

Confidentiality-Based Barriers to Advocacy and Survival

A White Paper for Empowering Foster Youth

In Memory of Regis Little

The Legal Needs of Children Committee of The Florida Bar formed a subcommittee to act upon recommendations of The Regis Little Task Force [hereinafter “Task Force”], following the untimely, yet sadly predictable death of the multiply challenged young man for whom the Task Force was named. The LNOCC’s Regis Little Subcommittee has embraced the priority recommendation of the Task Force to define and make available a system of critically needed, web-based information to be accessed by advocates who share responsibility for particular foster children.

“All children in foster care deserve the best care possible. In order to facilitate this, their caregivers must have access to as much information as possible about the child, including information from other agencies serving that child. Now that light has been shed on the issue of insufficient Child Resource Records, immediate action is needed on a statewide level.”¹

Authoritative sources in the Department of Children and Families [hereinafter “the department” or “DCF”], pointing to the massive database redesign and implementation underway within the agency over the past several years, dispute that the issue is one of insufficiency of Child Resource Records. Indeed, the LNOCC’s Regis Little Subcommittee, addressing this vast and multi-faceted problem, apprehends the issue as one of defining and enabling shared *access* to extant information needed by entities which form links in the service chain for children. Denied access to potentially life-saving information is the underbelly of well-meaning confidentiality enactments and policies interpreting and misinterpreting those enactments.² The LNOCC’s Regis Little Subcommittee acknowledges with this paper that the insufficiency “of records” concerns what is and what is not done with them, as much as any inherent inadequacy in the records themselves. As it is the procedural process for sharing essential information that is wanting, the beginning of a resolution requires articulation and publication of the urgency of the access problem, the building of consensus around policy-based resolution, and insistence that this problem be addressed at all levels and within all branches of government.

Following the catastrophic death of 11 year-old Nubia Barahona in February of 2011, the appointed investigative panel observed: “In Florida we talk about ‘a system.’ We would be much closer to a genuine system if the operating principle in the case of every child in the child welfare system was this: We will insist that *every piece of relevant information to a child’s life and future is available in one, constantly updated place where everyone responsible for that child’s well-being could see that information, discuss it, assess it.*”³ [Emphasis added.]

¹ Final Report of the Regis Little Task Force, April, 2010, p. 17

² See, e.g., Fla. Stat., 39.202, 39.306, 985.04, 985.045(2), 985.046, 985.047(2010).

³ The Nubia Report, The Investigative Panel’s Findings and Recommendations, March 10, 2011, pp. 2-3

More than ten years ago, the Confidentiality Subcommittee of The Florida Bar Commission on the Legal Needs of Children assessed the dueling interests of privacy—the right to be let alone⁴-- and the need to share information for the effective and efficient provision of services to “whole children.”⁵ Balanced against the need of children and families for boundaries on the disclosure of private and personal information for reasons of dignity and security is the imperative for the delivery of comprehensive, integrated services when children and families rely upon a network of public and private agencies on issues affecting life, health and safety. The need has become even more critical in present years where public funds and resources have declined, and children and families depend upon a patchwork of agencies and individuals whose coordination and connectivity can either salvage or defeat identified service goals.

The Confidentiality Subcommittee made the point that more information is not necessarily better information—that there is the danger of excess, irrelevant, and unreliable information thickening files, impeding efficiency and accountability. Significantly, more than half of the eighty-plus recommendations of the report following the 2009 death of Gabriel Myers centered upon achieving web-based access to and verification of information within data systems by all parties, parties’ counsel, and those responsible for a child’s care—with proper security safeguards and proper training.⁶ The Gabriel Myers Report cited misunderstandings regarding the intent and requirements of the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and the Family Education Rights and Privacy Act of 1974 (FERPA or the “Buckley Amendment”) as causing artificial barriers to needed sharing of information regarding foster children, particularly between and among schools and treating professionals.⁷

The Confidentiality Subcommittee further cautioned that unlimited police access to identifiable treatment information “may chill the ability of government agencies to work cooperatively with substance abuse programs, mental health providers, schools, health service providers, and other agencies serving youth.” Predictably, some years later, the Gabriel Myers Report described wide variation in law enforcement response to reported sexual behavior problems of children, confusion between criminal investigative interviews, forensic interviews, and assessment for treatment, and stigmatizing and damning labels which discourage accurate reporting and impede effective therapeutics. Nonetheless, the Confidentiality Subcommittee Report called for broad changes in the laws affecting access to information by state agencies, private contract providers, advocacy groups, foster parents, and children.⁸ The report called for amendment of chapters 39 and 985 to provide for interagency agreements for exchanging information, and to authorize DCF “to provide records and information to other agencies with an interest in these records for the purpose of providing services and treatment for children.”⁹

⁴ Final Report, Appendix C: Confidentiality Subcommittee Report, The Florida Bar Commission on the Legal Needs of Children, 2002, p. C2-3, citing *Olmstead v. United States*, 277 U.S. 438, 478 (1928).

⁵ *Id.*, at p. C6.

⁶ Report of Gabriel Myers Work Group on Child-On-Child Sexual Abuse, May 14, 2010, p. 11

⁷ *Id.*

⁸ Final Report, Appendix C: Confidentiality Subcommittee Report, The Florida Bar Commission on the Legal Needs of Children, 2002, at pp. C13-17, 21-25

⁹ *Id.*, at pp. C14, C17

Ten years later, exceptions in confidentiality provisions arguably have swallowed the rules. Social service agencies change placements, law enforcement agencies prosecute, news media publish, and school districts suspend and expel, based upon allegations concerning children, while children's advocates and legal counsel are often denied access to time-sensitive information, absent a court order.¹⁰ The question arises, from whom is disclosure of the child's sensitive, confidential information being protected? It is not surprising that, like Regis Little, many children aging out of foster care race for the nearest exits, frequently forfeiting college tuition and other valuable assistance, in the words of Justice Brandeis, just "to be left alone."

Current Record Sharing Needs

The need to share information among agencies, advocates, and families, which was recognized by the Legal Needs of Children Commission in 2002, persists. The systemic failure to address issues of information sharing and confidentiality has been cited as weighing in the tragic deaths of Regis Little and Gabriel Myers in 2009, and Nubia Barahona earlier this year.

As articulated in previous reports, many children and families are involved with several different service systems concurrently. Workers from each of these systems independently develop plans and strategies that may overlap and confuse the children as well as their advocates, and obstruct resolution of identified problems. The consolidation of disparate repositories of information into a web-accessible shared records database would be the actualization of a long recognized need. The database will use a balanced approach to protect the privacy of children while promoting the mandate to provide them with integrated services based upon relevant, accurate and complete data.

Every child entering an out-of-home placement has a hard copy paper file known as a Child's Resource Record (CRR), or "blue book," that contains copies of the basic legal, demographic, educational, medical and psychological information pertaining to a specific child¹¹ Existing

¹⁰ Fla. Stat., Section 39.202, 39.2021, 985.04, 985.045, 985.046, and 985.047 (2010).

¹¹ F.A.C. 65C-30.011(4) specifies what is to be contained in and who is responsible for creating and maintaining the record:

(4) The Child's Resource Record. A child's resource record shall be developed for every child entering out-of-home care. The person making the placement is responsible for the initial development, monitoring, updating and transporting of the child's resource record. The person making the placement shall review confidentiality requirements with each caregiver, who shall be provided a child's resource record. The caregiver is responsible for maintaining confidentiality of the child's resource record documents.

(a) Since some of the information necessary in the child's resource record is not available immediately upon initial removal, the documents required in the child's resource record shall be placed in the record as available. The child's resource record shall include the following information:

1. Medical, dental, psychological, psychiatric and behavioral history;
2. Copies of documentation regarding all on-going medical, dental, psychological, psychiatric and behavioral services, including child health check-ups provided through Medicaid;
3. Parental consent for treatment or court order;
4. Copy of the Medicaid card;
5. Copy of the Shelter Order;

administrative law provides that the Child's Resource Record shall be housed where the child is placed, shall accompany the child to every health encounter, and shall be updated as events occur.¹² All information in the CRR is to be recorded in the department's statewide automated child welfare information system.¹³ The Florida Safe Families Network (FSFN) serves as the Statewide Automated Child Welfare Information System (SACWIS) and contains extensive information about the history, needs and care of individual children in out-of-home care. Resource Records are usually initially created by Child Protective Investigators. As required by 65C-30.011(4), it is primarily the case manager(s) and caregiver(s) who are tasked with updating the record as events occur.¹⁴

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6. Copy of the court order or Voluntary Placement Agreement placing or accepting the child into out-of-home care;
 7. Copy of Predisposition Report;
 8. Copy of the Case Plan;
 9. Copy of the most recent Judicial Review Social Study Report;
 10. School records, including, as available,
 - a. Report cards;
 - b. FCAT results;
 - c. Any psycho-educational evaluations or other evaluations of the child made to determine the child's educational needs and/or eligibility for special educational services;
 - d. All disciplinary records;
 - e. All Individual Educational Plans, including meeting notes;
 - f. Any consents or communications from the child's parents; and
 - g. Any notes or information from the guidance counselor/guidance office.
 11. An envelope for storing pictures;
 12. The most recent photograph available;
 13. Copy of the child's birth certificate or birth verification certified by the Office of Vital Statistics, as appropriate;
 14. Documentation of immigration status, including certificate of citizenship, if available; and
 15. The names and phone numbers of staff to be contacted in emergencies.

(b) The child's resource record shall be provided to the initial out-of-home caregiver within 72 hours of placement and shall accompany the child during any change of placement. If the child's resource record does not accompany the child at the time of a placement change, it shall be provided to the out-of-home caregiver within 72 hours of placement.

(c) The child's resource record shall accompany the child to medical and therapist visits and shall accompany the child or caregiver to all school meetings.

(d) Where the department or contracted service provider has originals of documents required to be included in the child's resource record, the original documents shall be placed in the child's case file and the copies shall be kept in the child's resource record.

(e) Where medical or educational information is not available and accessible, written documentation of the efforts made to obtain the information shall be placed in the case file.

¹² Child's Resource Record is defined by Florida Administrative Code 65C-30.001(24), 65C-30.011(4).

¹³ Florida Administrative Code 65C-30.001(24).

¹⁴ "FSFN data are frequently incomplete and inaccurate. The information contained in FSFN is only as good as the information entered from the field; errors in input, regardless of the reasons for such errors, will continue to yield faulty information." Report of Gabriel Myers Work Group on Child-on-Child Sexual Abuse, *supra*, at p. 9.

Children with disabilities tend to have substantial records. This would include Individualized Education Plans and educational assessments, Comprehensive Behavioral Assessments, psychological or psychiatric assessments, Agency for Persons with Disabilities assessments, inpatient records and ongoing therapy reports. Despite the requirement that these records be maintained, there is no statewide system to monitor compliance. Critics of the present system state that these records are not routinely developed, verified for accuracy, and/or updated. Part of the difficulty in maintaining records is one of a lack of connectivity among care providers with varied levels of reliance upon electronic and internet technology, and the outdated use of paper as a primary mode to share information. The Final Report of the Miami Dade Grand Jury concerning Nubia and Victor Barahona, in making recommendations for changes to Florida's child welfare system, addressed the problem of timely access to the child's resource record as a significant impediment to getting "the big picture."¹⁵ Unsurprisingly, limitations in capacity are traceable to limitations in resources. "The technology to be able to achieve these . . . goals is not available at DCF presently. However, in discussing this with Secretary Wilkins, we discovered this was one of his priorities too. He has already positioned himself to ask the legislature for additional funding to bring these technological advances to this area."¹⁶

Children who are in foster-care are routinely moved around. They may be re-unified with parents or family, adopted, or placed in a residential treatment facility. Any of these scenarios create gaps in services while the new school or service providers are waiting to receive records. Since foster youth with disabilities are already at higher risk for poor educational outcomes,¹⁷ time is of the essence when linking these youth to school-based services.

The Proposed Solution

The Department of Children and Families, in partnership with statewide Community Based Care organizations, is presently accomplishing a massive transition to a statewide web-based database in which foster youth's Child Resource Records are maintained. Part of that process involves actively working to remove real and perceived barriers to interagency sharing of "confidential" information which properly belongs in the *whole* Child's Resource Record. The Regis Little Subcommittee proposal for a shared web-accessible service-directed database will make

¹⁵ "Another area of concern involved the Hotline and technology or more appropriately, the lack thereof. Here we begin to see the failure to obtain the whole picture. The shortcomings we noted with the Hotline system is the inability of the counselor to upload pertinent data while the caller is providing information. If the caller gives a name, address or other identifying information for a specific child, the counselor would be able to make a better assessment if he had at his fingertips information of prior Hotline calls or investigations involving the same child, the same address, the same family or the same parents, guardians or caregivers. The available data should also reveal the timing of when the other calls, reports or investigations took place. The availability of this additional information could prove priceless, as the counselor is able to get the whole picture of what has been happening, as opposed to a present evaluation of what may appear to be a singular incident. This additional historical data could also accompany the report sent by the counselor to the CPI and Case Manager." *Final Report of the Miami Dade County Grand Jury*, (Fall Term A.D. 2010) found at http://www.miamisao.com/publications/grand_jury/2000s/gj2011s.pdf

¹⁶ *Final Report of the Miami Dade County Grand Jury*, (Fall Term A.D. 2010) *supra* at p.6.

¹⁷ Jessica Feerman and Maura McInerney, *Comments and Recommendations for Regulations under the Family Educational Rights and Privacy Act*, (Education Law Center, Juvenile Law Center, May 2011) found at <http://www.americanhumane.org/assets/pdfs/children/ferpa.pdf>

available a defined subset of that extant information, with safeguards of tiered security, interagency agreements, and training-contingent access. The database should afford upload, download, flagging and verification capabilities.

The database will include:

- Appropriate Educational Records (ESE Status, IEP, intervention plan, school placement history)
- Education Records releases
- Placement Records
- Medical Records (name, specialty, and contact information for treating physician, diagnoses, treatment plan/s, medication lists, chronic conditions such as asthma, diabetes)
- Medical releases
- Psychological Assessment
- Detailed Family History
- Court Records
- Attorney names and contact information
- DJJ records post-adjudication
- Whether and when a child is home-schooled
- Evaluations
- Abuse reports history
- Detention history
- Baker Act history
- Other (specify)

At a minimum, access to this system should be given to Child Protective Investigators, Dependency Case Managers, Foster Parents, Guardians ad Litem, Attorneys ad Litem, the child, and the child's counsel, as appropriate. Tiers of access corresponding to levels of security clearance would afford the ability to upload updated information by Child Protective Investigators, Dependency Case Managers, Foster Parents, and others, as appropriate. This will help ensure efficient sharing of accurate information and will support the child receiving the highest quality of care possible. With specific reference to educational records, it is recommended the Florida School System utilize an appropriate state-wide electronic system (e.g., FASTER) that will allow computer sharing of records in as expeditious a manner as possible. This will help ensure foster children, especially those with disabilities, receive appropriate educational services immediately upon placement in a new school. Since this population also tends to change schools frequently, there is no reason this known gap, which is truly a disservice to the most vulnerable of foster youth, should continue.

The LNOCC's Regis Little Subcommittee recognizes that a shared statewide database is a rather long-term goal and that more immediate action is also needed. While the implementation of the planned statewide shared database is in progress, it is recommended that ongoing statewide quality assurance reviews of information presently maintained in the Department's Child Resource Records—as well as other service-relevant children's databases—by region, be shared

to help define voids, overlap, and potential for augmented capabilities. In the interim, a checklist of what should be contained in a web-accessible shared statewide database needs to be created and implemented for use by Child Protective Investigators, Dependency Case Managers, Foster Parents, Guardians ad Litem, Attorneys ad Litem, and the child, as appropriate¹⁸. This will help ensure all parties are fully aware of what should be contained in the shared statewide database, to include educational and other records from any agency serving the child, so that concerted efforts may be made immediately to increase the quality of such records and corresponding services. Training on this checklist and the intended shared statewide database needs to be delivered to all affected parties and participants in the system.

Plan for Implementation

There is a need to discuss the issues and concerns related to the proposed statewide shared database, and to build consensus. Needed changes in law and policy should be identified and examined. Additional resource requirements for development and implementation of the shared database need to be considered. Discussion forums that include all stakeholders should be held around the State. An agenda item on the next Dependency Summit would be helpful. In the interim, circulation of the white paper can be the basis for adoption of a recommendation by the LNOCC and endorsement by the Florida Bar.*

Respectfully Submitted to the Legal Needs of Children Committee

Gerard Glynn, Chair, Regis Little Subcommittee

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Alan Abramowitz, Chair
Legal Needs of Children Committee

*ADDENDUM

The Regis Little Subcommittee of the Legal Needs of Children Committee of the Florida Bar, continues to have dialogue with the Department, community based care agencies, direct service providers, community stakeholders, and advocates for children and families in foster care, as well as the children themselves. The Subcommittee acknowledges the massive efforts of the Department and its sister agencies to transform the Florida Safe Families Network database/platform, as well as its ongoing work to change and improve information sharing among entities in service of children. These efforts, inspired in part by the recommendations of independent child welfare professionals, seek both to clarify related legislative mandates and procure sufficient resources to carry them forward.

¹⁸ Final Report of the Regis Little Task Force, April, 2010, p. 3,4.