that work on this initiative will be ongoing, we must begin the process of improvement as soon as possible.

The steering committee cannot assume total responsibility for new outcomes in isolation. We need the guidance, vision, and commitment of all stakeholders (public and private), children, youth, and families to make meaningful change a reality. Considerable changes in the policy framework and financial resources are inevitable. For residential care to make an effective contribution to the service system, we all must re-examine our thinking and be willing to embrace the significant work that lies ahead. We look forward to the discussions that result from this paper and are eager to carry this important work forward.

Appendix N

Safety Net for Youth Committee Mission Statement (Approved September 2007)

Provide a multidisciplinary team with decision-makers from the human services systems in Erie County to assure that our community's children do not fall between the "cracks" in the various systems. To ensure that all children and families in Erie County receive the highest quality, least restrictive, most appropriate services in the safest and quickest time frame possible. All efforts will be made by supporting agencies to require that decision-makers are easily accessible to help expedite necessary actions. We are responsible for all children without regard to diagnosis, system involvement, or funding stream (No Rejection of Cases).

Guiding Principles

- We believe that every child deserves to be in a family that encourages healthy relationships.
- Each youth that comes to the attention of the committee will always be considered "our community's children", not from a particular system.
- Each individual requires our full attention and all efforts must be made to see that all decisions are centered around the needs of the youth him- or herself.
- All efforts will be made to triage and expedite the youth and family receiving the treatment support they require with multidisciplinary conference calls offered when determined as necessary.
- We operate from a strength based family driven perspective.
- We seek to help all individuals maintain connections to their natural family wherever possible, or if not, to recommend develop a caring, family-like environment for them (Permanency).
- We build on the values, preferences, beliefs, culture, in addition to the identity of the child, their family, and community.
- Our primary focus is community based services and natural supports.
- Out-of-Home Placements are for the shortest period possible and as close to the child's home and community as possible.
- Persistence, creativity and barrier resolution drives our work.
- Collaboration is paramount to meeting the needs of our families (Use of Multi-disciplinary Team).
- Measurable outcomes drive and direct our work, therefore there is a need to rely on data to show results (Data-Driven).
- We want serves to allow youth to be all they are capable of being and be given opportunities to transition into adulthood to live, learn, work and play with typical youth (Effective Transition to Adulthood).
- We seek to continually evaluate the effectiveness of our processes and seek feedback (Continuing Quality Improvement).

Appendix O



Wraparound Milwaukee

PROGRAM OVERVIEW

Unique Managed Care Entity

Wraparound Milwaukee is a unique type of managed care entity. It was initiated in 1995 with a six year, \$15 million grant from the Center for Mental Health Services. Its primary focus is to serve children and adolescents who have serious emotional disorders, in addition to who are identified by the Child Welfare or Juvenile Justice System as being at immediate risk of residential or correctional placement or psychiatric hospitalization. Wraparound Milwaukee serves an average enrollment of 570 youth and their families.

Funding

A combination of several state and county agencies, including the Bureau of Milwaukee Child Welfare, the County's Delinquency and Court Services, Behavioral Health Division, and the State Division of Health Care Financing who operates Medicaid, provide funding for the system. Funds from the four agencies are pooled to create maximum flexibility as well as sufficient funding source to meet the comprehensive needs of the families served. Part of the County's Behavioral Health Division, Wraparound Milwaukee oversees the management and disbursements of those funds acting as a public care management entity.

Care Coordination Services

Wraparound Milwaukee contracts with nine community agencies for the approximately 72 care coordinators who facilitate the delivery of services and other supports to families using a strength-based, highly individualized Wraparound approach. Wraparound Milwaukee has also organized an extensive provider network of 204 agency and individual providers that can offer an array of over 80 services to families. A Wraparound Milwaukee operated Mobile Urgent Treatment Team ensures families have access to crisis intervention services.

Role of the Family

Wraparound Milwaukee involves families at all levels of the system, aggressively monitors quality and outcomes. It operates from a value base that emphasizes building on strengths to meet needs; one family-one plan of care; cost-effective community-based alternatives to residential treatment placements, juvenile correctional placement as appropriate, and psychiatric hospitalization; increased parent choice and family independence; and care for children in the context of

their family and community.

<http://www.milwaukeecounty.org/WraparoundMilwaukeeP7890.htm>

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NYSOMH
People, Inc.

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Associate Vice President

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