EXECUTIVE ORDER
01.01.2003.02

CUSTODY RELINQUISHMENT AND ACCESS TO SERVICES FOR CHILDREN

FINAL REPORT

SEPTEMBER 1, 2003

Presented by
the
Council on Parental Relinquishment of Custody To Obtain Health Care

Chair
M. Teresa Garland, Esq.
Special Secretary

Governor's Office for Children, Youth and Families

ROBERT L. EHRLICH, JR. Governor	MICHAEL S. STEELE Lieutenant Governor	M. TERESA GARLAND, ESQ. Special Secretary

STATE OF MARYLAND EXECUTIVE DEPARTMENT
GOVERNOR'S OFFICE FOR CHILDREN, YOUTH AND FAMILIES

ROBERT L. EHRLICH, JR.
Governor

MICHAEL S. STEELE
Lieutenant Governor

M. TERESA GARLAND
Special Secretary

September 1, 2003

The Honorable Robert L. Ehrlich, Jr.
Governor of Maryland
State House
Annapolis, MD 21401

Dear Governor Ehrlich:

Thank you for your vision and leadership in establishing the Council on Parental Relinquishment of Custody to Obtain Health Care Services through the issuance of Executive Order 01.01.2003.02. I am delighted and honored to present to you the final report and recommendations of the Council with this transmittal.

I would like to acknowledge the Council and subcommittee members who gave willingly of their time and expertise and worked diligently to develop the comprehensive and thoughtful recommendations included in this report. I would also like to thank the parents and families who, through their advocacy, ensured that the issue of custody relinquishment received the level of attention it deserves.

The Council members have indicated their willingness to work with you both individually and collectively to implement the recommendations contained in the report. While some of the recommendations are envisioned as long-term strategies, I am encouraged that many can be implemented immediately with little cost to the State. I look forward to continuing to work with you on this important issue.

Sincerely,

M. Teresa Garland, Esq.
Special Secretary
Governor's Office for Children,Youth and Families

Council on Parental Relinquishment of Custody To Obtain Health Care

FINAL REPORT

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ABBREVIATIONS

CRASC-	**Custody Relinquishment and Access to Services Council**
CSA -	**Core Service Agency**
DBM -	**Department of Budget and Management**
DDA -	**Developmental Disabilities Administration**
DHR -	**Department of Human Resources**
DHMH -	**Department of Health and Mental Hygiene**
DJS -	**Department of Juvenile Services**
DSS -	**Department of Social Services**
GAO -	**General Accounting Office**
GOCYF-	**Governor's Office for Children, Youth & Families**
GOID -	**Governor's Office for Individuals with Disabilities**
ICF/MR-	**Intermediate Care Facilities For the Mentally Retarded**
LCC -	**Local Coordinating Council**
LMB -	**Local Management Board**
LSS -	**Local School System**
MIA -	**Maryland Insurance Administration**
MDLC -	**Maryland Disabilities Law Center**
MSDE -	**Maryland State Department of Education**
RTC -	**Residential Treatment Center**
VPA -	**Voluntary Placement Agreement**

COUNCIL ON PARENTAL RELINQUISHMENT OF CUSTODY TO OBTAIN HEALTH CARE SERVICES
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Acknowledgments

"The day I left my daughter at (the hospital), refusing to bring her home, was the worst I have ever experienced. Imagine leaving your child in a hospital, not knowing what was going to happen to her, facing the possibility of criminal charges, and trying to drive home on the beltway in rush hour traffic. I did it in tears. It was a miracle I made it home. She was also hurting, feeling unloved and unwanted, and her already low self-esteem sinking even lower."

-Public Hearing Testimony

The Council's report would have been impossible without the assistance of many people who participated throughout the process. Each has given of his or her valuable time with the goal of identifying alternatives to the practice of requiring parents to relinquish custody to obtain the support and services their children need.

The Council would like to thank each sub-committee chairperson for his or her dedication, commitment, and leadership.

The chairpersons and their subcommittees are: Rosemary King-Johnston and Cristine Marchand (Community Based Services); Lucy Shum and Jane Smith (Data Collection); Cathy Surace and Susan Tucker (Financial Strategies); and Jane Walker and Al Zachik (Local Systems).

We would also like to thank the parents who shared their time and experiences with us during our public hearings. Their input and testimony brought the issue to life and made it "real" for the Council members.

Sincere appreciation to the staff of the Council, Amanda Owens and Alisa Santucci, and to Malaika Anderson for her assistance with the Council meetings and with the production of the final report.

"We as parents of children with severe mental, emotional and behavioral problems wake up every morning worrying about what the day will bring for us and our children, what challenges and what emotional upsets. Most of us have been abused emotionally and physically by them, but we still advocate for them with the school system, with mental health providers and with insurance companies to get them the services that they so desperately need in order to survive and become productive members in this society."

-Public Hearing Testimony

EXECUTIVE SUMMARY

MARYLAND'S FAMILIES FACING CUSTODY RELINQUISHMENT

Many families who are unable without additional assistance to care for their children with disabilities have faced the difficult decision of giving up custody in order to receive necessary health care services for their children. These parents often face this dilemma because of limits of private health care plans, not being eligible for Medicaid, or limitations on Medicaid benefits. The cost of custody relinquishment becomes the responsibility of the State—typically at a much higher cost than prevention/early intervention services that could have been provided prior to this drastic step. After custody is relinquished, many families are also penalized by being placed on the State's Child Abuse and Neglect Central Registry.

Based on the best available data provided by the state Citizen's Review Board for Children, it is estimated that at least 200 children and families in Maryland are affected annually. However, this is considered an underestimation for the following reasons: (1) lack of systematic data for children; (2) reluctance of parents to seek help from DSS due to stigma; and (3) inability to track children who may enter another system of care, such as the Department of Juvenile Services (DJS).

Maryland families and our State are not alone in facing the challenges surrounding this nationwide dilemma. According to a General Accounting Office report released in April 2003, about 12,700 children with mental illnesses were placed in the custody of 19 states and 33 counties because their parents could not obtain treatment for them.

In addition, the U.S. Senate Committee on Governmental Affairs recently held two days of hearings to address custody relinquishment titled: *Nowhere to Turn: Must Parents Relinquish Custody to Secure Mental Health Services for Their Children?* Senator Susan M. Collins (R-Maine), Chair, has expressed her intent to introduce federal legislation to address this practice. In some key areas, Maryland has brought leadership and model initiatives, however, additional steps are necessary.

ACTION BY THE GOVERNOR AND STATE LEGISLATURE

On January 17, 2003, Governor Robert L. Ehrlich signed Executive Order 01.01.2003, "Custody Relinquishment and Access to Services for Children." establishing a Council on Parental Relinquishment of Custody to Obtain Health Care Services." The charge of

this Council was to identify alternatives to the practice of requiring parents to relinquish the custody of their children, who have significant and complex mental health needs and/or developmental disabilities, in order to access needed services.

The Governor's Executive Order also required the Department of Human Resources (DHR) to designate a special unit or staff person in every jurisdiction to be responsible for handling situations involving children with significant and complex mental health needs and/or developmental disabilities separate and distinct from abuse or neglect situations. In response to this charge, DHR has developed a preliminary protocol to address how its local Departments of Social Services will implement these responsibilities at the local level.

During the 2003 Maryland legislative session, three pieces of legislation—HB 405, SB 458, and HB 534—that address custody relinquishment were enacted.

- HB 405 requires the State to apply for additional Medicaid funds. If the State does receive additional federal funds, the funds will be used for home and community based services and placements for children who are at risk of custody relinquishment.
- SB 458 requires local departments of social services to offer voluntary out-of-home placements to children with disabilities without taking custody of the child and without a time limit.
- HB 534 prohibits families from being placed on the Child Abuse and Neglect Central Registry when they refuse to take children home from a psychiatric hospital or other facility because of a reasonable fear for the safety of their child or other family members.

COUNCIL TAKES ACTION

The Council on Custody Relinquishment and Access to Services for Children had a diverse membership reflective of the major stakeholders involved: decision makers from child serving and budgetary state agencies, parents, and advocates for children with mental health and developmental disabilities. The Council's efforts, which spanned six months, included intensive subcommittee work that broadened participation in the Council's deliberations, including expertise from the provider community, the medical community, and the Bazelon Center for Mental Health Law. The Council also sought input from the general public through hearings and written comments.

RECOMMENDATIONS

A summary of the final recommendations of the Council identified five themes:

- Access to services
- Data collection to support decision-making
- Targeted resources
- Maximizing federal resources
- Service coordination

In recognition of the state's fiscal condition and the complexities involved in implementing its recommendations, the Council identified some recommendations for immediate implementation that have no or low cost (less than $1 million). More costly and complex recommendations were proposed for implementation within 3 or more years.

A total of 45 recommendations were developed by the Council and its subcommittees and are discussed in detail in the following report. The recommendations below provide a summary of the some of the major strategies suggested by the Council in response to its charge from the Governor.

<> ACCESS TO SERVICES

1. Coordinated Information and Referral Service

The Subcabinet for Children, Youth and Families[1] (Subcabinet) should ensure that the local child serving agencies designate and train staff to provide telephone and in-person information from one office to families of children with intensive needs about the services available from all of the child serving agencies that their child may qualify for and how to apply for such services.

2. Hospital and RTC Staff Training

The Subcabinet agencies should provide on-going statewide training for hospitals and residential facilities staff on voluntary placement agreements, on aftercare, and on the discharge planning requirements set out in COMAR regulations as well as on the resources available in every jurisdiction.

3. Residential Crisis Beds

The Maryland Insurance Administration should take action to ensure that health insurers and HMOs licensed in Maryland are aware of their obligation to provide coverage for residential crisis beds to those insured in accordance with Maryland Law.

<> DATA COLLECTION TO SUPPORT DECISION-MAKING

1. Data Collection Coordination

The Subcabinet agencies should continue to develop and standardize, as resources allow, data collection across agencies for the purpose of being able to collect information on this population regardless of which agency is able to serve them. In addition to children placed, explore methods to collect data on children at risk of placement, and the costs of services and placement.

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[1] The Subcabinet promotes interagency collaboration and increased partnership opportunities across the State and includes the following members: the Secretaries of the Departments of Aging; Budget and Management; Health and Mental Hygiene; Housing and Community Development; Human Resources; Juvenile Justice; Office of Planning; the State Superintendent of Schools; the Special Secretary for Children, Youth, and Families; the Executive Director of Crime Control and Prevention; the Director of the Office for Individuals with Disabilities and representatives from other State Agencies as designated by the Governor.

2. Subcabinet for Children Youth and Families Information System (SCYFIS)

The Subcabinet should explore the opportunity presented by the SCYFIS to centralize the tracking of the needed data elements across state agencies to continually monitor the number and type of situations involving custody relinquishment.

3. Information Sharing Barriers

The Subcabinet, working with families, should address any barriers to appropriate information sharing presented by state confidentiality requirements.

<> TARGETED RESOURCES

1. Services

The Subcabinet agencies should ensure that an array of services is available to every family caring for a child with special needs. Services include but are not limited to: respite care services, in-home and community based services, crisis response services, and DDA emergency behavioral services.

2. Case Management

The Subcabinet agencies should make certain that an appropriate level of case management/ resource coordination commensurate with the needs of those eligible children at risk of custody relinquishment is available in every jurisdiction. This case management function should meet recognized national standards and caseload ratios.

3. Wrap-Around Case Rate Model

The State should implement a wraparound case rate (partial capitation) as a model for provider reimbursement. The goal of the wrap-around case rate is to provide more flexibility in accessing services.

<> Maximizing Federal Resources

1. Waiver

The Department for Health and Mental Hygiene (DHMH) should apply to the federal government for a waiver, which would allow more children within the target population to be covered by Medicaid.

2. Community Services Initiative/HB 405

The Subcabinet should maximize current resources within its fund dedicated to the Community Services Initiative. Funds realized as a result of the State's proposed rehabilitation option (HB 405) should be used to continue to finance home and community based services and placements for children who are at risk of custody relinquishment.

<> Service Coordination

1. Interagency Team Model

Utilizing existing structures, the Subcabinet should ensure that interagency teams are designated to respond to children at risk of custody relinquishment in every jurisdiction. The team shall include representatives from the following agencies: Department of Social Services, Developmental Disabilities, Local Management Boards, Juvenile Services, Core Service Agencies and the Local Education Agency. Any agency, hospital, provider or family may contact or make a referral to the Local Department of Social Services to request an interagency team meeting.

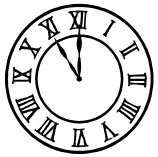
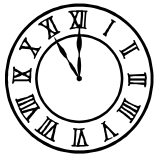
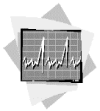
2. Training

The Subcabinet agencies should provide statewide training to the local interagency teams, hospitals, RTCs, law enforcement, judiciary, and advocates to inform them of state policies and assure consistent implementation of policy in all jurisdictions. Trainings should include information on the following: Voluntary Placement Agreements, State policies and protocols pertaining to custody relinquishment such as prohibiting the use of threats of abandonment or neglect, available resources, and discharge planning and case management.

MARYLAND'S OPPORTUNITY

The work and recommendations developed by the Council offer a concrete and thoughtful approach to address the needs of children with intensive needs. Many of these children can best be served at home and in their communities. These recommendations set the course for allowing this to happen.

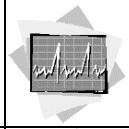
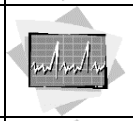
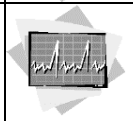
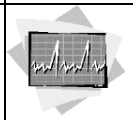
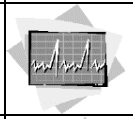
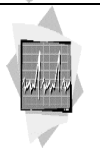
RECOMMENDATIONS CHART KEY

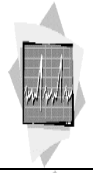
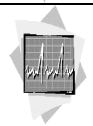
IMPLEMENTATION	KEY FOCUS AREA	COST	LEAD AGENCY
Immediate **Within 1 year**  **Short-term** **Within 3 years**  **Long-term** **3 years or more**	 **LocalSystems for accessing services**  **Community based services**  **Data Collection**  **Insurance**  **Financial Strategies**	**No Cost** Re-allocation of existing resources/staff at no additional cost **Low Cost $** Up to 1 million dollars **Medium Cost $** 1 million to 10 million **High Cost $** 10 Million or Above **Considerations** Cost could be annualized or one time. Costs may or may not include administrative or management fees.	**DHMH** – Department of Health and Mental Hygiene **DHR** – Department of Human Resources **DJS** – Department of Juvenile Services **MHA** – Mental Health Administration **OAG** – Office of Attorney General **SBA/RA** – State Budgetary Authority/Requesting Agency **Subcabinet Agencies** – statewide agencies serving children

IMMEDIATE IMPLEMENTATION	KEY FOCUS AREA	COST	LEAD AGENCY
State Standards **1**. All child-serving State and local agencies and administrations should develop and disseminate department policies and protocols on children at risk of custody relinquishment that may come in contact with their agency.		No Cost	Subcabinet Agencies
Taskforce to Study Access to Mental Health Services **2.** Request that the Taskforce to Study Mental Health Services address the need of private insurance providers to provide a larger array of community based mental health services rather than by default shifting that cost and burden to governmental agencies. Members of the Council should be invited to participate in the work of the Taskforce.		No Cost	MIA/DHMH
Interagency Dispute Resolution Process **3.** The Interagency Dispute Resolution process currently in development through the Subcabinet for Children, Youth and Families should include the ability to address the cases of children with intensive needs (including children at risk for custody relinquishment who are not eligible for the statutory SCC / LCC process. Both agencies and / or parents should be able to invoke this process.		No Cost	Subcabinet/ SCC
Interagency Team Model 4. Utilizing existing structures, interagency teams shall be designated to respond to children at risk of custody relinquishment. The team shall include representatives from: Department of Social Services, Developmental Disabilities, Local Management Boards, Juvenile Services, Core Service Agency and the Local Education Agency. Each agency shall have a primary and alternate member assigned to the team. The interagency team may be the Local Coordinating Council or another entity determined by the local jurisdiction (a full description of the Interagency Team Model can be found in Section A).		Medium Cost Note: Implementation will be Immediate/Short as there will be a phase-in process)	Subcabinet Agencies
Coordinated Information and Referral Service 5. The local child-serving agencies (DSS, DJS, LMB, CSA, LSS, DDA) should designate and train staff to provide telephone and in-person information from one office to families of children with intensive needs about the services available from all of the child-serving agencies that their child may qualify for and how to apply for such services. In developing this approach, we should first attempt to utilize new and existing resources that are available through the Subcabinet for Children, Youth and Families Information System (SCYFIS) and the 211system		Low to Medium Cost	Subcabinet Agencies

IMMEDIATE IMPLEMENTATION	KEY FOCUS AREA	COST	LEAD AGENCY
Targeted Case Management and Discharge Planning 6. The DHMH's Mental Hygiene Administration and the Core Service Agencies should evaluate the availability, caseload, and current use of mental health targeted case management under the Maryland Medical Assistance Program. (Note: Implementation is immediate to conduct evaluation, but short-term to provide service).		Low Cost to evaluate Medium Cost to provide service	DHMH
State Medicaid Plan 7. Explore amending the State's Medicaid Plan to provide targeted case management to Medicaid eligible children at risk of custody relinquishment in hospitals and residential treatment centers (a state match would be required for this service).		No Cost	DHMH
Hospital and RTC Staff Training 8. Provide on-going statewide training for hospitals and residential facilities staff on voluntary placement agreements, on aftercare, and on the discharge planning requirements set out in COMAR regulations as well as on the resources available in each county and Baltimore City. Hospitals should require its psychiatrists with hospital privileges to attend these trainings since they are responsible to authorize any discharge plan. These trainings should include a component on the issues surrounding abandonment. Discharge planning should begin when the child or adolescent enters the hospital or residential facility.		Low Cost	Subcabinet Agencies
DHMH Discharge Policy 9a. DHMH should convene a workgroup to include representatives from hospitals, residential treatment centers, MHA, MSDE, DHR, DJS, OCYF and families to review discharge policy as it relates to the COMAR 10.21.05 Aftercare Plans. b. Procedures such as a checklist that can be given to families and policy announcements should be put into place to ensure that hospitals and residential facility staff are adhering to the discharge requirements outlined in the regulations.		No Cost	DHMH
Respite Care Options 10. Information about respite care services should also be available for distribution at the single point of entry.		No Cost	Subcabinet Agencies

IMMEDIATE IMPLEMENTATION	KEY FOCUS AREA	COST	*LEAD* AGENCY
Respite Care Definition 11. Respite care should be defined broadly to include a full array of respite care services.		No Cost However, this has a cost if it increases the package of covered services	Subcabinet Agencies
Maryland Medical Assistance Training 12. Expand the information and training provided by the Maryland Medical Assistance Program to recipients, and employees of state and local agencies and private providers working with recipients about the in-home and community based services available under Medical Assistance and how to access these services.		Low	DHMH
Information and Communication 13. Implement the work of the Communication Subcommittee of the Medicaid Special Needs Children Advisory Council (SNCAC) by ensuring there is adequate funding in the department's budget for publications and training programs. Brochures being developed by the Subcommittee, with assistance from Baltimore Health Care Access, can be distributed to employees as well as to beneficiaries to fulfill this recommendation.		Low	SNCAC/ DHMH
Crisis Response System 14, State agencies should be provided with funding to develop and implement a plan to provide crisis response services to all families and children in need to ensure services are available to recipients in every county of the state.		No Cost	MHA
Insurance 15. The Maryland Insurance Administration should take action to ensure that health insurers and Health Maintenance Organizations (HMOs) licensed in Maryland are aware of their obligation to provide to their clients coverage for residential crisis beds in accordance with Maryland law. MIA action will include distribution of another bulletin to licensed insurers and HMOs clarifying the specifics of the mandate. The MIA has authority to take action against a licensed insurer or HMO that fails to comply with Maryland law. In addition, DHMH shall develop and disseminate materials to providers and the public, publicizing the specifics of the residential crisis bed law.		Low	MIA/DHMH Subcabinet Agencies
Education 16. MSDE shall convene a workgroup to address the needs of children in the education system who have complex mental health and/or behavioral disorders, including children in special education.		No Cost	MSDE

IMMEDIATE IMPLEMENTATION	KEY FOCUS AREA	COST	LEAD AGENCY
Data Collection Coordination 17. The Subcabinet should continue to develop and standardize, as resources allow, data collection across agencies to gather information on this population of families regardless of which agency is serving them. Explore methods of collecting data on not only children who are already placed but also those at risk of placement, as well as the costs of services and placement.		No Cost	Subcabinet Agencies
Subcabinet for Children Youth and Families Information System (SCYFIS) 18. Explore the opportunity presented by the Subcabinet for Children, Youth and Families Information System (SCYFIS) to centralize tracking of needed data.		No Cost	Subcabinet Agencies
Data Collection Coordination/Executive Order 19. Coordinate data collection efforts of activities established through the Executive Order (i.e. the local DSS designees) and protocols being developed by DHR to implement the provisions of SB458. Determine what data should and can be collected by other agencies.		No Cost	Subcabinet Agencies
Data Collection for Voluntary Placement Agreements 20. DHR/DSS Should collect data on the implementation of SB 458 relative to Voluntary Placement Agreements (VPAs) such as, numbers requested, placements made under VPAs, cost of those placements, IV-E or other federal eligibility, agency responsible for payment as well as child support or other third party contributions, children diverted to community-based programs, other outcomes of VPA requests, such as parents deciding not to pursue, CINA proceedings pursued instead, courts denying petition, etc.		Low Cost	DHR
Information Sharing Barriers 21. Address any barriers to appropriate information-sharing presented by confidentiality provisions. Family input should be included in the process.		No Cost	Subcabinet Agencies/ OAG
Data Collection of Acute Care Characteristics 22. Repeated emergency room visits and hospitalizations for acute care are characteristic of the population at-risk of custody relinquishment. The Subcabinet should follow up on the offer of the Maryland Hospital Association to provide information on emergency room visits and hospital admissions		No Cost	Maryland Hospitals

IMMEDIATE IMPLEMENTATION	KEY FOCUS AREA	COST	LEAD AGENCY
Data Collection Responsibility 23. If interagency teams are established as recommended by the Access Subcommittee, consider assigning data collection responsibility to them for efforts of all agencies involved with this population.		No Cost	Subcabinet Agencies
DJS Pilot Program 24. DJS should establish a pilot program to assist in tracking youth who are at risk of custody relinquishment and have come to its attention. The pilot program would incorporate questions related to custody relinquishment into the risk and needs assessment currently used by DJS for a random sample of youth throughout the State of Maryland.		Low Cost	DJS
Subcabinet/CSI Fund Examination 25. Maximize current resources within the OCYF fund dedicated to Return/Diversion and the Community Service Initiative by drawing down new federal funds. Use funds realized as a result of the State's proposed rehabilitation option (HB405) to continue to finance services through OCYF. a. The HB1386 Planning Committee shall examine how Subcabinet funds that support the Community Services Initiative (CSI) can be maximized, including: Ensuring that protocols are in place that require other funding sources be accessed before CSI funds are used to pay for services; specific attention should be given to funds available to State agencies referring children for CSI and the feasibility of funding all or part of a child's individual plan of care through Medicaid Developing policy guidance on eligibility for CSI funds for children with special needs who are not at risk of residential placement.		No Cost	Subcabinet Agencies
Key Service Determination 26. Determine the key services -- including one-on-one, personal care, therapeutic behavioral aides and in-home nursing -- that would benefit the children in the Council's target population and complete a Medicaid rate analysis of them to determine disparities, capacity issues, comparison to the market rate for services, etc. This process should be conducted by DHMH in an open manner with notice to and input from service providers, families and advocates.		No Cost	DHMH
Feasibility Workgroup 27. Convene a workgroup to determine the feasibility of implementing a family contribution to share the costs of care.		No Cost	Subcabinet Agencies

IMMEDIATE IMPLEMENTATION	KEY FOCUS AREA	COST	LEAD AGENCY
Autism Waiver 28. Reapply for the Autism Waiver using additional state funds.		High ($12M assuming 900 children)	DHMH/ MSDE
RTC Care 29.In its December report, the HB1386 planning committee should address how RTC care and educational services can be accessed without the need to relinquish custody of children who are medically eligible for RTC care and who, as determined by their local school system, do not qualify for special education or do not need special education services in a nonpublic day-school program.		Neutral	HB 1386 Planning Committee
Insurance - Market Conduct Report 30. Forward the findings from the Market Conduct Report to the HB1386 workgroup to inform the recommendations to the Subcabinet plan for serving children with intensive needs.		No Cost	MIA

SHORT-TERM IMPLEMENTATION	KEY FOCUS AREA	COST	LEAD AGENCY
Implement the following uniform standards for case management: 31a. Provide (or broker) a comprehensive assessment of the child's needs and circumstances, including necessary diagnostic assessments. Assessment must evaluate the child's needs in a family context. b. Determine the scope and intensity of the child's needs, and to extent appropriate he family's service needs, including consideration of the parent's assessment of needs. c. Identify the service agencies that should provide or pay for needed services. d. Develop a service plan in collaboration with the child's parent(s) and agencies responsible for providing or paying for needed services. Ensure that the plan identifies clear goals and measurable objectives and places the child in the least restrictive appropriate environment. e. All case managers should perform case reviews consistent with state agency regulations The case manager should report to all stakeholders in writing and when necessary the interagency team should be reconvened to re-visit the plan of care. Parents and stakeholders should be involved in all reviews. f. Document all case reviews specifically citing progress or lack thereof and steps taken to modify plan goal, objectives or strategies when progress is lacking.		Low Cost	Subcabinet Agencies
Families as case managers 32. The Mental Hygiene Administration should explore the use of families as case managers as other states have done.		Low	MHA
Funding for Case Management/Resource Coordination 33. Provide funding to allow for an appropriate level of DDA case management/resource coordination commensurate with the needs of those eligible children at risk of custody relinquishment.		Medium Cost	SBA/RA
Respite Care Service Availability 34. Respite care services should be available to families in every jurisdiction caring for a child with special needs using all funding options including: expansion of state funds, private funds, private insurance and family contribution		Medium	Subcabinet Agencies/ SBA/RA
In-Home and Community Based Services 35. Expand access to home and community based supports following a wraparound model.		Medium	SBA/RA
Quality Assurance 36. Develop quality assurance mechanisms to ensure that existing and new in-home and community based services are outcome focused, culturally competent, and strongly encourage and support the involvement of families in the planning and care of their children.		Medium	Subcabinet Agencies

SHORT-TERM IMPLEMENTATION	KEY FOCUS AREA	COST	LEAD AGENCY
DDA Emergency Behavioral Services 37. For children with developmental disabilities, an expansion of funding is recommended for DDA emergency behavioral services, that includes behavioral consultation, specialized behavioral respite and temporary augmentation of staff. Additional federal funding for these services should be explored.		Medium	MIA/SBA/RA
RTC Waiver (eligibility expansion) 38. Reapply for a residential treatment center (RTC) waiver if President Bush's 2004 budget allowing implementation of RTC waivers is approved. If we do not receive federal approval to implement RTC waivers, apply for a hybrid RTC/TEFRA waiver application.		Medium -$6.8 M (assuming 150 children based on 1998 application)	DHMH
Hybrid RTC/TERFA Waiver (eligibility expansion) 39. Work with CMS to pursue a hybrid RTC/TEFRA waiver. These concepts may be incorporated into an RTC waiver application pending passage of President Bush's 2004 budget allowing implementation of RTC waivers. The hybrid RTC/TEFRA waiver is a better option than a TEFRA State Plan change.		Medium $6.2 M Assuming 200 children	DHMH
DD Waiver (strengthen services) 40. Increase State funding and potentially the number of slots for the Developmental Disabilities Waiver for children.		Low - $3.6M (assuming 35 residential children and 379 in-home children)	SBA/RA/DHMH
VPA Funding 41. Provide funding for DHR if the availability of Voluntary Placement Agreements result in more children going into placement.		Unknown with potential to be high	SBA/RA
Wrap-around Case Rate (provider reimbursement system) 42. Implement the wraparound case rate as a model for provider reimbursement, which could be applied to the RTC or hybrid RTC/TEFRA waivers for children with emotional disabilities who are already eligible for Medicaid.		Rate to be developed by UMBC	Subcabinet Agencies
Disability Entitlement Advocacy Program (DEAP) 43. Examine expanding the Disability Entitlement Advocacy Program (DEAP) contract to assess eligibility of VPA children for Supplemental Security Income (SSI).		Low Cost	DHR

LONG-TERM IMPLEMENTATION	KEY FOCUS AREA	COST	LEAD AGENCY
Expand Access 44. Expand access to community-based residential placements as a last resort for children with intensive needs.		High	SBA/RA
Crisis Services Availability 45. State agencies should be funded to develop and implement a plan to provide crisis response services to all families and children in need in every jurisdiction. a. The specific crisis services funded by the Public Mental Health System in each jurisdiction should be surveyed. Crisis service programs that provide services listed in the State Medicaid Plan should be available to Medicaid recipients statewide.		Medium	SBA/RA

"The meeting did not go well on Friday. I became a blubbering idiot, just as I suspected. My emotions overtook me, as I felt all alone in the struggle to keep custody of our son. To the others, it is just a formality one goes through to receive assistance. …The meeting left me feeling like we had no options. No time to make changes in a system gone awry. All alone on a rock in the middle of a stream. … I left the meeting with tears in my eyes and a stake in my heart. A promise of a phone call, and a court date pending where we will be forced with reluctance to go through the shameful, humiliating, and injudicious act of yielding our son the guidance of the state and not of the parents who born him! Please tell me this cannot be happening! Surely, I shall wake from this nightmare and find my boy fast asleep in his own bed, the one I stare at each night. The one that is empty and calls his name."

- Entry from a Mother's Journal

Dedication

The Council on Parental Relinquishment Of Custody To Obtain Health Care Services would like to dedicate this report to the Maryland children and families facing this challenge.

"He loves Legos, animals and music. He is as likely to watch the Discovery Channel as he is to watch Cartoon Network...He is fiercely devoted to his immediate and extended family and friends who have rallied around him in his crisis this spring. He has had great successes in dodge ball and kick ball games...His other interests include fishing, bird feeding, helping in the garden and taking care of the family pets. With the proper medication, behavior modification therapy, school and community supports, we strongly believe he can become a solid, contributing adult- a citizen that Maryland can be proud of."

-Public Hearing Testimony

I. INTRODUCTION

a Duties of the Council

On January 17, 2003, Governor Robert L. Ehrlich signed Executive Order 01.01.2003.02, "Custody Relinquishment and Access to Services for Children ("CRASC")" (Appendix I, attachment A). Pursuant to the Executive Order, the Administration established a Council on Parental Relinquishment of Custody to Obtain Health Care Services ("Council") whose charge was to identify alternatives to the practice of requiring parents to relinquish the custody of their children who have significant and complex mental health needs and/or developmental disabilities, in order to be eligible for publicly funded services.

Section D of the Executive Order specifically charges the Council with the following duties: (1) Review the procedures and practices currently in place at both the State and local levels regarding child custody relinquishment; (2) Identify and analyze possible long-term alternatives to forced custody relinquishment; and (3) Identify and provide a summary of costs and benefits of federal resources available to Maryland.

Through the creation of the Executive Order, the Administration recognized that families must be supported and assisted as they seek services for their children, and both must take necessary steps to develop long-term solutions to this complicated issue. Concerns outlined in the Executive Order go beyond merely creating a plan for its implementation. A true partnership between agencies is necessary to achieve a meaningful resolution to this problem and, as such, each agency must establish and activate interagency protocols to effectively manage the delivery of services.

b Process

The full Council on Parental Relinquishment of Custody to Obtain Health Care Services had a series of eight meetings beginning on March 14, 2003 and ending on August 27, 2003. At the first meeting, the Council approved the coordination of its efforts with an existing legislative mandate, House Bill 1386. This mandate requires that the Subcabinet for Children, Youth and Families ("Subcabinet") form a committee to plan for enhanced community-based services for children with special needs. This committee must have the similar membership to the Council, and its charge embodies many of the core elements that are requirements of the Executive Order. The HB1386 Committee will continue to meet beyond the dissolution of the Council and will submit its final report to the Governor on December 1, 2003.

The Council invited public participation through two public hearings held on June 3, 2003 and June 12, 2003. The testimony given at the hearings can be found in (Appendix I, attachment B). The Council developed five subcommittees to

encompass the following key focus areas: Local Access to Services, Community Based Services, Data Collection, Insurance and Financial Strategies. These subcommittees were headed by agency/advocate Co-Chairs. The subcommittees met frequently and were given specific charges that fulfilled the mandates of both the Executive Order and HB1386. The full subcommittee reports are included in (Appendix I, attachments C-G). Finally, the full Council held extended meetings on August 1, 2003 and August 12, 2003, whereby the recommendations included in the subcommittee reports were discussed and voted upon for inclusion in this report.

II. OVERVIEW

a Background

Historically, a long series of efforts have addressed the issue of forced child custody relinquishment in Maryland before the issuance of the Executive Order establishing the Council on Parental Relinquishment of Custody to Obtain Health Care Services. These efforts have informed the work of the Council and facilitated the Council's ability to move forward and expand upon these efforts.

In response to HB99 (July 1998), the State applied to the former Health Care Financing Administration (now the Centers for Medicaid and Medicare Services) for a Home and Community Based Services Waiver to provide services in the community for children who need a residential treatment center level of care but who would not otherwise be financially eligible for Medicaid. CMS denied the application in October 2000. Federal law requires that a child meet an institutional level of care to be eligible, and CMS determined that residential treatment centers[2] do not meet the definition of "institution."

In 1999, as a result of concerns expressed by agency personnel, parents, advocates and legislators about the complex problems encountered when parents or other caregivers are unable or unwilling to continue caring for a child who is discharged from a hospital or psychiatric facility, the Mental Hygiene Administration (MHA) and the Subcabinet for Children, Youth and Families agreed to lead the development of a system to identify and provide services to these children. As part of this response, the Subcabinet adopted a policy for serving children awaiting discharge from psychiatric facilities on December 10, 1999 (Appendix II, Attachment A). On October 12, 2000 the Subcabinet adopted a final protocol to assist in the implementation of this policy. (Appendix II, Attachment B).

The first year of the policy's implementation was focused on developing protocols and procedures for hospital and public agency staff, and training large

[2] A residential treatment center is a long- term care facility that provides specialized treatment to individuals determined in need of care, supervision and treatment outside of their home and their communities.

numbers of personnel. Unfortunately, the lack of consistent funding for those at risk of custody relinquishment frustrated Maryland's ability to meet their needs.

From June 2000 to June 2001, the MHA committed $2 million of the Comprehensive Community Mental Health Services Block Grant on a one-time-only basis to help fund service plans for youth who were hospitalized in psychiatric units and whose families were unable to care for them at home. This effort provided needed services to children and families and allowed the State to gain valuable information regarding the nature of the custody relinquishment problem in Maryland and the services needed to address it. However, there is no longer any specific funding attached to this initiative.

In April 2000, the Bazelon Center for Mental Health Law, a national health advocacy organization, issued a report, *Relinquishing Custody: The Tragic Result of Failure to Meet Children's Mental Health Needs,"* which highlighted the national dilemma faced by parents of having to choose to relinquish custody of their child to the State or to "abandon their child in order to access much needed care." At that time, the Federal Substance Abuse and Mental Health Services Administration (SAMHSA) offered a competitive grant program for states to work with and receive technical assistance from the Bazelon Center to explore options to address this national problem. The MHA, under the aegis of the Subcabinet for Children, Youth and Families, applied for and received this grant, making Maryland one of three states selected to participate in the program. The partnership with the Bazelon Center laid the foundation for the September 2002 study titled "Relinquishing Custody — An Act of Desperation." completed by the Maryland Coalition of Families for Children's Mental Health with support from DHMH. That report helped document the problem of custody relinquishment to access services and the need to move toward effective solutions.

In the Summer of 2001, the Subcabinet convened a series of meetings regarding Maryland Annotated Code Article 49D, which establishes the Subcabinet and interagency processes for serving children with special needs. This review culminated in a final report addressing two specific issues: (1) interagency financing strategies and (2) mechanisms to make more effective use of existing resources and ensuring access to services for children with intensive needs and their families. This study resulted in the passage of HB1386, which mandates the development of a Subcabinet Plan for the improvement of community-based services for special needs children, especially those with intensive needs who are currently underserved. Foremost among these children is the population at-risk of custody relinquishment. In March of 2002, the Department of Human Resources (DHR) issued the "Roundtable Report on Stuck Kids, Closing the Gap on Inappropriate Placements," highlighting key strategies to assist in providing services to vulnerable children and their families.

b. Current Efforts

Since January 17, 2003, when Governor Robert L. Ehrlich, Jr. issued Executive Order 01.01.2003.02 establishing the Council, significant developments have occurred. Section A of the Executive Order requires that DHR, through its local Departments of Social Services (DSS), designate a special unit or staff person from existing staff to be responsible for handling situations involving children with significant and complex mental health needs and/or developmental disabilities separate and distinct from abuse or neglect situations. In response, DHR has developed a preliminary protocol to address how its local departments will implement these responsibilities locally. While DHR is currently receiving feedback from its local departments and other stakeholders, the following is a draft outline for the DHR Protocol:

DHR and Local DSS role:

1. Act as lead agency in coordinating overall process of ensuring the needs of children are met.

2. Serve as initial contact for these families: receive calls from family or provider.

3. With each new referral, immediately convene the multi-disciplinary team established to review the case, determine which agency is appropriate to be the lead to provide case management and placement services to the child and family, and determine support that is necessary from other State agencies.

4. Act as lead agency for those children who meet abuse/neglect criteria of DHR mandated mission for Child Welfare Services.

5. Serve as facilitator for placement funding (or funding source, with special consideration to foster care deficit issues and to the availability of State funds) for those children/families without payment capability but whose service and case management needs are most appropriately met by one of the partnering State agencies.

Additionally, DHR has identified some important interagency factors that are essential for successful service delivery to these needy children and families. The children identified in the Order have significant and complex mental health, developmental disability, educational and juvenile delinquency issues that are separate and distinct from DHR-mandated abuse and neglect situations. Every State department and agency identified for membership on the Governor's Council on Relinquishment of Custody to Obtain Health Care Services plays a significant role and is essential to successfully addressing these children's issues. As a result, the partnering agencies will also need to act as the lead

agency for placement and case management as appropriate, based on the needs of each child. Additionally, partnering agencies will need to establish a similar protocol for effective service delivery since one is not established through the current eligibility/intake process.

Subsequent to the Executive Order, three pieces of legislation — HB 405 (Appendix II, attachment C), SB 458 (Appendix II, attachment D), and HB 534 (Appendix II, attachment E) — were passed during the 2003 legislative session. HB405 requires the state to apply for Medicaid coverage of additional rehabilitation services and to use resulting federal funds to provide additional home- and community-based services and placements for children who are at risk of custody relinquishment. HB405 requires DHMH to apply to CMS for a Medicaid State Plan amendment to allow it to receive certain matching federal funds for part of the non room and board portion of certain residential care costs. The recouped funds would be directed to a resource fund established by the Subcabinet for Children, Youth and Families to provide community-based services and community-based out-of-home placements needed by children at risk of custody relinquishment.

SB458 requires local Departments of Social Services to offer voluntary out-of-home placements to children with disabilities without taking custody of the child and eliminates any time limit to the placement. The law prohibits a local DSS from seeking legal custody of a child under a voluntary placement agreement. A voluntary placement agreement would be allowed if the child has a developmental disability or a mental illness and the purpose of the out-of-home placement is to obtain treatment or care related to the child's disability that a parent is unable to provide. The bill also allows such a child to remain in an out-of-home placement under a voluntary placement agreement for more than 180 days if the child's disability necessitates care or treatment there and a juvenile court finds that a continuation of the placement is in the best interest of the child. HB534 prohibits families from being placed on the Child Abuse and Neglect Central Registry when they refuse to take children home from a psychiatric hospital or other facility because of a reasonable fear for the safety of their child or other family members.

c. <u>Statement of Need</u>

Many families who are unable to care for their children with disabilities without assistance have made the difficult decision to give up custody of them so that they will be eligible for publicly funded services. Most of these children have a mental health illness, and many are diagnosed with both a developmental disability and a mental health condition. Once custody is relinquished, families could face the penalty of being placed on the State's Child Abuse and Neglect Central Registry. In addition, the cost of custody becomes the responsibility of the State and is high compared to providing proactive preventative early interventions to help children remain with their families in their local communities.

It is the charge of the Council to evaluate the costs associated with any initiative to serve children with intensive needs at risk of custody relinquishment, and we would be remiss to exclude mention of costs to families caring for these special children. The families who testified during two public hearings hosted by the Council, information from other sources and reports by the Maryland Coalition for Children's Mental Health say that these costs have a tremendous financial impact on families.

This economic impact is felt in numerous ways ranging from extraordinary expenses to lost wages and to the loss of future potential productivity for all family members. Several parents reported being underemployed or unemployed to meet eligibility criteria for Medicaid, reducing the current potential income tax base for the State. Many families reported being unable to find appropriate day care and after-school care for their intensive needs children and were thus unable to keep full-time jobs. The majority told stories of tremendous stress, causing reduced productivity for those caregivers who are employed. Families were often called away from work due to repeated emergencies, hospitalizations, school meetings and family or individual therapy sessions. This pattern of time away from work frequently results in the loss of employment.

Families also told of their depleted financial reserves and their concerns about the future. Families were concerned for siblings who may not get appropriate attention for schoolwork because of the other child's behaviors. They were also concerned about the prospect of their children not being able to attend college for lack of financial resources caused by the large burden attributed to a single child. Families described costs for repairs to their homes or other property as a result of their child's uncontrollable behavior. In some instances, families incurred unexpected and considerable legal bills when their child was accused of committing a crime.

Families covered by private insurance recounted the high cost of co-payments under the existing mental health parity law and described limited access to services that were unequal to the range of care available under Medicaid. One family reported being denied coverage of community-based services by the best private insurer**.** Several parents described multiple episodes of emergency intervention from police and fire companies to transport unsafe children to crowded emergency rooms where little help was available. Repeated short-term hospitalization did little to care for these intensive needs children who were unable to achieve stability prior to discharge, resulting in a cycle of repeated crises and hospitalizations. This short-term care model often left the neediest children to become vulnerable to the threat of custody relinquishment.

Maryland is not alone in facing the complexities that arise in these circumstances. According to a General Accounting Office report released in April 2003, about 12,700 children with mental illnesses were placed in the custody of 19 states and 33 counties because their parents could not obtain treatment for

them[3]. This number is likely higher since no formal or comprehensive federal or state tracking of such placements occurs; and 32 state officials, including those from the 5 states with the largest population of children, did not provide data. On July 15 and July 17, 2003, the U.S. Senate Committee on Governmental Affairs held two hearings to explore custody relinquishment titled: *Nowhere to Turn: Must Parents Relinquish Custody to Secure Mental Health Services for Their Children?* Senator Susan M. Collins (R-Maine), Chair, has expressed her intent to introduce federal legislation to address this practice. However, it is the experience of a number of states that due to the multitude of factors that lead to custody relinquishment, the issue is difficult to legislate away without implementing other changes.

d. <u>Prevalence</u>

Within Maryland**,** no agency specifically collects data on this population although many agencies touch the families in this group. Even so, there has been much debate about how many such children there are. This situation is further complicated by the different "vocabularies" used by each agency. Standardization of data collection with a common vocabulary would be an appropriate first step, with the most desirable outcome being a central repository for the information across agencies.

Based on the best available data, provided by the Citizen's Review Board for Children (see chart below), an estimated 200 children and their families are affected by custody relinquishment annually. This is considered an underestimation for the following reasons: (1) lack of systematic custody data for children; (2) reluctance of parents to seek help from DSS due to stigma; and (3) inability to track affected children who enter another system of care, such as the Department of Juvenile Services (DJS).

NUMBERS OF ENTRIES INTO OUT-OF –HOME PLACEMENT THROUGH LOCAL DEPARTMENTS OF SOCIAL SERVICES PRIMARY REASON: CHILD'S SPECIAL NEEDS OR CHILD'S BEHAVIOR

FISCAL YEAR	NUMBER OF EPISODES INITIATED
1998	174
1999	168
2000	175
2001	167
2002	218

[3] The Department of Health and Mental Hygiene submitted a letter to the General Accounting Office clarifying some points in the representation of Maryland and about the federal requirements under the TEFRA option in the report (Appendix II, Attachment F).

For purposes of the financial strategies discussion, the Council estimated that more than 400 children in Maryland with serious mental illness are at risk for custody relinquishment. This is based on the number of children who it is estimated have had their custody relinquished in a year (200), and the assumption that as many are at risk.

e. Definitions

In an effort to identify the specific population of children within the scope of Executive Order 01.01.2003.02, the Council recognized that "children at risk of custody relinquishment in order to receive services" constitute one population of a larger group of children with unmet needs who are defined under Maryland law as "children with intensive needs."
In Art. 49D, § 13(D), a "**child with intensive needs"** is defined as:

> **A child:**
>
> **Who has intensive behavioral, education, developmental, or mental health needs that cannot be met through available public agency resources because:**
>
> 1. **The child's needs exceed the resources of a single public agency; and**
> 2. **There is no legally mandated funding source to meet the child's needs.**

A "child with intensive needs" may, but need not be in State custody; may, but need not have an "entitlement" to a portion of needed services; and may have public, private or no insurance to cover services. As the legislative history of HB1386 indicates, Subcabinet representatives and legislators plainly intended it to include the group of children referred to as "stuck kids" or "children at risk of forced custody relinquishment." [4]

Under the Executive Order, the Council's findings and recommendations must specifically address the needs of "children at risk of custody relinquishment to receive services." Thus, the target population for this report is further refined to encompass "**Children at risk of custody relinquishment,"** who include:

> **A. A child with intensive needs for whom needed services may be accessed only if the parents relinquish custody of the child to a public agency.**

[4] Other groups of children discussed as "children with intensive needs" include, for example, children with severe developmental disabilities, youth with mental health needs in the juvenile justice and child welfare systems, and children who are Medicaid-eligible for residential placement but lack educational funding.

B. Such children may include:

(1) A child in an out-of-home placement who has been recommended for discharge, whose family is unwilling or unable to have the child return home; or
(2) A child who is at risk of requiring an out-of-home placement whose family is unable to provide appropriate care without additional services; or
(3) A child who has been recommended for out-of-home placement by a treating professional whose family is unable to provide appropriate care without additional services.

It is important to distinguish two types of custody – physical and legal. Physical custody refers to responsibility for care and for decision-making authority as to the child's everyday needs. Legal custody refers to the right to make important decisions about the child's life, especially those pertaining to education, non-emergency medical care and religion, in other words, an agency assumes not only care but a parental decision-making role in the course of the child's life.

Finally, we note that, in Maryland, children typically do not enter State custody after age 18. However, the needs of children in this population do not abate at age 18 and, in Maryland, youths move to adult systems of care at various ages between 18 and 22. Thus, in this report, data may be presented to include youths through 21 years of age.

KEY FOCUS AREAS AND FINDINGS

a. Local Systems for Accessing Services

Current Status of Relevant Resources, Services and Processes

The specific procedures that are utilized to handle potential cases of custody relinquishment vary across jurisdictions. Some counties use the Local Coordinating Council[5] (LCC), while others may use a Multi-Disciplinary team or another interagency committee. In addition, several jurisdictions have developed separate teams, such as the Hospitalization Intervention Team (HIT) model in Cecil County, (Appendix III, attachment A) that specifically work with the facility, family and court systems around custody relinquishment situations.

[4]Local Coordinating Council's are interagency bodies made up of child serving agencies that develop interagency plans for children to assure placement in the least restrictive environment appropriate; and recommend to agencies the development of new and enhanced community-based programs to serve children with disabilities who might otherwise remain in restrictive placements that are distant (out-of-state or out-of-county) from their families and communities.

Statewide, there are an estimated 61 voluntary placements annually[6]. The use of voluntary placements varies by jurisdiction. It is anticipated that this will lessen as a result of SB458, which permits local Departments to offer voluntary out-of-home placements to children with disabilities without taking custody of the child and without a time limit. Other resources, which have been accessed by some counties through Local Management Boards to help serve children at risk of custody relinquishment, include Interagency Family Preservation (IFP) and/or Community Service Initiative (CSI) services. Detailed information on both of these initiatives may be found in Appendix III, attachment B.

At the state level are a number of teams that meet regularly to review children who are ready to be discharged from hospitals or who are being recommended for out-of-state placement. The latter group, those recommended for out-of-state placements, are children with such complex needs that they have either exhausted or are not appropriate for community or in-state programs. The current state review teams are the State Coordinating Council (SCC), the Placement Review Committee of the SCC, and the Multi-Agency Review Team (MART). State agencies work with their local representatives in trying to resolve these situations. Currently, there is no state review team that focuses on children at risk of custody relinquishment.

I have always been concerned about parents' ability to access services for children who have serious mental health needs. I have on many occasions represented parents/ caretakers whose primary reason for having contact with the local department of social services is their need to access services for their children. I have found these individuals by and large to be caring, concerned parents who have exhausted their personal resources before pursuing this option.
-Public Hearing Testimony

<u>Identified Issues</u>:

Currently, there is little consistency on how custody relinquishment situations are handled across the state on the local level. Information gathered from the state, and responses to a survey sent to child-serving agencies by the Local Access Subcommittee revealed that there are mechanisms and structures that departments use to address the situations as they arise[7]. These arrangements can be either formal or informal ranging from interagency meetings to a consultation over the phone with the family regarding local resources.

The local response to the needs of families often depends on the child's insurance status. In situations where the family has private insurance, community mental health services are severely limited, and the child generally does not have a lead agency that can advocate for his or her needs. There is general consensus between families and agencies that limitations on private insurance coverage often force families into the public system, therefore placing an additional burden on public agencies and state funding. The public system alone is insufficient, given constraints on funding and federal rules limiting Medicaid eligibility.

[6] SB 458 does not take effect until 10/1 so this number includes only voluntary placements that meet the current criteria. This is that the parent or guardian is temporarily unable to care for the child because of their (the parent or guardian's) hospitalization, incarceration or other temporary circumstance. In FY 2002, there were 61 children who entered voluntary placement who also had special needs.

[7] Responses to the survey are included as an attachment to the full committee report.

Families testifying at the public hearings or before the legislature provided an important perspective on interagency processes. Families voiced frustration about the difficulty they had accessing services. In search of help, families called every agency and were often told they were not eligible for services, especially if they had private insurance. As their child's condition escalated, the number of trips to the emergency room and hospitalizations rapidly increased until families reached a point that they no longer felt it was safe to bring the child home.

When parents reached this point of desperation and refused to take their child home, hospital staff often told them, the family would be charged with abandonment and neglect. Several families were charged and even had their names placed on the registry of abusers. If the child was particularly violent, families may have been told to contact the Department of Juvenile Services and press charges as a means of accessing care for their child. This perspective underscores the need for consistent points of contact and statewide procedures for children at risk for custody relinquishment.

Another issue identified by the subcommittee is that many of the children involved have special needs (developmental disabilities, intensive mental health needs, post-adoption, aggressive behaviors) and that most less intensive residential placements are not equipped to handle them. There is a concern that a number of children will not be served appropriately due to the lack of special programming available to meet their needs.

Local Access to Services Recommendations:

1. **State Standards**
   All child-serving State and local agencies and administrations should develop and disseminate department policies and protocols on children at risk of custody relinquishment who may come in contact with their agency.

2. **Interagency Dispute Resolution Process**
   The Interagency Dispute Resolution process currently in development through the Subcabinet for Children, Youth and Families should include the ability to address the cases of children with intensive needs including those at risk for custody relinquishment who are not eligible for the statutory SCC/LCC process. Agencies and/or parents should be able to invoke this process.

3. **<u>Local protocol</u>**
Based on state policies and protocols, local jurisdictions should establish a local protocol for responding to situations where there is a possibility of custody relinquishment.

Families need a central point of entry for care. They do not need denials, excuses or referrals to other agencies.

-Public Hearing Testimony

4. **<u>Interagency Team Model</u>**
Utilizing existing structures, interagency teams shall be designated to respond to children at risk of custody relinquishment. The team shall include representatives from: Department of Social Services; Developmental Disabilities; Local Management Boards; Juvenile Services; Core Service Agency; and the Local Education Agency. Each agency shall have a primary and alternate member assigned to the team. The interagency team may be the Local Coordinating Council or another entity determined by the local jurisdiction.

a. <u>Criteria</u>: The following criteria should be used to determine which families and children will be referred to the interagency team:
- Children and families who meet the definition approved by the Council on Custody Relinquishment;
- Children who are at imminent risk of custody relinquishment regardless of insurance status or eligibility; and
- Children entering through any system of care including state agencies such as the Department of Juvenile Services and the Department of Human Resources.

b. <u>Referrals to the Team</u>: Any agency, hospital, provider or family may contact or make a referral to its local Department of Social Services to request an interagency team meeting. If the family and child meet the criteria, an interagency team will be convened.

c. <u>Timeline</u>: The team shall be convened within 4 working days of the initial call to identify the needs of the family and child and to begin developing a plan of care with available resources. A plan of care will be developed within 15 working days. The initial meeting may be convened by telephone.

d. <u>Lead Agency</u>: A lead agency will be determined at the first meeting based upon the needs of the child[8].

e. <u>Community Response</u>: While DSS is the initial point of entry, all agencies should share responsibility for developing a plan of care.

[8] The lead agency is not necessarily the sole funding source. A process and procedures for the designation of a lead agency will be developed through the work of the HB 1386 Planning Committee.

Teams should also solicit input from treating professionals in the community or in facilities where the child is currently placed.

f. Child and Family Focused: The meeting will center on service needs of the child and family. Families will be included in all meetings and decisions pertaining to their child. Families will also be given contact information about family advocates who can provide support and possibly accompany families to meetings.

g. Case Management: An identified case manager will assist the team and will stay involved until there is satisfactory resolution to the crisis, or longer if needed. The case management function should meet recognized national standards and caseload ratios.

h. Confidentiality: All teams are responsible for complying with HIPAA regulations pertaining to confidentiality and release of information. Families must be fully informed about the nature of the information that will be shared, who will have access to the information and what will happen to the information that is shared.

i. Dispute Resolution: If a situation cannot be resolved within the timeline, the team, the family or the provider may request that the situation be referred to the State Dispute Resolution process being developed by the Governor's Office for Children, Youth and Families. Training and technical assistance on dispute resolution should also be provided for local interagency teams.

j. Training: Statewide training should be provided to local interagency teams, hospitals, residential treatment centers, law enforcement, judiciary and advocates to inform them of state policies and ensure consistent implementation of policy in all jurisdictions. Training should include information on:

- Voluntary Placement Agreements
- State policies and protocols pertaining to custody relinquishment such as prohibiting the use of threats of abandonment or neglect.
- Accurate contact information for each jurisdiction
- Discharge planning and case management
- Informing families about confidentiality protections

k. Data Collection: The Office for Children, Youth and Families should develop a template for data collection so that statewide information can be gathered to continually monitor the number and types of situations involving custody relinquishment

I. **Monitoring:** The Office for Children, Youth and Families should conduct evaluations of the state policies and local teams consistent with implementation to ensure that:
- State policies are effective and being implemented consistently throughout the state
- Local teams are functioning and effective

5A. Implement the following uniform standards for case management

1. Provide (or broker) a comprehensive assessment of the child's needs and circumstances, including necessary diagnostic assessments. Assessment must evaluate the child's needs in a family context.

2. Determine the scope and intensity of the child's needs and, to extent appropriate, the family's service needs, including consideration of a parent's assessment of needs.

3. Identify the service agencies that should provide or pay for needed services.

4. Develop a service plan in collaboration with the child's parent(s) and agencies responsible for providing or paying for needed services. Ensure that the plan identifies clear goals and measurable objectives and places the child in the least restrictive appropriate environment.

5. All case managers should perform case reviews consistent with state agency regulations. The case manager should report to all stakeholders in writing and, when necessary, the interagency team should be reconvened to re-visit the plan of care. Parents and stakeholders should be involved in all reviews.

6. Document all case reviews specifically citing progress or lack thereof and steps taken to modify plan goals, objectives or strategies when progress is lacking.

5B. Families as case managers

The Mental Hygiene Administration should explore the use of families as case managers as other states have done.

The Maryland Developmental Disabilities Administration (DDA) already does this in many programs — particularly with support services. In 1998, the Center for Mental Health Services in the Substance Abuse and Mental Health Services Administration (SAMHSA) published a monograph on "***New Roles for Families in Systems of Care***." The monograph highlights states[9] that have implemented case management services by

[9] States include: Rhode Island, Kansas, Illinois and Maine

"This past year has been a very long nightmare. My family has been living in fear of our lives for a year. Each morning, we thank God that we did not die at the hands of our son."
-Public Hearing Testimony

employing family members who have a child with mental health needs as Family Service Coordinators to assist other families entering the system.

The role of service coordinator or case manager has generally been reserved for professionals and, in some cases, requires a graduate degree. Research done by Koroloff et al. (1996)[10] found that "when family members serve as service coordinators, they not only help other families, but also sensitize administrators and providers and open up the system to involve and work with families more effectively." Several states including Kansas and Georgia have used waivers to provide Medicaid reimbursement for families as case managers.

6. **Taskforce to Study Access to Mental Health Services**
   Request that the Taskforce to Study Access to Mental Health Services address the need of private insurance providers to provide a larger array of community based mental health services rather than by default shifting that cost and burden to governmental agencies. Members of the Council should be invited to participate in the work of the Taskforce.

b. Community-Based Services

Current Status of Relevant Resources, Services and Processes

The availability of community based services for the CRASC target population is inconsistent statewide. Identified services needed by the target population come from a variety of agencies, at varying rates of frequency. Services are dependent upon availability of service providers, funding, whether the child has Medical Assistance, private health insurance or is uninsured, and the specific agency's capacity to respond to the identified need.

To support the work of the Council, the Office for Children, Youth and Families (OCYF) compiled information from the Local Management Boards[11] (LMBs) detailing what the LMBs saw as the needs of local communities in an effort to meet the varying needs of the targeted population of children, families and service providers in terms of custody relinquishment and services (Appendix III, attachment C). The following needs were identified as priorities by the LMBs:

- In-home treatment programs;
- Respite Care Options, including emergency or drop-in respite resources;

[10] Koroloff, N., Elliott,D., Koren, P., & Friesen, B. (January 1996*). Linking Low-Income Families To Children's Mental Health Services: An Outcome Study*. Journal of Emotional and Behavioral Disorders, 4(1), pp.2-11.

[11] Local Management Boards (LMBs) exist in all 24 jurisdictions in the State of Maryland. With local child-serving agencies, local child providers, clients of services and other community representatives on board, they act as the conduit for collaboration and coordination of child and family services on the local level.

- Protocol for discharge planning that is preventive, proactive and inclusive of families and natural community supports;
- Revisions to COMAR regulations to allow parents to sign a voluntary agreement to access out-of-home placement services, allowing the local DSS to work with other community services to avoid the long term surrender of children to State care; and
- Increased availability of community-based intervention services.

Because of the interest in finding ways to expand the accessibility and availability of respite care for families as noted above, the committee recommended that an application be submitted to the federal Centers for Medicaid and Medicare Services (CMS) under its "Real Choice Systems Change Grants for Community Living" grant opportunity. The purpose of this specific grant is to enable states to explore the development of Medicaid projects to provide respite for caregivers of children, "as if it was a Medicaid service," to a limited target group of children with disabilities. In coordination with the Custody Relinquishment Council, the Maryland Caregiver Support Coordinating Council, and the Mental Hygiene Administration has submitted an application for consideration under this grant opportunity. Funding decisions will be made prior to October 1, 2003.

The Mental Hygiene Administration (MHA) has also applied for an additional grant to develop an infrastructure to study the implementation of Evidence Based Practices (EBPs) for children and adolescents, and to implement methods for providing ongoing feedback about the success of EBP implementation. The ultimate goals of the project are to:

- Develop a system that engages key stakeholders in decision-making about implementation of EBPs for children and families, including "feedback loops" about implementation practices;
- Pave the way for more specific and more extensive service, research and training proposals to NIH, SAMHSA and other funders; and
- Provide a national model for statewide implementation of EBPs for children and families.

Issues Identified:

The cost of custody relinquishment inevitably becomes the responsibility of the State and this cost is high compared to the provision of proactive preventive early interventions to children and families within local communities. Regardless of where children live in Maryland and whether they have Medicaid, private insurance or are uninsured, the needs of these children require the provision of:

- Respite care options;
- In-Home and Community Based Services;
- Crisis Response System;
- Case Management;
- Appropriate discharge planning when they are hospitalized; and

- General and special education services, as determined appropriate, in accordance with the Individuals with Disabilities Education Act (IDEA).

To provide these services, a coordinated system of case management should be established by linking all child-serving agencies based on a child-centered framework that targets the function-specific needs of Maryland's children rather than agency-specific functions. According to Stroul and Friedman[12] such a system should be:

- Child-centered and family-focused, with the needs of the child/youth with intensive needs and family dictating the types and mix of services provided.
- Family- and community-based, with the focus of services as well as management and decision-making responsibility resting at the family and community level.
- Culturally competent, with agencies, programs and services that are responsive to the cultural, racial and ethnic differences of the populations they serve.

Community Based Services Recommendations

1. **Coordinated Information and Referral Service**
   The local child-serving agencies (DSS, DJS, LMB, CSA, LSS, DDA) should designate and train staff to provide telephone and in-person information from one office to families of children with intensive needs about the services available from all of the child-serving agencies that their child may qualify for and how to apply for such services.

   In developing this approach, future and existing resources that are available through the Subcabinet for Children, Youth & Families Information System (SCYFIS) and the 211 system should be utilized.

   It would be helpful for a single source to have the capacity to provide information to all families, even though access to services varies by insurance status. Support to families should include access to information, workshops, support groups and literature for the families and caregivers of children with intensive needs.

2. **Targeted Case Management and Discharge Planning**
   DHMH's Mental Hygiene Administration and the Core Service Agencies should evaluate the availability, caseload and current use

[12] Adapted from Stroul, B & Friedman, R. (1986). *A system of care for children and youth with severe emotional disturbances* (rev. ed., p. 17). Washington, DC: Georgetown University Child Development Center, National Technical Assistance Center for Children's Mental Health.

of mental health targeted case management under the Medicaid Program.

The Public Mental Health System has a proactive plan to offer coordinated case management to eligible children at risk of custody relinquishment who are high cost users of the Public Mental Health System. This plan should be reviewed as part of this evaluation to ensure that these high cost users at risk of custody relinquishment are receiving targeted case management. Implementation will involve coordination among Maryland Health Partners, hospitals and residential treatment centers that come in contact with and can identify these children.

"The most important thing, is that we would still be there for our children and they would know that, no matter where they are, we still love and care for them and they are not being left behind. No child should feel like they are being left behind."
-Public Hearing Testimony

2a. Explore amending the State's Medicaid Plan to provide targeted case management to Medicaid eligible children at risk of custody relinquishment in hospitals and residential treatment centers. A state match would be required for this service.

Case management is recommended as a critical part of the interagency team model recommended by the Local Access Subcommittee and approved by the Council. For those children who are Medicaid eligible, we should maximize federal dollars and bill Medicaid for targeted case management. But many children at imminent risk of custody relinquishment who will be referred to the interagency teams will be "stuck kids" in hospitals and RTCs who currently cannot receive federal financial participation for targeted case management under the Maryland Medicaid State Plan. CMS has informed states that they may bill for case management for institutionalized persons. DHMH believes that a Medicaid State Plan amendment will be necessary to bill for these services.

3. **<u>Funding for Case Management/Resource Coordination</u>**
Provide funding to allow for an appropriate level of DDA case management/resource coordination commensurate with the needs of those eligible children at risk of custody relinquishment.

The Developmental Disabilities Administration (DDA) provides case management/ resource coordination to those eligible children at risk of custody relinquishment. The intensity of this service as it is currently funded (staff to family ratio) may not always provide the level of support that some of these families require, therefore we recommend funding providing a level of case management/resource coordination commensurate with the needs of these children and their families.

4. **<u>Hospital and RTC Staff Training</u>**
Provide on-going statewide training for hospitals and residential facilities staff on voluntary placement agreements, on aftercare and on the discharge planning requirements set out in COMAR

regulations as well as on the resources available in each county and Baltimore City. Hospitals should require its psychiatrists with hospital privileges to attend these trainings since they are responsible to authorize any discharge plan. These trainings should include a component on the issues surrounding abandonment. Discharge planning should begin when the child or adolescent enters the hospital or residential facility.

5. **Discharge Policy**
   a. **DHMH should convene a workgroup to include representatives from hospitals, residential treatment centers, MHA, MSDE, DHR, DJS, OCYF and families to review discharge policy as it relates to the COMAR 10.21.05 Aftercare Plans.**
   b. **Procedures such as a checklist that can be given to families and policy announcements should be put into place to ensure that hospitals and residential facility staff are adhering to the discharge requirements outlined in the regulations**.

6. **Respite care options**
   a. **Information about respite care services should be available for distribution at the single point of entry.**

      The Maryland Caregivers Support Coordinating Council has begun assembling information on all agencies that provide respite in the state. This information, along with additional detailed information on how to apply and the criteria for acceptance, should be collected and disseminated to families in a document that is easy to read and understand.

   b. **Respite care should be defined broadly to include a full array of respite care services**.

      Generally, respite care is defined as a planned break from the rigors of care to allow the caregiver to rest and recharge. However, in many instances, the need for this care intensifies as a child's behavior worsens, leaving little time for much advanced planning. Thus, there is a need for both planned respite and other flexible support services that can offset or defuse a pending crisis.

      In addition, in the current interagency system, respite care is a service that utilizes many approaches, including short-term weekend placements in group settings, overnights in foster home settings, respite workers coming to the home from licensed respite programs, stipends paid to caregivers who find their own respite care workers and a number of other variations. These variations allow families to choose the approach best for their situation. In some cases, the term "respite

care" is used inappropriately to describe programs that serve more as shelters for youth pending long-term placement or as in-school suspension, which can confuse families seeking relief.

c. Respite care services should be available to families in every jurisdiction where they are needed and use all funding options including: expansion of state funds, exploration of possible federal matching funds under Medicaid as outlined earlier in the description of the recent MHA grant application, federal discretionary grants, private funds, private insurance and family contribution.

DHMH's Mental Hygiene Administration recently released a report, "Respite Care for Maryland's Families." (Appendix III, Attachment D), which states, "More families than ever are caring for their children with special needs and challenging behaviors at home." Providing support for these families as they attempt to carry out this enormous challenge has been a critical health care policy. It is the need for these placements that typically triggers custody relinquishment. The Maryland Blueprint for Children's Mental Health also documents the need for expanding the array of family support services, including respite care, and supports several other recommendations for service expansion made by this subcommittee.

7. **<u>Home and Community Based Services</u>**

a. Expand access to home and community based supports following a wraparound model.

A wraparound model has been defined as:

> '…a definable planning process that results in a unique set of community services and natural supports that are individualized for a child and family to achieve a positive set of outcomes' (Burns & Goldman, 1999). Wraparound is child- and family-centered, focuses on child and family strengths, and is community-based, culturally relevant, flexible and coordinated across agencies. [13]

There are many in-home and community-based services covered by Medicaid that could assist families in managing to care for their child with disabilities at home and thus prevent the need for out-of-home placement or custody relinquishment. Families and providers can be better educated on how to access medically necessary services.

[13] Burns, B. & Hoagwood, K. (Eds.) *Community-Based Interventions for Children and Families.* Oxford: Oxford University Press.

However, it may be difficult to access some services due to a lack of providers. These in-home and community-based services include:

- Therapeutic behavior support services (in-home aides);
- Personal Care Services (in-home assistance with activities of daily living such as bathing, eating, toileting and mobility);
- Psychiatric Rehabilitation Program Services;
- Mental health crisis services;
- Mental health targeted case management;
- Continued Medicaid eligibility and access to all medically necessary mental health services for 90 days following discharge from an out-of-home placement.
- Service coordination for children with developmental disabilities;
- Home health services; and
- Therapeutic nursery services.

b. Expand access to community-based residential placements as a last resort for children with intensive needs.

Home- and community-based services will not meet the needs of all children. Some children will need out-of-home services, which may include community-based residential services or an institutional type placement. While Medicaid covers institutional placements, community-based residential programs are not covered unless a child is eligible for a waiver offering such a service. State funding for the Developmental Disabilities and Autism waivers and other programs (e.g. Return Diversion) to access these community-based residential programs is not sufficient to meet the need and demand for these services. In some cases, this has led to custody relinquishment and in other cases to recommendations for residential treatment center care and placement in unnecessarily restrictive and costly settings.

c. Expand the information and training provided by the Maryland Medicaid Program to recipients, employees of state and local agencies and providers working with recipients about the home- and community-based services available under Medicaid and how to access these services.

A recent survey by the Maryland Developmental Disabilities Council found that of the approximately 60 families surveyed, all of whom receive Medicaid, some did not know how to access specialty services and when they had tried to obtain them, they had been unsuccessful. Some of the children may be eligible for Medicaid services such as Therapeutic Behavioral Support (TBS) but are not receiving them or are not aware of them. The reasons are unclear. In contrast, most

families are aware of the out-of-home placements such as hospitalization and residential treatment center care.

> *"We as parents of children with severe mental, emotional and behavioral problems wake up every morning worrying about what the day will bring for us and our children, what challenges and what emotional upsets. Most of us have been abused emotionally and physically by them, but we still advocate for them with the school system, with mental health providers and with insurance companies to get them the services that they so desperately need in order to survive and become productive members in this society."*
>
> *-Public Hearing Testimony*

d. Implement the work of the Communication Subcommittee of the Medicaid Special Needs Children Advisory Council (SNCAC) by ensuring there is adequate funding in the department's budget for publications and training programs. Brochures being developed by the Subcommittee, with assistance from Baltimore Health Care Access, can be distributed to employees as well as to beneficiaries to fulfill this recommendation.

   Moreover, additional training about the Medicaid Program is recommended for professionals, private providers and state and local agency employees who work with families with children who have special needs. Again, discussions have centered on the need to secure outside grants to support such training.

e. Develop quality assurance mechanisms to ensure that established and new in-home and community-based services are outcome-focused, culturally competent, and strongly encourage and support the involvement of families in the planning and care of their children.

8. <u>Crisis Response System</u>

a. **State agencies should be funded to develop and implement a plan to provide crisis response services to all families and children in need in every jurisdiction. These services should include:**

- **24-hour telephone lines;**
- **Urgent assessment;**
- **Walk-in clinics;**
- **In-home mobile crisis treatment or**
- **Psychiatric rehabilitation services; and**
- **Residential crisis beds.**

Families point to crisis response services as one of the most important services in helping them to continue to care for a child who has severe behavioral problems regardless of whether that child has a mental illness or a developmental disability. Yet there is wide disparity across the state, also depending on the nature of a child's disability and whether the child qualifies for Medicaid (or is eligible for the gray zone[14]), and whether families can access these services.

[14] Term used for individuals who are uninsured or under insured and meet eligibility requirements.

b. The specific crisis services funded by the Public Mental Health System in each jurisdiction should be surveyed.[15] Crisis service programs that provide services listed in the State Medicaid Plan should be available to Medicaid recipients statewide

Medically necessary Medicaid State Plan crisis services are covered for Medicaid beneficiaries statewide *and c*risis service providers should be accessible statewide. Existing crisis response programs may be geared to adults, not children, and some are available to people enrolled in specific programs such as Psychiatric Rehabilitation Programs (PRPs).

Medicaid State Plan crisis services include: community mental health program services and intervention; psychiatric intervention that provides an immediate and urgent assessment of a patient's needs and provides intensive support and services to ameliorate exacerbated psychiatric symptoms as a part of PRPs; and crisis assistance or management as part of case management for those eligible.

c. For children with developmental disabilities, an expansion of funding is recommended for DDA emergency behavioral services, including behavioral consultation, specialized behavioral respite and temporary augmentation of staff. Additional federal funding of these services should be explored.

While some mental health crisis services may respond to children with developmental disabilities, they are unable to provide ongoing crisis services if the child does not have a mental illness. DDA has emergency behavioral services statewide but those are not comprehensive enough, not all regions offer the full array of needed services nor are they sufficient to meet all needs. There is a need to expand these services statewide and to coordinate them with the mental health crisis response system in each area. Medicaid funding for these services should be explored.

d. The Maryland Insurance Administration should take action to ensure that health insurers and Health Maintenance Organizations (HMOs) licensed in Maryland are aware of their obligation to provide to their clients coverage for residential crisis beds in accordance with Maryland law. MIA action will include distribution of another bulletin to licensed insurers and HMOs clarifying the specifics of the mandate. The MIA has authority to take action against a licensed insurer or HMO that fails to comply

[15] Crisis response services are available under the Public Mental Health System to a population that is broader than the Medicaid population.

with Maryland law. In addition, DHMH shall develop and disseminate materials to providers and the community publicizing the specifics of the residential crisis bed law.

Section 15-840 of the Insurance Article and COMAR 36.11.06.03A(4) requires certain insurers, HMOs and non-profit health service plans to provide residential crisis services on a short-term basis in a community-based setting by an entity licensed by DHMH. Enforcement of state law will provide access to these services to those children who are covered.

The purpose of this mandate is to prevent an inpatient admission or a shortened length of stay of an existent admission. The mandate applies to an existent policy upon renewal. Since the mandate has not been in effect for a full year, not all health plans are required to offer this coverage at this time. In addition, this mandate only covers insurance plans governed by Maryland law such as individuals with private insurance who are not federal employees or military or are covered under a self-insured plan governed by the Employee Retirement Income Security Act (ERISA).

The Maryland Insurance Administration expects that most, if not all, eligible policies will be subject to the mandate after October 1, 2003, with the exception of policies issued under the Comprehensive Standard Benefit Plan. Access to this mandated private insurance benefit should relieve some of the demands made on the Public Mental Health System.

9. **<u>Education</u>**

MSDE shall convene a workgroup to address the needs of children in the education system who have complex mental health and/or behavioral disorders, including children in special education. The workgroup shall be comprised of representatives from the Mental Hygiene Administration, local school systems, Core Service Agencies and family members caring for a child with complex mental health and/or behavioral needs. Family members should represent children placed in a variety of educational settings. The workgroup shall develop recommendations to develop consistency throughout the state on issues pertaining to:

1. **Identification and assessments including functional behavioral assessments;**
2. **Determination for special education services;**
3. **Educational environments and placement options;**
4. **Academic achievement for students with complex mental health and/or behavioral needs;**

5. **Behavior plans including positive behavioral supports;**
6. **Training for administrators and educators in mental health and behavioral disorders and treatment including medication options; and**
7. **Integration of education in a community plan of care for a child with complex mental health and/or behavioral disorders.**

c. Data Collection

Current Status of Relevant Resources, Services and Processes

As mentioned previously, state agencies are not collecting specific data on the population of children at risk of custody relinquishment. In addition many agencies interface with the families in this group, which further complicates the collection of data since each agency uses different "vocabularies" and data collection systems. Although agencies were not able to provide specific data regarding the number of children at risk of custody relinquishment, the following available child data was collected:

Department of Human Resources/Departments of Social Services

In 2002, 3,611 children entered out-of-home care. Out-of-home care includes all levels of placement from “regular” foster care through higher cost facilities. However, most are placed in lower cost settings. Of the 3,611, the reasons for entry of 147 were “child special needs;” 260 were “child disruptive behavior;” and 417 were “abandonment.” All of these categories could include children in the subject population. The subcommittee also looked at 103 children entering the DSS system on a voluntary basis. The numbers for this group included the following:

Category	Number of Children
Child Special Need[16]	28
Child Disruptive Behavior[17]	33
Abandonment[18]	3

[16] "Special needs" includes anything from a physical disability, to emotional/behavioral problems, developmental disability, visual or hearing impaired, pregnant, part of a sibling group, medically fragile and “other."

[17] This categorization is usually used for children whose caregiver (whether parents or substitute care placement) needs to have a child placed elsewhere due to their "disruptive behavior."

[18] "Abandonment" means leaving a child without an adult caregiver or without providing for the child. It has also been used in this arena for situations where the parents have refused to take their child home from a hospital or DJS.

Of the 103 children, 44% entered a high cost placement at some time during the time they were removed from their homes.

The caveats in considering this data are as follows: In 2002, it was not general practice for DSS to take voluntary placements unless they met the criteria governing at the time. Therefore, the numbers of children who fall in the subject population are undoubtedly greater. Those children either would not have come into the state system at all, would have come into the DSS system under a CINA petition[19] (not considered voluntary), or could have gone into the DJS system on delinquency charges. The nature of the coding by the individual worker also may not capture all conditions bringing the child into the child welfare system. The data system only accepts a maximum of 4 and the entry reasons may be subject to some interpretation by the worker. Further, for DHR/DSS the term "special need" can mean more than issues concerning the child's emotional/behavioral needs. It can also mean the child is older, part of a sibling group, and/or African-American.

Because of these factors, it was seen as a fair assessment that the number of children at risk of custody relinquishment or whose custody was relinquished to access services is greater than this data would indicate.

Department of Juvenile Services

DJS screens youth at Intake for both needs and risk. If the screening indicates, a clinician may further assess the youth. Needs assessed relate to substance abuse, mental health, somatic health, family problems and education. Johns Hopkins University, Bloomberg School of Public Health summarizes the findings of the intake screen and submits monthly summary reports to the Department. These findings, however, do not flag youth who are at risk of custody relinquishment.

DJS also does not capture this specific data but provided the following: In March 2003, there were 194 children pending placement, with the longest wait being 253 days. All were children found to have committed delinquent offenses who had been committed by the court. The largest number was from Baltimore City. Of the 10 children who had been waiting for placement the longest, 4 had low IQs or special education needs, 3 had histories of fleeing from programs, 2 were sex offenders and 1 had a history of aggressive behavior. This data highlights the need for more specialized placement capacity to avoid such waits.

[19] State law (COMAR 07.02.11.06B and Family Law Article §5-525(a)) now requires that if a DSS determines that a child needs intervention longer than 6 months, a local DSS must file a CINA petition. SB 458 will change this as well as the current law and practice requiring the transfer of more than physical custody when a child is placed voluntarily solely for reasons relating to the child's disability.

Developmental Disabilities Administration

DDA provides services to those who qualify, but also does not track custody information at this time. These services are not entitlements but are available as long as funding allows. DDA differs from other agencies in that it considers those under age 22 to be children. The following data is provided for those under 18, who would be the subject population for custody relinquishment.

Placement	**Number of Children**
Alternative Living Units	13
Group Homes	7
State Residential Center	2
Individual Family Care	7
Crisis Resolution	35
Crisis Prevention	60
Waiting List For Services (Current Need)	584

Mental Hygiene Administration

The Mental Hygiene Administration, through Maryland Health Partners (MHP), approves mental health services to those children who are eligible for Medicaid. Services are provided without the need for custody relinquishment, and data on custody is not currently tracked by MHA or MHP.

Department of Education

In fiscal 2002, the Department had reviewed requests from local school systems and approved funding for residential care for 329 children. A few of these are co-funded with another agency.

System Capacity

This following data on system capacity was gathered by telephone contact with each facility admissions office in June 2003.

Facilities	**Number of Beds**
Crownsville (state run)	25
Finan Center (state run)	23
Private	190
Total	238

In addition, some adult beds are used on occasion for adolescents. There are also 138 beds in facilities in Washington, D.C., and Delaware.

Residential Treatment Centers

There are 199 Residential Treatment Beds in the public system for children and adolescents. There are 550 private RTC beds, plus an additional 26 for DJS referrals only.

Issues Identified:

- Limitations and non-compatibility of current data systems.
- Implementation of SB458 will require policy and training to standardize data collection on children whose families are seeking voluntary placement.
- Additional court activity (including data tracking) will be required at the Juvenile Court level.

The current system capacity was reviewed recognizing that custody is only one part of the issue. Other major issues are financing, availability of appropriate resources and case-management expertise. At this time, resources are not available in any agency to capture children at risk of custody relinquishment or those families who have relinquished custody. Some information does exist at a very general level on the needs of children coming to DHR/DSS and DJS, but only at certain points in those systems under current laws.

Senate Bill 458, Children with Disabilities – Voluntary Placements, will be effective in October 2003. To identify those children placed voluntarily under the provisions of this statute, DHR/DSS has added a "state use" code to the current data system. This will allow tracking of this population of children. While this could provide helpful information, it will still not identify those children who are at risk.

DJS recognizes the importance of this issue and is examining several options that will enable it to collect data relating to custody relinquishment. DJS is exploring the possibility of incorporating questions at intake utilizing the current risk- and needs-screen. This will ensure that DJS can track youth at risk of custody relinquishment and/or those who have come to DJS's attention. DJS can then collect this data and report aggregate numbers of youth at risk of custody relinquishment.

The Subcabinet for Children, Youth and Families Information System (SCYFIS) is an electronic information system intended to help frontline case managers, service providers, Local Coordinating Councils, Local Management Boards and the Subcabinet for Children, Youth and Families document the results of services to children and families. SCYFIS can be enhanced to help local interagency groups, such as LCCs, to address the needs of families whose children are at risk of custody relinquishment.

This enhancement, part of a new SCYFIS addition known as the Psychiatric Hospitalization Tracking System for Youth, is intended to document (with parental consent) the efforts of the interagency team responsible for assisting families who are considering relinquishment of children under psychiatric hospitalization, to have their children's longer-term needs met.

Once this enhancement is completed[20] and has proved to be useful for addressing the needs of these hospitalized youths, SCYFIS could be enhanced further to document interagency efforts in other situations where parents are considering custody relinquishment. Considered as Phase Two, SCYFIS could be linked (again with parental consent) to other State agency information systems whenever parents are considering custody relinquishment.

Data Collection Recommendations

1. **Data Collection Coordination**

   The Subcabinet should continue to develop and standardize, as resources allow, data collection across agencies to gather information on this population of families regardless of which agency is serving them. Explore methods of collecting data on not only children who are already placed but also those at risk of placement, as well as the costs of services and placement.

   (a) Explore the opportunity presented by SCYFIS to centralize tracking of needed data.

   (b) Coordinate data collection efforts of activities established through the Executive Order (i.e. the local DSS designees) and protocols being developed by DHR to implement the provisions of SB458. Determine what data should and can be collected by other agencies.

Data Collection for Voluntary Placement Agreements

2. DHR/DSS should collect data on the implementation of SB458 relative to Voluntary Placement Agreements (VPAs) such as, numbers requested, placements made under VPAs, cost of those placements, Title IV-E or other federal eligibility, agency responsible for payment as well as child support or other third party contributions, children diverted to community-based programs, other outcomes of VPA requests, such as parents deciding not to pursue, CINA proceedings pursued instead, courts denying petition, etc.

Information Sharing Barriers

3. The Subcabinet with family input should address any barriers to appropriate information sharing presented by confidentiality provisions.

[20] It is anticipated that this enhancement will be completed in the Spring of 2004.

Data Collection of Acute Care Characteristics

4. Repeated emergency room visits and hospitalizations for acute care are characteristic of the population at-risk of custody relinquishment. The Subcabinet should follow up on the offer of the Maryland Hospital Association to provide information on emergency room visits and hospital admissions.

Data Collection Responsibility

5. The Subcabinet should consider assigning data collection responsibility to the interagency teams outlined in the Local Access subcommittee recommendations for efforts of all agencies involved with this population.

DJS Pilot Program

6. DJS should establish a pilot program to assist in tracking youth who are at risk of custody relinquishment and have come to its attention. The pilot program would incorporate questions related to custody relinquishment into the risk and needs assessment currently used by DJS for a random sample of youth throughout the State of Maryland. Once it is established that these pilot questions effectively capture the necessary information, the questions will be included in the screenings statewide, and data and recommendations will be shared with the Subcabinet.

d. Insurance

Current Status of Relevant Resources, Services and Processes

The Maryland Insurance Administration (MIA), with assistance from The Delmarva Foundation, has conducted a preliminary data collection from Private Review Agents (PRAs) that administer behavioral health care services for the largest number of Maryland members. Its purpose is to perform a market conduct examination of some of the mental health PRAs in the State in an effort to analyze the use of private insurance by children who have certain special needs that require intensive behavioral health services.

Criteria for data collection:

- Two (2) or more inpatient admissions within a year for patients ages 1-18.

Data received:

- In response to its request, the MIA received files of 255 individual patients with a primary psychiatric diagnosis, ages 5-18 years. The total admissions for those individuals are approximately 657. The total percentage of admissions from the emergency room was 6%. The total percentage of patients with follow-up care is 59%.

The Delmarva Foundation will take the next steps to select files and conduct further review, as outlined below:

- Screening – The Foundation will search the files by diagnosis codes to "screen out" diagnoses that are uncharacteristic of or not traditionally linked to children in the Council's target population.
- Selection – It will select a sample of files that contain characteristics of children with special behavioral health needs. Those files will undergo further investigation, as explained below.
- Request for Complete Files – It will contact the facility to which the sample individuals were admitted and ask the facilities for complete medical records for the particular individuals.
- In-Depth File Review – It will review the complete medical records for 5 to 10 selected individuals to determine what care was provided, what care was considered and what care could have or should have been provided.

Insurance Recommendations

"Many of the community-based programs for mentally ill children, such as psychotherapeutic services are only available to children who are Medicaid eligible. And even with the Medicaid coverage, there is not a guarantee of services. The natural cycles of mental illness dictate that children like mine will often have periods of improvement or good behavior, which make them ineligible for services."
-Public Hearing Testimony

1. Market Conduct Report

The MIA will draft a market conduct report outlining its findings. The Report will identify what services were provided as well as what services could have or should have been provided. The PRAs involved in the market conduct investigation have 30 days to review the Draft Report. The Report will then be issued as a public document and will be available on the MIA Web site, www.mdinsurance.state.md.us. It is anticipated that the Report will be available as of December 31, 2003.

2. The findings from the Market Conduct Report will be forwarded to the HB1386 workgroup to inform the recommendations to the Subcabinet plan for serving children with intensive needs.

A. Financial Strategies

Current Status of Relevant Resources, Services and Processes

The Department of Health and Mental Hygiene (DHMH) offers numerous services for children with special health care needs. These services are provided by Medicaid (also referred to as Medical Assistance), the Developmental Disabilities Administration (DDA), and the Mental Hygiene Administration (MHA) and are summarized in (Appendix III, attachment E) Services for Children with Special Needs).

The Maryland State Department of Education (MSDE), the local lead agencies for infants and toddlers birth to age 3, and the local school systems serving children with disabilities from 3 to the end of the school year that a child turns 21, offer services under the Individuals with Disabilities Education Act. The services

for children with disabilities are funded through federal, State and local funds with local funds paying 73% of the costs of special education and related services. In addition, the Home and Community Based Services Waiver for Children with Autism Spectrum Disorder is administered through MSDE, the local school systems and local lead agencies.

The Subcabinet for Children, Youth and Families offers services for children with special needs described a chart that can be found at Appendix III, attachment B. The Maryland Department of Human Resources (DHR) also offers a variety of services for children with special health care needs. (Appendix III, attachment F)

"Nobody knows the life for families with disabled children, particularly behavior problems, changes completely. How we have to adjust our lives accordingly. It's hard for anyone to imagine unless you walk a mile over and over again yourselves.... I have to be very strong every day and ask God for strength day by day. Dealing with the system is not a very easy task."
-Public Hearing Testimony

Issues Identified

These publicly financed programs provide essential services to eligible populations. However, eligibility is often limited by income or is capped by resource limitations. Privately financed programs are needed to meet the needs of privately insured children. Private insurance policies generally cover inpatient psychiatric hospitalization, medication management and a certain number of traditional outpatient visits. In some cases they include co-payments that may not be affordable by all. These policies do not cover many of the home and community-based services available under Medicaid or under the Medicaid waiver program.

There are reports that families of children on Medicaid have also experienced problems and relinquished custody as well due to obstacles in accessing some services. The federal Medicaid program does not cover all of the care that disabled children need, such as community-based residential programs and respite care, unless a child is in a waiver program that offers such services.

If not treated early with appropriate care, most of these children will move through the system into more costly higher levels of care, usually residential placement. This trajectory continues into adulthood and, often, the resulting costs are seen in the adult corrections system or in homeless shelters. The State and local communities pay the high price for this loss of human potential as well as the loss of prospective income tax revenues. The Packard Foundation captured a useful statistic to succinctly capture the issue: for every $1 not spent today, $7 will be spent in the future.

Finance Recommendations

1. **Reapply for a residential treatment center (RTC) waiver if President Bush's 2004 budget allowing implementation of RTC waivers is approved. If federal approval to implement RTC waivers is not approved, apply for a hybrid RTC/TEFRA waiver application.**

Maryland applied to CMS several years ago for a 1915(c) Home & Community Based Services (HCBS) waiver to provide services in the community for children

needing RTC level of care. CMS denied the application. CMS' reason for the denial was that RTCs don't meet the definition of "medical institutions" under the federal law. The law states that a child eligible under a HCBS waiver must require institutional level of care, defined as a hospital, nursing home or Intermediate Care Facility for Mental Retardation (ICF-MR).

This problem is in other states. Federal legislation has been proposed to include RTCs in the definition of medical institutions. President Bush's current budget proposal requests a 10-year demonstration to include RTCs as institutions. If there is a change at the federal level we would be interested in reapplying. We would need new general funds for the State match. DHMH's estimate from the original waiver application was $6.8 million annually for 150 children.

2. **Work with CMS to pursue a hybrid RTC/TEFRA waiver. These concepts may be incorporated into an RTC waiver application pending passage of President Bush's 2004 budget allowing implementation of RTC waivers.**

The hybrid RTC/TEFRA waiver is a better option than a TEFRA State Plan change. It will be targeted to children with serious mental illness. Covering mental health services for this population will prevent the practice of custody relinquishment. This initiative will increase equity under Maryland Medicaid because Maryland Medicaid already has waivers in place to cover physically disabled and developmentally disabled children regardless of parental income. There is no comparable coverage for children who are disabled due to mental illness.

Under the Model Waiver, children with physical disabilities who meet institutional levels of care are eligible to receive community-based services and the full package of Medicaid benefits. Under the Developmental Disability and the Autism waivers, children with developmental disabilities who meet institutional levels of care are eligible to receive community-based services and the full package of Medicaid benefits. The goal of these waivers is to prevent institutionalization by delivering services in the community.

Maryland Medicaid would develop a new program to cover mental health services for children with serious mental illness. The new program would be based on the following principles:

- **Population:** Target children with serious mental illness.
- **Financial Eligibility:** Disregard parental income in the eligibility determination to allow children in families with moderate or higher incomes to obtain coverage. This is consistent with Maryland Medicaid's other programs for disabled children.
- **Population Size:** Initially limit the number of program slots to 200, depending on funding. Capping the slots is necessary to make the program budget feasible given the State's current fiscal crisis. We estimate 400 children in Maryland with serious mental illness to be at risk for custody relinquishment. This estimate is

based on the number of children who actually have had their custody relinquished in a year (200), and the assumption that as many are at risk. The number of slots should be small in the first years of implementation because new programs are more successful when brought up incrementally.

- **Services:** Mental health services will include some waiver services, such as respite care. If the wraparound case rate model discussed below is used as the provider reimbursement system, the waiver would enable children to access a broad array of services. This waiver would cover mental health services but not the full Medicaid package of somatic services for children who have private insurance (which meets standard benefit package requirements). This promotes continued use of private insurance. Cover the full Medicaid package of somatic services for children who are uninsured or whose insurance does not meet the standard benefit package requirements.
- **Cost Sharing:** Require families to pay a monthly sliding scale premium. These families are able to share costs given that they are at higher incomes than the traditional Medicaid population. Other states, including Arkansas and Minnesota, have implemented premiums when covering this population.

We estimate that this program would cost approximately $12.4 million (total funds) annually, based on the assumptions below. The State portion would be $6.2 million annually. Premiums would offset some small portion of the program cost.

- 125 children with private health insurance will participate at an average annual per child cost of $60,000 in total funds.
- 75 children without private health insurance will participate at an average annual per child cost of $65,000 in total funds.

This program may be cost-effective in the long term by providing a targeted package of services to children to prevent them from entering the foster care system or institutions and becoming eligible for the full package of Medicaid benefits. It also increases equity under Maryland Medicaid by making services available to disabled children regardless of underlying cause of disability.

3. Increase State funding and potentially the number of slots for the Developmental Disabilities Waiver (DD Waiver) for children.

The DD Waiver serves individuals of all ages who require Intermediate Care Facility for the Mentally Retarded (ICF/MR) level of care. We recommend increasing the number of children who can be served through the DD Waiver by increasing the DDA allocation, then requesting from CMS the corresponding number of slots in the DD Waiver. The DDA Waiver currently affords a full range of services to children and their families that do not require custody relinquishment. Some of these services include respite care, in-home personal support, behavioral services, resource coordination and small community residential homes. All are

community-based and deem only the child's income/assets for financial eligibility determination for the DD Waiver.

While the array of services available in the waiver is great, the funding resources are finite. As of June 2003, there were more than 10,000 children and adults waiting for services from the DDA. To serve the 35 children under 18 in the most urgent level of need (crisis resolution) whose families are requesting residential services, it would cost $3.5 million at an average cost of $100,000 per child. The State general share would be $1.75 million. To serve the 379 children under age 18 in the most urgent need (crisis resolution) for in-home support services, it would cost $3.79 million at $10,000 annually per family. In-home support services would delay or prevent a need for those deeper end services that may lead to custody relinquishment. The State share would be $1.895 million. All of these funds would need to be annualized to continue long-term support to the children and their families.

4. Provide funding for DHR if the availability of Voluntary Placement Agreements results in more children going into placement.

In accordance with SB458, DHR will maximize the use of Voluntary Placement Agreements instead of filing CINA Petitions. This will prevent relinquishing custody of children with disabilities who need out-of-home placements but who have not been subject to abuse or neglect. This can be accomplished without any loss of Title IV-E federal revenue for eligible children.

DHR will develop a new Voluntary Placement Agreement to implement legislation (SB458) and to meet the requirements and provisions of section 472(a)(1) of the Social Security Act for continued federal financial participation for eligible children placed through VPAs. The provisions require State agencies administering the Title IV-E program that use VPAs to file a petition with the court and obtain a judicial determination within six months of the child's placement, and to clearly state that remaining in the home would be contrary to the child's welfare.

DHR is currently updating an interagency Memorandum of Agreement (MOA) with DJS to govern the completion of Title IV-E eligibility determination and re-determination through information gathered by DJS. DJS is responsible for obtaining legal custody, completing case planning and management, documenting case services and securing the placement of children into appropriate settings for their care and treatment. Documentation processes and placement settings must meet stipulated Title IV-E program policies and regulations. DJS also files quarterly claims with DHR for federal matching of its expenditures for Title IV-E eligible children. DHR has been designated by the U.S. Department of Health and Human Services (DHHS) as the Single State Agency for federal reimbursement of the costs of care for Title IV-E eligible cases.

DHR will develop similar interagency MOA with other applicable child-placing state agencies that meet the Title IV-E criteria. These agencies will include DHMH, OCYF and MSDE. The agreements would specify how DHR will assist the others in completing Title IV-E eligibility determination and re-determination for children whose parents have given the agency the authority to make placement determinations and decisions about the day-to-day care of the child, and how the other state agencies will secure the necessary documentation to meet the Title IV-E claiming criteria. Federal financial participation is claimed at a 50% rate for eligible children.

5. **Examine expanding the Disability Entitlement Advocacy Program (DEAP) contract to assess eligibility of VPA children for Supplemental Security Income (SSI).**

   DHR will ensure that its DEAP Program contracts provide for assistance to children potentially eligible for SSI who are placed through VPAs. For children placed through VPAs and determined ineligible for Title IV-E, SSI funding eligibility will be assessed and, if eligible, accessed for children. DHR, through its Family Investment Administration (FIA), has a current contract under DEAP with Health Management Associates (HMA), a private organization that generates a monthly list of all foster care cases determined ineligible for Title IV-E. HMA then requests local Departments to assess filing SSI applications for those cases. DEAP also represents the State in SSI-denied cases at all levels of Social Security Administration appeals. The current DEAP contract with DHR will expire June 30, 2004, but a Request for Proposals is being developed to seek bids to continue this service.

6. **Implement the wraparound case rate[21] as a model for provider reimbursement, which could be applied to the RTC or hybrid RTC/TEFRA waivers for children with emotional disabilities who are already eligible for Medicaid.**

   A group of Maryland agency representatives and advocates has been meeting to develop a case rate model for high-end children with serious emotional disturbance who have been high cost users of the Maryland Public Mental Health System or of the services of other state agencies such as DJS and DHR. It is modeled on Wraparound Milwaukee and similar programs in other states. Eligible children will be assigned to a provider who will be paid a case rate. The portion of the case rate paid for by Medicaid will receive a 50% federal Medicaid match. It is believed that this model will prevent the costly cycle of hospitalization, RTC care and detention center care that has led to custody relinquishment.

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[21] The term "wraparound case rate" refers to a per person payment over a set period of time. The provider entity receiving the per person ("capitated" or "case rate") payment would deliver the services covered under the capitation payment that are needed during the month.

Subcabinet agencies should develop and implement a plan to divert children in or at risk of entering state custody from hospitals, RTCs, residential schools, detention centers and expensive out-of-home residential placements by offering their families the choice of enrolling in the wraparound case rate model where available. The steps to develop and implement the wraparound case rate model are:

a. Direct all relevant State agencies to fund and implement a case rate demonstration project using the wraparound intervention and governance structures described in greater detail in the Real Choices consultant's report. The wraparound case rate model will serve as a vehicle to improve and streamline services as well as improve efficiency of current State expenditures through reduced costs and increased federal matching participation.

b. Ensure adequate funding for the above demonstration project from multi-agency sources in several sites across the State. An estimate of the wraparound case rates will be available after the University of Maryland, Baltimore County, develops a rate-setting methodology. The rate will be based on actual use of Medicaid services for a comparable serious emotionally disturbed population.

c. Develop and implement a detailed evaluation plan of the above demonstration, including a grant application to the Services Research branch of the National Institute of Mental Health or other appropriate federal agency to fund the study of: individual and family outcomes; effectiveness of services; and cost benefits to the State budget as a whole by documenting the number of children diverted and the estimated savings realized, impact on RTCs and other institutional utilization, and other variables determined to be of importance.

d. Reinvest any cost savings realized from the demonstration project to either expand the number of children served in initial demonstration sites or to defray costs of new demonstrations in other Maryland communities. Have each agency that realizes savings agree to invest the savings in a single stream of funding to support the Wraparound Case Rate Model. A careful study should be undertaken to see if the State could reduce its reliance on RTC beds, thus making funding available for models such as the case rate model.

   Funding may come from DHMH, DHR, DJS, MSDE and OCYF. For example, the following may be funding sources: return diversion program funds, DHR funding for room and board services for children in State custody, DJS funds for children who would otherwise enter detention centers, MSDE funds for nonpublic school tuition for children who would otherwise enter nonpublic schools in RTCs or other children who can remain in the public schools as a result of entering the case rate model.

7. Maximize current resources within the OCYF fund dedicated to Return/Diversion and the Community Service Initiative by drawing down new federal funds. Use funds realized as a result of the State's proposed rehabilitation option (HB405) to continue to finance services through OCYF.

OCYF currently funds a range of services, shown on the continuum of care spectrum below. These funds could be used as the State match portion for one of the waiver options to leverage new federal funds, facilitating an expansion of eligibility for publicly funded services while continuing to serve the current OCYF population.

Continuum of Care

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Interagency Family Disability Preservation (Short-term intervention)	**Return Diversion and Community Services Initiative (intermediate intervention) (intermediate intervention)**	**Chronic (lead agency/ long-term intevention)**

Interagency Family Preservation (IFP)
IFP Services are time limited, intensive family centered services for families in crisis whose children are at imminent risk of out-of-home placement. The goal of the IFP is to prevent the removal of a child from the family by providing the services that would promote the integration of the family and avoid inappropriate out-of-home placements. The Subcabinet Partnership Team and the Local Management Boards (LMB) are working to clarify current eligibility criteria, which may allow additional children and families to access these services by redefining "crisis" to a lower level of risk in the LMB manual.

Return/Diversion and Community Services Initiative (R/D and CSI)
The Return/Diversion (R/D) and Community Service Initiative (CSI) Initiative was established by the Subcabinet for Children, Youth and Families to reduce the number of children placed in out-of-state facilities by providing community-based services to keep children closer to home and to increase the number of children served by avoiding the costliness of out-of-state services. In HB1386, the initiative was expanded to include services for children at risk of in-state residential placement and for children who can be served in less restrictive, community based environments.

Use of OCYF funds should be consistent with the following principles:

1. Re-affirm the R/D and CSI Initiative priority list contained in the SCC/LCC regulations. The priorities are set out below:

    I. A child in need of out-of-state placement
    II. A child in need of out-of-state placement already placed out-of-state;

III. A child in need of residential placement, awaiting discharge from an in-state residential placement;
IV. A child in need of residential placement, recommended for in-state placement; and
V. A child with intensive needs[22], including those not in State custody.

2. Maximize funding by getting federal matching dollars for children who are eligible for the proposed RTC or hybrid waiver and (1) are newly or currently receiving services through the R/D and CSI Initiative or (2) are currently being served by child-serving agencies (DHR, MSDE, DJS, DHMH). R/D and CSI funds should be used to provide the State match for these children. New federal matching funds may also be available from the State's proposed rehabilitation option (HB405).

3. Any federal funds realized as a result of the federal match for services covered under the State's proposed rehabilitation option will be used to fund services for children through OCYF.

4. R/D and CSI funding should be accessed only when agency funding is unavailable. To facilitate this process, a checklist should be developed for use by the LCC to ensure that all potential agency funding streams have been fully investigated.

5. A waiting list should be maintained for the R/D program so that as funds are available, children can be served quickly in order of priority. In addition to formalizing the method of accessing R/D and CSI services, it will allow the State to more accurately document the need for these services.

6. Once a child is approved for services, funding has been identified and services have begun, the services should continue within an approved level of care until they are no longer needed or the child ages out of the program. R/D services are generally intended to last for 2 years, subject to limited exceptions. (This limitation and other R/D standards are embodied in proposed regulations approved by the Subcabinet and soon to be published in the Maryland Register).

7. Children currently receiving services through R/D and CSI should not be discontinued through the implementation of these recommendations.

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22 A child with intensive needs has been defined as a child:
(a) who has behavioral, educational, developmental, or mental health needs that cannot be met through available public agency resources because:
(i) the child's needs exceed the resources of a single public agency;
(ii) there is no legally mandated funding source to meet the child's needs; and
(b) who may be referred to the LCC subject to the availability of additional state funding and in accordance with the Subcabinet plan developed under section 4 of House Bill 1386 (2002).

7a. The HB1386 Planning Committee shall examine how Subcabinet funds that support the Community Services Initiative (CSI) can be maximized, including:

- **Ensuring that protocols are in place that require other funding sources be accessed before CSI funds are used to pay for services; specific attention should be given to funds available to State agencies referring children for CSI and the feasibility of funding all or part of a child's individual plan of care through Medicaid.**
- **Developing policy guidance on eligibility for CSI funds for children with special needs who are not at risk of residential placement.**

8. Reapply for the Autism Waiver using additional State funds.

The Autism Waiver was approved by CMS for July 1, 2001 to June 30, 2004. It was initially approved for 250 children in Year 1, 300 in Year 2 and 350 in Year 3. Due to requests by the school systems, parents and advocates, MSDE, through DHMH, requested that the number be revised to 500, 750 and 900, respectively. There are currently 750 children on the waiver, 300 con the Registry and 150 applications are being reviewed to fill the additional Autism Waiver slots that became available on July 1, 2003 when the total slots available became 900.

CMS informed Maryland that for the Autism Waiver to be re-approved in Year 4, beginning July 1, 2004, the day-habilitation services provided in the schools that are available to a child under IDEA would not be reimbursed by Medicaid. This will have a devastating effect on funding for the waiver. MSDE is using a portion of these savings as the State share of the Medicaid costs and the cost of additional Waiver Services needed to maintain the children in their home and community. The purpose of these services is to prevent an out-of-home placement. In the event an out-of-home placement is needed for health and safety reasons, children can be placed in a residential setting through the Autism Waiver. This opportunity may afford families the resources necessary to avoid custody relinquishment of their child. Residential habilitation service is utilized when the families cannot manage the child's behavior even with additional services in the home. In FY 03, eight children were receiving residential services solely through the Autism Waiver. These children were at extremely high risk of entering a psychiatric hospital and at risk of getting "stuck" at such a facility.

Core waiver services include respite care, intensive individual support services and residential habilitation. The waiver also covers family training, environmental accessibility adaptations, therapeutic integration services, supported employment and day habilitation. Service coordination for the Autism Waiver is provided by the local school systems and local lead agencies. Families have stated that these services have made it possible for their children to remain at home.

Loss of these services could have a number of consequences. It would be expected that families would hire attorneys to take agencies to court in an attempt to find a funding source for the services previously provided by the Autism Waiver. It is likely that families may seek to access services through the DD Waiver, although funding for that expansion is not allocated in the DDA budget. Should the waiver be terminated, recipients would still be covered under it for 30 days from the notice of termination. When faced with termination and loss of residential and/or intensive community based services, many families whose child would still be on Medicaid for the 30 days could seek placement of their child in an ICF-MR[23] or in the alternative level of care under the DD Waiver. Thus, termination of the waiver could result in cost shifting from MSDE to DDA, as opposed to a reduction of overall State spending.

To continue the Autism Waiver in FY 05, a separate line item for State dollars will be needed to fund the State's share of the Managed Care Organizations (MCOs) costs for HealthChoice, the state's share of the waiver costs, and other Medicaid costs incurred when a child is on the Waiver. For the waiver to prevent out-of-home placements, community-based services must be available to support the children in the home.

Estimated New State Dollars for the Cost to Operate the Waiver for 900 Recipients

Capitated Rate	
Average cap rate$338 per month 60% of pop./2	1,095,120
Other State Plan Costs	
Average $250 per month per child 20% of pop.	540,000
Respite Service	
168 Hours X $20/per Hour/2	1,360,800
Average usage 90% of population	
Family Training	
60 Units X $86.per Hour/2	1,161,000
Average usage 50% of population	
Environmental Accessibility Adaptations	
$1500 per 3 years/2	
Average usage 50% of population	112,500
Supported Employment	Not used
Residential Habilitation	
20 recipients @ Intensive rate	751,900
Intensive Individual Support Services	
Average usage 50% of population (20 hrs. wk)	6,142,500
Therapeutic Integration Service	

[23] ICF/MR =Intermediate Care Facilities for Persons with Mental Retardation: An ICF/MR is an institution which meets Federal CoPs (conditions of participation) and has its primary purpose the provision of health or rehabilitation services to individuals with mental retardation or related conditions receiving care and services under the Medicaid program.

	3 service per week per child Average usage 20 % of population	1,179,3600
Total		**$12, 344, 180**

9. **In its December report, the HB1386 planning committee should address how RTC care and educational services can be accessed without the need to relinquish custody of children who are medically eligible for RTC care and who, as determined by their local school system, do not qualify for special education or do not need special education services in a nonpublic day-school program.**

   Possible solutions to consider include expanded state reimbursement for on-grounds RTC schools, maximization of Medicaid reimbursement for education that is a necessary part of RTC care and ensuring changes in local and state policies/regulations that provide for children in all RTCs in Maryland to access local public schools whenever this is consistent with IDEA.

10. **Determine the key services -- including one-on-one, personal care, therapeutic behavioral aides and in-home nursing -- that would benefit the children in the Council's target population and complete a Medicaid rate analysis of them to determine disparities, capacity issues, comparison to the market rate for services, etc. This process should be conducted by DHMH in an open manner with notice to and input from service providers, families and advocates.**

    Medicaid payment rates for some services are low. To promote equity in the Medicaid program it would be optimal to increase rates for a number of home- and community-based services, not just for on. Examples of cost rate increases for selected services are:

    Therapeutic behavioral services (TBS): The current budgeted $20 hourly rate results in $6.7 million in total funds, $3.35 million in State funds annually, based on the assumption of 5 hours of services, 5 days a week, for 250 children and an initial assessment and treatment plan development at $800 per child. Increasing the payment would cost an additional $1.63 million in total funds, $813,000 in State funds annually.

    Additional funding for this rate increase would be needed if waiver expansions described in the recommendations above occur, making more children eligible for Medicaid. The cost of the $5 increase for an additional 200 children would be $650,000 in State funds ($1.3 million in total funds). Therefore, the total cost of the payment rate increase may be $1.46 million in State funds ($813,000 + $650,000). A sufficient amount of any increase in payment rates should be passed through TBS agencies to the actual TBS service providers, resulting in salary increases. This would require additional monitoring.

Private Duty Nursing: Increasing payment rates for private duty nursing from $28.50 to $35.00 would require an additional $10.9 million in State funds for FY 2005.

Personal Care: Increasing payment rates for personal care services from $10 to $15 per day for Level 1, from $20 to $25 and $20 to $30 for different populations within Level 2, and decreasing Level 3 rates from $50 to $46 per day but adding a $15 overnight rate would require an additional $3.3 million in State general funds in FY 2005.

11. **The HB1386 Planning Committee should examine the existing rate structure for foster and adoption family subsidies and benefits to remove financial disincentives to the adoption of children with complex needs and to prevent custody relinquishment.**

12. **Convene a workgroup to determine the feasibility of implementing a family contribution to share the costs of care.**

    A workgroup, reflecting the citizens of Maryland with respect to race, gender, income, education and geography, should be established to consider how families and communities should share the cost of care for children with special needs who require intensive services. At least half of the workgroup should be made up of family members who care for a child with special needs. The group should also contain service providers, representatives of state agencies and disability advocacy organizations.

    The Workgroup on Sharing the Cost of Care should consider:

    The feasibility of implementing a structure for sharing the cost of care with families including:

    1. Researching the experiences from other states on the use of premiums or fee scales (Appendix XIV shows Arkansas' TEFRA Waiver premium schedule)
    2. Researching experiences of other disability groups
    3. Compiling fee structures and mechanisms used by agencies in Maryland
    4. Determining the method for financial contribution that would be used such as fees for services, premiums or tax credits

    Potential advantages and disadvantages of sharing the cost of care including:

    1. Short-term budget and revenue impacts
    2. Social and emotional consequences for children and families

3. Long-term community and societal consequences

Guidelines/regulations should be developed:

1. The types of services that could be accessed by sharing the cost of care
2. Criteria for the amount of family contribution
3. Procedures to protect confidentiality of financial information
4. Evaluation process and timeline

Procedures to inform families about:

1. Eligibility for Medicaid
2. The method used to determine the amount families would pay

Payment procedures: Any mechanism for cost sharing should be based on the following fundamental principles.

1. The amount that a family is able to share for the cost of their child's care should not affect the quality of the child's care.

2. Family contribution should not impose an undue burden on the family or force impoverishment before their child can receive services.

3. Procedures to assess the family contribution should take into consideration the number of dependents; the costs families routinely incur to care for their child and extra-ordinary expenses related to any family member.

4. Private insurance should be accessed to the fullest, and family contribution and agency funding should only be used to augment such coverage if necessary.

IV. FISCAL CONSIDERATIONS

The Council was very cognizant of the State's fiscal condition in making its recommendations. As such, the Council did not believe that it was appropriate to make recommendations and expect their immediate implementation. The Council sought to establish a schedule whereby recommendations could be implemented over time. Generally, recommendations made by the Council for immediate implementation have no or low cost (less than $1 million). More costly proposals are recommended for adoption within 3 years, in most cases. Additionally, the Council felt that more costly proposals could be phased in over a number of years as the State's fiscal condition improves.

The Council's recommendations also seek to access additional federal resources when available. However, in most instances the receipt of additional federal funds will also require the expenditure of State funds. Despite this, the Council believed that it was important to make use of all available resources and to ensure the highest level of fiscal efficiency attainable with current State expenditures.

As part of its deliberations, the Council also decided not to exclude potentially costly proposals solely on the basis of cost. It was the Council's belief that effective programs and services should be recommended regardless. Finally, the Council noted that significant investment of funds up front often helps prevent the need for more costly services later.

As this report makes clear, children and families facing the possibility of custody relinquishment suffer serious negative emotional, health and financial consequences. The Council's review of public agency responses to the issue leads to the conclusion that the inadequacy of services to prevent the need for custody relinquishment also results in significant costs to the State.

Those costs, however, are difficult to estimate. Just as Maryland's current data-gathering limitations have frustrated the Council's ability to assess the number of children in the target population addressed by the Executive Order, current information makes it impossible to estimate precisely the costs to receive services from public agencies that can be attributed to custody relinquishment. However, it is self-evident that such costs are incurred whenever children are placed in State custody solely to obtain needed services, or when access to those services is delayed until a child's situation reaches a crisis stage requiring hospitalization or residential placement.

To provide at least a gross estimate of what some of those costs may be, data from the December 2, 2002 Joint Chairmen's Report on Out-of-Home Placements and Family Preservation may be useful. Last year's report, compiled by OCYF from information provided by the Subcabinet agencies, contained comprehensive data regarding the numbers of children served in various out-of-home programs and the annual costs of those initiatives. From this information, it is possible to make a gross estimate of the monthly costs that public agencies may incur to address unnecessary custody relinquishment and inadequate community-based services for the Council's target population.[24]

For example, if parents believe that they must relinquish custody to receive services, or a child enters State custody through the juvenile services system, the custodial agency faces both residential and administrative costs. In 2002, in aggregate, those monthly costs were as follows:

[24]These estimates calculate monthly average costs for all children placed in the types of services indicated during FY 2002. They include typical "room and board" and associated costs and agency administrative costs, but do not include medical or other therapeutic services that may be accounted for and billed separately.

SERVICE	FY 2002 MONTHLY COST
Family Foster Care	**$1,770**
Juvenile Services	
Detention – (FY 02)	**$5,095**
Commitment – (FY 02)	**$3,640**

Similarly, if a child's condition reaches crisis proportions in the absence of available, community-based interventions, thus requiring acute psychiatric hospitalization at a State facility or admission to a residential treatment center under Medicaid or to a group home under State custody, the costs can be substantial. In 2002, the average monthly costs of such inpatient care were:

LEVEL OF RESIDENTIAL CARE	FY 2002 MONTHLY COST
State Psychiatric Hospital	$ 14,685
Residential Treatment Center Admissions	$ 17,690
Community placements (group homes, ALUs, etc)	$ 5,350

As policymakers weigh the costs and benefits of implementing the various recommendations made by the Council, the above estimates provide at least a frame of reference for evaluating costs to the State of failing to address the needs of children at risk of custody relinquishment.

V. CONCLUSION

The work and recommendations developed by the Council offer a concrete and thoughtful approach to address the needs of children with intensive needs. Many of these children can best be served at home and in their communities. These recommendations set an initial course for allowing this to happen.

While some of the recommendations are envisioned as long-term strategies, the Council is encouraged that many can be implemented immediately with little cost to the State. The Council members both individually and collectively look forward to working with the Governor and other stakeholders in implementing the recommendations outlined in this report and in other efforts to address the issue of custody relinquishment.

We are good parents with references of such. We work in our community. My husband and I started the Habitat for Humanity in our county...and are helping to build homes for those in need. We want to retain custody of our son and receive the funding that is needed. If it is agreed that home is not the correct and safe placement for our son, why do we have to relinquish our rights?

-Public Hearing Testimony

VI. APPENDICES

APPENDIX I

Attachments

A: Executive Order 01.01.2003.02
B: Public Hearing Testimonies
C: Community Based Services subcommittee report
D: Data Collection subcommittee report
E: Financial Strategies subcommittee report
F: Insurance subcommittee report
G: Local Access to Services subcommittee report

Appendix II

Attachments

A: Policy for Serving Children Awaiting Discharge from Psychiatric Facilities
B: October 12, 2000 Protocol adopted by the Subcabinet
C: HB 405
D: SB 458
E: HB 534
F: DHMH response to the GAO report

Appendix III

Attachments

A: Hospitalization Intervention Team (HIT)
B: Interagency Family Preservation and Community Services Initiative
C: LMB compiled information
D: DHMH report on respite care
E: Services for Children with Special Needs (DHMH)
F: Services for Children with Special Needs (DHR)

VII. Resources

Child Welfare and Juvenile Justice, Federal Agencies Could Play a Stronger Role in Helping States Reduce the Number of Children Placed Solely to Obtain Mental Health Services (General Accounting Office, April 2003). This report (number GAO-03-397) can be accessed through the GAO by its website located at www.gao.gov.

Department of Human Resources Roundtable Report on "Stuck Kids": *Closing the Gap on Inappropriate Placements* (DHR, March 25, 2002). Please contact Malaika Anderson at (410) 767-6211 if you would like to receive a copy of this report.

For a copy of HB 1386, please contact Malaika Anderson at (410) 767-6629

For a copy of the local DSS point of contact for each jurisdiction, please contact Jane Smith at jsmith1@dhr.state.md.us.

*Maryland's Blueprint for Children's Mental Healt*h (Maryland Committee on Children's Mental Health, March 2003). This report can be accessed on the Advocates for Children and Youth (ACY) website (www.acy.org).

Relinquishing Custody: An Act of Desperation: A study conducted by the Maryland Coalition of Families for Children's Mental Health (MD Coalition, September 2002). This study may be accessed at www.mdcoalition.org

Relinquishing Custody: The Tragic Result of the Failure to Meet Children's Mental Health Needs (Executive Summary), Bazelon Center for Mental Health Law (Bazelon Center, March 2000). This report may be accessed through the Bazelon Center's website which is located at www.bazelon.org.