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David O. Childers, Jr., MD
Chief, Developmental Pediatrics
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University of Florida, Jacksonville
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Jacksonville, FL 32217

October 6, 2009

Dear Dr. Childers:

Thank you for inviting me to visit the Developmental Pediatrics program at the University of Florida, Jacksonville. The atmosphere in which the site visit took place was one of friendliness, openness and honesty. I was able to meet with the various members of your staff on an individual and private basis. The faculty and staff were quite welcoming, and provided me with a wealth of information about the program. I greatly appreciate the candidness about the perceived strengths and weaknesses of your center. As you know, the main purpose of my visit was to objectively evaluate your center's level of care for neurodevelopmental and behavioral services for children and adolescents with developmental disorders and their families. As a reminder, I had not previously met or had contact with you, any UF faculty, or any of your staff prior to my visit in September.

One of the most immediate and prominent features is your extremely dedicated faculty and staff and the 'esprit d 'corps' that exists. I know the program has been through many transitions in recent years. You, the faculty, and your staff were all quite open about the problems, which have been significant. I feel that the dedication of the current personnel has clearly helped make the difference, and allow your center to move forward in a positive manner during your rebuilding phase. I was also quite impressed by the support from the Department of Pediatrics Chairman, Dr. Chui. He clearly recognizes the importance of serving persons with disabilities and their families, and is committed to continued support of your division.

The strength of your center is the interdisciplinary nature of the program. Since moving to your new space, you have been able to integrate and improve services, increase the number of staff, and improve community support. Medical and psychological services are cohesive and integrated. The core disciplines for programs serving persons with developmental disabilities are neurodevelopmental-behavioral pediatrics and psychology. The Center is understaffed for

both disciplines. Your program is enhanced by special education, child neurology, genetics and consultative child and adolescent psychiatry. Your evaluation and treatment services are evidence-based, which is entirely appropriate for a state-funded academic medical center. A weakness of the Center is the lack of on-site speech-language services. Consultative occupational therapy and physical therapy services appear to be readily available although also not part of the interdisciplinary team.

My understanding is your center's funding is through the State of Florida (CARD and FDLRS programs), Florida School for the Deaf and Blind, fee-for-service, and the Department of Pediatrics. The state funding is substantial and provides significant support for Developmental Pediatrics. Although the funding allows you to provide the appropriate services for the CARD and FDLRS programs it does not provide for center growth. Diversifying funding resources is recommended, given the tenuous nature of state funding in current times.

General Clinical Services

The goal at the Center is integrated, 'one-stop shopping' for families of youth with neurodevelopmental and behavioral disorders. Group triage occurs once a week, with key personnel from developmental pediatrics, child neurology, FDLRS, CARD, and Ms. Bowles. All evidence points to vastly improved service delivery system and better collaboration between professionals and the different programs. Interim suggestions are provided to the parent during the lag time between the referral and appointment. It appears that a professional or family can make a single phone call to access the Center's services. Intake issues are being addressed, such as reviewing additional records that come in after the initial referral. You have 4 administrative staff that handles support for all centers. Division of administrative services appears appropriate although they are quite busy.

Space. Your new clinical space is exceptional. It is set up well for patient and family care, and allows appropriate privacy and space for clinical assessment and treatment. Having your services centralized is a great improvement over your previous division of services. This allows for improved communication, enhancement of services, and decreases unnecessary overlap of services. There is more than adequate room for patient care/evaluation services, parent programs, and faculty and staff offices.

Fee-for-service clinics. Children and adolescents with the broad range of neurodevelopmental and behavioral disorders are served in your fee-for-service clinic. The greatest challenge is your long waiting list. Recruitment of a neurodevelopmental or developmental-behavioral faculty member, ideally with expertise in psychopharmacology, is recommended to improve your center's ability to provide timely assessment and treatment services. Recruitment of a physician extender (pediatric nurse practitioner) could also help in this regard. Long waiting lists for developmental-behavioral services are the rule rather than the exception in academic medical centers across the country. That being said, your center's waiting list for those that are not part of the CARD program or FDLRS program is longer than many. I understand that you and your faculty are under tremendous stress to efficiently and quickly see more patients. I reviewed your scheduling protocol and it appears appropriate for the type of patients and level of care

you are providing. In order to add faculty, you will need to be able to cover salary with contracts, grants, and/or clinical service. Current CPT payment methods are not optimal for cognitive services such as neurodevelopmental and behavioral pediatrics. However, our field has significantly advanced in terms of optimizing payment and assuring that all provided services are paid. We discussed some specifics of appropriate billing and coding at the time of my visit. Additionally, I know you have attended workshops on practice management; this is to be commended and is evidence of your dedication to improving your center's services.

Florida Diagnostic and Learning Resource Center (FDLRS)

The FDLRS program has substantially increased its activity in the last few years. Its services are different from the CARD, given it is also focused on assessment as well as technical assistance at IEP meetings and for school personnel training. I met with Candice Rosenberg, M.Ed, the FDLRS Educational Coordinator, as well as other faculty regarding the FDLRS program and direction. A significant plus is the ability of FDLRS to collaborate with CARD to provide assessment services and avoid duplication of services. Linking diagnostic assessment with services is the most effective model. It is strongly suggested that a speech language pathologist and psychologist be recruited to improve the comprehensive services that exist. For the FDLRS program as well as the CARD program, the access to other specialists is a significant benefit.

University of Florida-Jacksonville Center for Autism and Related Disabilities ("UF-Jax CARD")

The UF-Jacksonville CARD is led by you as Executive Director, Dr. Mae Barker as Clinical Director, and Ms. Jeannie Bowles as Administrator. I spent a large percentage of the site visit meeting with CARD personnel, reviewing CARD requirements, and the extent to which the UF-Jax-CARD is meeting state service requirements and needs of the community and families.

Dr. Mae Barker, the Clinical Director and board certified behavior analyst, was an invaluable resource about the program. Although junior faculty and not long out of her training, by all accounts she is quite knowledgeable and has an excellent reputation in the community. I also met with one of the educational consultants, Ms. Marlena Fuller, BCaBA, who was quite helpful in helping me understand the day-to-day operations.

The activities of the UF-Jax CARD certainly fulfill the grant requirements. You offer regional support to individuals with autism and related disabilities and their families, service providers, and educational professionals. Service delivery is center-based, home-based, and school-based, although due to budget cuts will be primarily center-based for this fiscal year. Service delivery involves individual and direct family assistance, technical assistance/consultation, parent and professional training, and general public education. The UF-Jax CARD is also involved in statewide collaborations and initiatives.

Diagnostic assessment is certainly an important part of your provided services to individuals with autism although not specifically a task of CARD as outlined by the state mandate. Given the recommendations from the Governor's Task Force on ASD 2009 (www.healthyfloridians.com/autism.html), I would recommend increasing diagnostic services. The task force includes assessment by a medical specialist as part of the multidisciplinary

assessment, which your center is very qualified to complete. Continued thought should be given to providing additional treatment/intervention services through Developmental Pediatrics, e.g. Applied Behavior Analysis therapy. I understand there has been involvement with training in this regard on several different levels. It would be excellent if an ABA intern training program could be further developed given the rich clinical resources available.

Community support has been erratic. This is clearly related to the past problems regarding diversion of CARD funds and is mainly concerning families of individuals with autism, and not the other related disabilities of persons served under the grant. All evidence points to the current faculty and staff working diligently to develop better relationships with the CARD families. I was spontaneously contacted by two parents of children with autism that clearly expressed their dissatisfaction with the UF-Jax CARD. Their dissatisfaction appeared related to previous problems. From their communication, I could not ascertain that clear evidence of current mismanagement existed. I was not provided with comments from families pleased with autism (or related disability) services, so that the unsolicited comments must be considered anecdotal. Although certainly important, these feelings are not necessarily a reflection of the region.

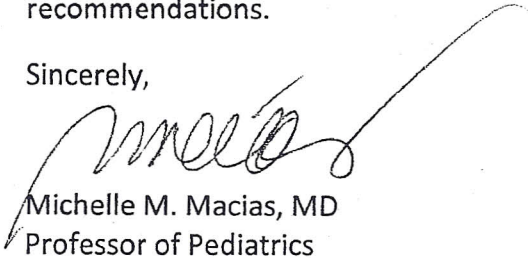
I was able to speak freely with Mr. Joe Golon, of the CARD Advisory Board, who represented parents of children with autism and related disabilities. He expressed concern about poor communication between UF-Jax CARD and the community. Public relations have not been effective. Families are not clear on what the 'medical model' constitutes, and some suspicion exists given the understanding that the primary role of each CARD is for educational services. By his report, the UF-Jax CARD has provided good services for lower functioning individuals with autism with more serious medical and behavioral problems. However, individuals with autism at a higher level of functioning have been less attended to. In addition, the perception is that significant roadblocks exist regarding families of individuals with autism volunteering at the CARD and becoming more involved. Some families feel that the additional provision of medical services rather than just educational services is a negative. In the past, there have been problems with timely return calls to families and communication regarding CARD activities. Focusing on community relations should continue to be a high priority.

The UF-Jax CARD is providing a collaborative support system and utilizing the 8 best practice principles outlined for support and intervention programs. They are not providing the exact same services as other CARD programs, and some other programs are felt to be providing superior educational services. Independence of service provision is allowed and so differences between the CARD programs is not a negative, although it is important to consider what the other CARD programs are doing when decisions about service are made. The UF-Jax CARD needs to continue to work with its constituency to provide best practice and to change negative perceptions in the community. Thought should be given to convening a focus group, using an independent facilitator to find common ground and to assess what families need and want and provide good data on the needs of the community.

Thank you for the opportunity to review your program. I certainly hope I have been able to provide you with the appropriate feedback to help guide your progress. Please don't hesitate to

contact me if there is anything I did not address or if you would like additional details about my recommendations.

Sincerely,

A handwritten signature in black ink, appearing to read "Michelle M. Macias", with a long, sweeping flourish extending to the right.

Michelle M. Macias, MD
Professor of Pediatrics
Director, Developmental-Behavioral Pediatrics