The Outpatient Developmental Services Project: Integration of Pediatric Psychology With Primary Medical Care for Children Infected With HIV

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Objective: To present a model in which pediatric psychology services are programmatically integrated into the primary care of children seen in a special immunology program. The program centers around serial neurodevelopmental/neuropsychological evaluation of children infected with HIV.

Method: We describe the population served and the particular services provided, with specific focus on how the program was developed. We include a discussion of the barriers to service provision that have been encountered and the strategies employed to overcome these challenges.

Conclusions: This approach, while not ideal, serves as a good example of how pediatric psychology can merge with primary medical care to maximize the benefits of both specialties for a patient population that is underserved in many respects.

Key words: pediatric HIV; perinatal HIV; AIDS; neurodevelopment; cognitive functioning; primary care; integrated clinical services.

As experience with children infected with HIV enters a second decade, physicians caring for these children will increasingly serve in a primary care role as opposed to an acute, consultative role (O’Hara & D’Orlando, 1996; Ulmer et al., 1997). The development of early treatment using combination antiretroviral therapy, along with prophylaxis for opportunistic infections, has gradually resulted in reduced concern about acute, life-threatening complications and more concern about chronic and long-term functional impact of the disease (Pizzo, 1990). One of the more significant chronic aspects of HIV, particularly in children perinatally infected, has been the impact on the growth and development of the central nervous system (CNS) and related behavioral manifestations. Since 1988, we have been involved in serial neurodevelopmental evaluations of children infected with HIV, beginning in the early stages as part of the Pediatric AIDS Clinical Trials Group protocols, and currently as part of integrated neurodevelopmental assessment and intervention supported by the Ryan White Title I program. The purpose of this article is to describe the population served and the services provided, specifically, how these pediatric psychology services
programmatically integrated into the primary care of children seen in a special immunology program.

Background

Infection with HIV is rapidly becoming the predominant infectious cause of perinatally acquired developmental disorders (Brouwers, Belman, & Epstein, 1991). Developmental delay and neuropsychological impairment are common consequences of HIV infection. The pattern and severity of delays in a given child depend on the course of the disease. Sequelae of HIV-related encephalopathy, opportunistic infections, neoplasms, vascular changes, and other biomedical problems all combine to yield varying patterns of neurocognitive delay and deficit, which have been documented in 85%-90% of children infected with HIV (Belman, 1990; Belman et al., 1985; Belman et al., 1986; Brouwers et al., 1991; Epstein et al., 1986; Gay et al., 1995; Mintz, 1992; Mintz & Epstein, 1992; Sharer et al., 1986; Williams, Levin, & Hillman, 1990). The resulting developmental delays may be global in nature, emerging as mild to moderate mental retardation across all areas of functioning (i.e., speech, cognition, motor). In many cases, subtle central nervous system changes, such as slowed myelinization and calcification of the frontal cortex and connecting tissues, frequently result in more specific learning problems or disorders (Armstrong, Seidel, & Swales, 1993; Belman, 1990; Epstein et al., 1987). Specific deficits have been noted in visual-spatial skills, attention and concentration, processing speed, sequential memory, and motor functioning (Armstrong et al., 1993; Aylward, Butz, Hutton, Joynor, & Vogelhut, 1992; Diamond et al., 1990; Levenson, Mellins, Zawadzki, Kairan, & Stein, 1992).

As has been noted in much of the literature, the effect of HIV on CNS development may include an active, progressive deterioration of functioning but more likely involves an interruption or slowing in developmental acquisition of neuropsychological abilities (Belman et al., 1985; Brouwers et al., 1991; Epstein et al., 1986; Mintz, 1992; Mintz & Epstein, 1992; Mintz, Epstein, & Koenigsberger, 1989; Sharer et al., 1986). Consequently, this process requires serial evaluations to monitor the child’s abilities, since his or her level of functioning at one point in time may be drastically altered by either disease progression or substantial benefit of medical intervention (Armstrong et al., 1993). Neurodevelopmental evaluation of these children thus may serve a number of functions. First, the evaluation may produce information supporting continued use of a medical intervention or, in some cases, may signal the failed effectiveness of that intervention and the necessity for a new treatment approach (Brouwers et al., 1991; Buckingham & Van Gorp, 1988). Second, repeated evaluations help to track the developmental course experienced by a child, leading to research protocols designed to describe this progression and to suggest critical points for intervention (Brouwers et al., 1991). Third, serial neurodevelopmental evaluations provide important information about current functioning that can be used to facilitate learning and, in some cases, slow or ameliorate some of the negative consequences experienced by the children (Brouwers et al., 1991; Falloon, Eddy, Wiener, & Pizzo, 1989; Kaplan & Bedell, 1989; Taylor & Lavallee, 1989). Traditional models relying on outside referral may be quite limited in serving these functions. For this reason, we have developed a comprehensive, integrated care model wherein pediatric psychology services are provided in the medical setting as part of ongoing primary care.

The Medical Setting

In most traditional assessment settings, children undergoing neurodevelopmental evaluations are assessed in a psychologist’s office or a school. For children infected with HIV, scheduling of additional appointments beyond the routine of care for HIV infection may represent a significant burden and result in higher rates of failure to keep appointments. Medical care of the complications of HIV requires frequent visits to the medical clinic and occasional hospitalizations. A high level of commitment to medical treatment consequently results in significant time spent away from work by parents and away from school by children due to illness factors that require home or hospital care. The time and financial burden of an additional appointment (e.g., neurodevelopmental evaluation) may decrease the likelihood that nonmedical services will be used. Further, the child’s medical health may have a significant impact on his or her performance on any assessment instrument on any given day. Acute factors such as an infection, anemia, or exposure to a particular drug or drug regimen may adversely influence performance (Koppel, 1992; Markowitz &
When the pediatric psychology program was initially structured, all children from birth through 18 were provided services within the context of a single, global outpatient developmental services program. As the program grew, two separate programs were implemented, one for children birth to 5 years of age and one for children 5 to 18 years of age. Children under the age of 5 years are screened every 6 to 12 months, with referrals to appropriate services, such as physical therapy, occupational therapy, speech therapy, and audiology, provided as needed. Children over 5 years of age are evaluated approximately once per year, with additional evaluations conducted as clinically necessary. Less frequent evaluations with the older children occur because of our observation that the changes in functioning in the older children are more subtle and less likely to be detected at shorter intervals than in younger children. Practical considerations related to the availability of professional resources, difficulty in scheduling school-age children for more time-consuming test administration sessions, and concerns about limiting unnecessary exposure to tests needed to measure developmental changes also contributed to the decision to expand the interval between evaluations. In all cases, however, interim evaluations are conducted whenever there is another clinical indication, either based on observation of behavior or school performance or on changes in medical indices such as encephalopathy or infection status.

Neurodevelopmental/Neuropsychological Evaluations

The primary goal of the program is to provide longitudinal neurocognitive evaluation services to all children who are provided care in the pediatric special immunology program. The evaluation strategy has evolved over years and is based on an ongoing integration of research results derived from federally funded institutional studies of neurodevelopment in the children, as well as results from multi-institutional clinical trials. Currently, a standard evaluation consists of an interview with a parent or legal guardian to obtain consent for the evaluation and to collect information about a child’s developmental, physical, cognitive, familial, and psychosocial history. Based on this information, a hypothesis-generation approach to evaluation is used. A core battery of standardized, developmentally
normed instruments is administered to all patients. These measures include commonly used tests of developmental and intellectual functioning such as the Bayley Scales of Infant Development II (Bayley, 1993), Wechsler Preschool and Primary Scales of Intelligence-Revised (Wechsler, 1989b) or Wechsler Intelligence Scale for Children-III (Wechsler, 1989a), as well as newer tests used for children with special disabilities or in need of culturally sensitive instruments such as the NEPSY (Korkman, Kirk, & Kemp, 1998); Differential Abilities Scales (Elliott, 1990), and Woodcock-Munoz Batera (Woodcock & Munoz-Sandoval, 1996a, 1996b). Once these measures of global intellectual functioning have been administered, the results are reviewed to identify areas of strength and weakness. These patterns are combined with research information describing common areas of functional deficit among children infected with HIV to develop a function-specific battery of tests focusing on attention and concentration, processing speed, memory, sensorimotor integration, visual spatial integration, and other areas as indicated by specific performance of individual children. Instruments routinely used in this assessment are listed in Table I.

Once a neurodevelopmental evaluation is completed, a comprehensive interpretive report is developed that integrates test data, social history, and medical information not related to the child's HIV status. Consent is obtained from parents or caregivers for the psychologists to have access to the medical records of the children, as well as direct contact with each child's primary pediatrician. Thus, information about the child's health status, disease progression, previous health events, and past and current medications is taken into consideration for the interpretation of test findings and formulation of recommendations. At this point a significant ethical issue must be addressed. The need to completely protect the confidentiality of individuals infected with HIV often precludes the inclusion of medical information related to this diagnosis. While this information is used in the formulation of recommendations, reference to it is not included in the body of the test report, nor in communication to school personnel without specific consent from the parent to release this information. Even with parental consent, information about the child's HIV status is released only when there is a prevailing and convincing need that cannot be met by other means. Unfortunately, the absence of critical medical information available from neuroradiologic reports and medical records of treatment side effects within the neurodevelopmental report often makes it difficult to fully justify recommendations for intervention. However, this information is readily available for interpreting clinical findings for physicians in a way that may have an impact on direct clinical care.

### Table I. Tests Routinely Used in the Neurodevelopmental Evaluation

<table>
<thead>
<tr>
<th>Test</th>
<th>Reference</th>
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<tbody>
<tr>
<td>Woodcock Johnson Revised, Tests of Achievement (Broad Reading and Broad Math Clusters)</td>
<td>Woodcock &amp; Johnson, 1989a</td>
</tr>
<tr>
<td>Sensory Perceptual Examination</td>
<td>Klave, 1963</td>
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<tr>
<td>Grooved Pegboard</td>
<td>Klave, 1963</td>
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<tr>
<td>Purdue Pegboard</td>
<td>Tiffin, 1987</td>
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<tr>
<td>Finger Oscillation Test</td>
<td>Reitan &amp; Wolfson, 1985</td>
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<td>Trail-making Test</td>
<td>Reitan &amp; Wolfson, 1985</td>
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<tr>
<td>Developmental Test of Visual Motor Integration</td>
<td>Beery, 1997</td>
</tr>
<tr>
<td>Wide Range Assessment of Memory &amp; Learning</td>
<td>Sheslow &amp; Adams, 1990</td>
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<tr>
<td>Conners' Continuous Performance Test</td>
<td>Conners, 1994</td>
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<tr>
<td>Corsi Blocks</td>
<td>Milner, 1971</td>
</tr>
<tr>
<td>Tactual Performance Test</td>
<td>Reitan &amp; Wolfson, 1985</td>
</tr>
<tr>
<td>Intermediate Booklet Category Test</td>
<td>Byrd, 1985</td>
</tr>
<tr>
<td>Peabody Picture Vocabulary Test, Revised</td>
<td>Dunn &amp; Dunn, 1981</td>
</tr>
<tr>
<td>Verbal Fluency Test</td>
<td>Gaddes &amp; Crockett, 1975</td>
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Barriers to Provision of Pediatric Psychology Services

Children’s access to behavioral and mental health services is an issue of concern in many areas of health care (Armstrong & Drotar, in press; Drotar, 1995). For children with a serious, stigmatizing illness such as HIV, a number of specific barriers must be addressed to facilitate the assessment and school-related intervention services provided by this project. Some of the barriers are specific to the health care environment where these children are seen and include (1) a general unfamiliarity with the nature and benefits of psychological services by other health care providers, the children, and their caregivers; and (2) environmental barriers such as limited office space and overlapping medical appointment schedules. Other barriers are related to the demographic parameters of the population served, including (1) limited financial resources for travel to and from appointments, (2) increased time demands on patients and their caregivers because of multiple medical appointments, and (3) factors associated with serving a multicultural, multilingual population. In the following sections, we will attempt to describe the specific nature of the barriers we have confronted, as well as the steps that have been taken to address and overcome these challenges.

Education of Colleagues and Consumers

In the context of providing medical services to children with a serious, life-threatening illness, the primary focus of care is appropriately given to providing treatments that address medical complications and improve the quality of life for these patients. Given this primary objective, many members of the pediatric HIV health care team were slow to consider the issues associated with neurodevelopmental assessment and school intervention, as these issues were viewed as peripheral to saving lives. In addition to this setting of priorities, many members of the health care team have minimal exposure to the field of pediatric psychology, and even less exposure to the appropriate use and benefits of neuropsychological assessment and intervention. Therefore, one of the first tasks undertaken in establishing pediatric psychology services for children with HIV was education of the health care team. Several steps were taken as part of this educational process. First, multiple meetings were held with the attending physicians in order to establish their goals for care of the children and the role that pediatric psychology and neurodevelopmental evaluations might play in the achievement of those goals. Second, in-service sessions were held with other medical support staff (nurses, medical students) and the psychosocial team (social workers and case managers). These sessions described the nature of psychological testing and how it could be used to the benefit of the patients. These sessions included pragmatic information (e.g., descriptions of tests involving motor movement and why such tests could not be performed when a child was connected to an intravenous line with an arm board). This led to minor changes in nursing procedures that facilitated completion of testing. The sessions also provided information about the use of neuropsychological test data in identifying areas in need of intervention that might improve quality of life of the children. This latter issue was of significant concern to the psychosocial team members, individuals who played a significant role in the recruitment and follow-up of the patient population. The members of the psychosocial team maintain a close relationship with the families, are able to provide information in an informed consent process that help to assuage concerns about HIV disclosure to other staff and school personnel, and are aware of other social issues (e.g., legal custody, current living situation) that are critical to interpretation of test data. Perhaps most important, these team members are best able to identify which children are most in need of neurodevelopmental services. Ongoing education about the procedures involved in accessing special education services within the public school system has also been provided to physicians, nurses, and members of the psychosocial team. By negotiating these relationships, and providing ongoing education about the use of neurodevelopmental assessment in addressing problems faced by the children, an integrated approach to patient care has been facilitated.

Logistics

In most situations, psychological testing of a child is ideally conducted in a quiet, spacious, and calming environment. Unfortunately, such a setting is not readily available in most urban, high-volume medical centers, and insistence on such a setting in the early days of our program resulted in significant nonenrollment of children in both research and
clinical projects for a number of reasons. First, many of the families served by this program do not have the financial and social support resources to make repeated trips to the medical center beyond those deemed necessary for acute medical care. Additional appointments entail transportation costs, absence from school, loss of time from employment for parents and guardians, and sometimes a need for child care services for other siblings during the appointment. These obstacles are substantial, and we recognized early in the project that neurodevelopmental testing would need to occur within the context of ongoing, regular medical care.

Conducting neurodevelopmental evaluations in conjunction with a medical clinic visit significantly helps to overcome some of these obstacles but presents new ones as well. The medical clinic is often associated with negative and sometimes painful experiences, and many children, particularly younger children, are initially distressed upon entering any clinic room. To reduce this distress, members of the neurodevelopmental assessment team make a point to avoid the use of lab coats or white clothing associated with physicians or nursing care. Members of the team also make a point to spend time with the child in a play area or waiting area, providing the child with an opportunity to interact with the examiner in a nonthreatening, safe environment. Only after a positive interaction has been established with the child is he or she moved into the testing situation. Anecdotally, as the program has evolved, it has not been uncommon for children to run to greet the examiners as they enter the clinic, often with the question, “Is it my turn to be tested today?”

Involvement in clinic planning sessions and accessing medical information regarding scheduled appointments (e.g., medical acuity, medication regimens) are two components that have contributed to better integration of neurodevelopmental services into the HIV primary care setting. This information enables the assessment team to be aware of what types of lab work, radiology studies, and other procedures are planned for a given visit. This helps to determine how long a child will be available for evaluation, as well as when during the visit the evaluation can be conducted. For instance, it has been determined that procedures such as respiratory therapy, undergoing a lumbar puncture or other painful procedure, or cardiology studies often require too much time to permit a neuropsychological evaluation to be completed. Further, many of these procedures result in significant distress or acute side effects that interfere with the child’s optimal performance. Armed with this information, the examination team does not attempt to conduct an evaluation in conjunction with these clinic visits. However, this opportunity is often used to arrange for an evaluation at a future visit and to prepare both the child and the caregiver for an extended visit at that time. Information about the procedures to be performed are also useful in planning what neurodevelopmental instruments will be administered. Decisions about tests to be used include consideration of the potential time available, and tests that do not have a reasonable chance of being completed during the clinic visits are not administered. This procedure results in evaluations that consist of a global measure of intellectual or developmental functioning along with an academic screening administered during one clinic visit, followed at the second visit by a group of specific tests of neurodevelopmental functioning.

**Space Limitations**

At the beginning of the program, there was no dedicated, available space provided for neurodevelopmental testing. Children were evaluated in unoccupied clinic examining rooms or in hallways separated with a sheet. Extended negotiations were conducted with the medical directors and administrators of the clinic area to identify rooms that could be specifically set aside for neurodevelopmental testing. These discussions led to the allocation of one small room available on a regular basis, a second room available when not scheduled for use by other support staff, and occasional use of a medical examining room under unusual circumstances. In those cases where a separate appointment can be scheduled for neurodevelopmental testing, evaluations are conducted in a more traditional office setting. The difficulty with space allocation is not, in our experience, an unusual one in busy medical settings. Programs considering the inclusion of pediatric psychology services as part of an integrated, primary care approach must address the issue of space allocation early in the negotiation process.

**Time Limitations**

Despite the attempt to integrate neurodevelopmental evaluations into the comprehensive primary care model, there have remained a number of diffi-
culdies related to time. When a child attends an appointment at the medical clinic, he or she may be scheduled for a neurodevelopmental evaluation, a physical examination, blood drawing for laboratory studies, radiology studies, and interim history interviews by psychosocial team members. Even when neurodevelopmental evaluation is considered a priority, the pragmatics of time often limit the ability of examiners to complete a planned psychological battery within the context of a single visit. For this reason, the majority of neuropsychological evaluations are planned to be conducted over two or more clinic visits, resulting in the battery being completed over multiple sessions, sometimes weeks apart. This strategy has both benefits and adverse consequences. One benefit is that it allows the psychology team the opportunity to review a child's performance in a variety of areas on tests administered at the initial visit, permitting refinement of the test battery to address both strengths and weaknesses identified in the preliminary evaluation. The importance of this strategy cannot be overstated. Assessment on global functioning is often of limited usefulness in making acute clinical decisions. Adverse effects of disease or treatment frequently present in specific functional areas such as memory, attention, gross-motor coordination, and sensory perceptual skills, rather than in global intellectual functioning. Review of patterns of performance on a preliminary evaluation often leads to better precision in test selection at subsequent testing sessions. A second benefit of this multiple-session evaluation model is that the role of fatigue in children's performance can be minimized, particularly given the frequency that fatigue is noted in children receiving antiretroviral therapy (Koppel, 1992; Markowitz & Perry, 1992).

This strategy has some drawbacks as well. There is always a significant risk that a child will not return for a second visit within a time frame that permits comparison of test scores using the same age-based norms. Second, if the interval between the evaluations is greater than 2–3 weeks, significant changes in health status and cognitive functioning may occur (Belman et al., 1986; Epstein et al., 1986), which makes interpretation of the findings difficult. However, changes within this interval may be significant indicators of worsening disease or increasing ineffectiveness of drug therapy and thus may play an important role in the clinical management of these children. For this reason, integration of neurodevelopmental services into the primary care setting permits rapid communication of test results to the physician, who may in turn quickly acquire additional neuroradiologic or laboratory testing to confirm the change and monitor the child's disease status.

Serving a Diverse Population

Children perinatally infected with HIV represent a challenging population for coordinated primary care. Not only do these children have a life-threatening, chronic illness but the nature of the epidemic in its patterns of transmission often places these children at high risk for psychological and developmental problems in general (Kalichman, 1995). The vast majority of children with perinatally acquired HIV are of low socioeconomic status and acquired the infection from mothers who were infected following sexual contact or intravenous drug use. In our medical center, this population of children is predominantly African American, Haitian, or Hispanic. This ethnic distribution is associated with a variety of cultural practices and beliefs, and a large number of the children are bilingual (Spanish-English or Creole-English) or live in a home where the sole language is not English. These factors (poverty, lifestyle, ethnicity, cultural practices, and multilingualism) have had a major impact on the selection of tests, training of examiners, and interpretation of findings. Last, given the stigmatizing nature of HIV, a number of confidentiality issues enter into the determination of how to interpret and communicate the findings of evaluations.

The integrated primary care model has developed a number of mechanisms to deal with poverty and socioeconomic issues. Community funding and the development of service demonstration projects have provided the financial means for transportation to and from clinic appointments. For a number of the patients served by pediatric psychology, transportation is provided using cab service funded by an outside grant. In addition to financial support, each family is closely followed by a case worker, who helps to coordinate all aspects of both maternal and child health care. These steps have significantly helped to overcome some of the barriers that had been previously encountered in serving a low-income population.

Ethnic and cultural diversity have also represented substantial challenges to providing services to this population. The neurodevelopmental evaluation is the first contact that many of these families
have with professional psychology, and a significant amount of education about the reasons for testing, meanings of test results, interpretation of test findings, and use of test results to obtain intervention services is necessary. Despite an effort to provide direct communication about these issues, cultural interpretation is frequently needed. Because a substantial portion of these families are recent immigrants, a level of distrust about the use of any kind of information is frequently encountered. Although some families have immigrated to the United States for economic reasons, a number of other families left their home countries because of political persecution and threat to their lives. A number of patients have indicated that information about oneself in some countries is collected only to be used against the informant. This concern typically does not apply to communication with physicians, but sharing information with psychologists is usually met with apprehension. To address this issue, collaboration between the physician and the psychologist that is witnessed by the patients increases the acceptability of the psychological assessment and intervention. Further, using members of the staff who have previously established relationships with the families to explain the nature and the usefulness of the testing process has significantly facilitated participation by children and families in the program. However, once relationships are established between the pediatric psychology team members and the families, many of these cultural issues cease to be a factor. In fact, it is not uncommon for parents of all ethnic backgrounds to contact the examiners with questions and requests for follow-up evaluations and school consultation once a professional relationship has been established.

Not as easily addressed is the issue of multilingualism. Explaining the evaluation process, obtaining informed consent, and providing interpretations of test results all require the use of an examiner or interpreter fluent in the native language of the child and parents or guardians. This level of communication is addressed through the use of interpreter services, bilingual case managers, and bilingual members of the pediatric psychology team. Evaluating children who are bilingual represents a different level of complexity. Until recently, there were few neurodevelopmental measures with test instructions in languages other than English, and normative data for children of a bilingual background were largely nonexistent. Even though there has been some advancement in this area in the recent past, these advances have been predominantly for Spanish or Spanish-English bilingual patients and remain nonexistent for certain Spanish dialects or for individuals whose primary language is Creole, an Asian dialect, or some other language. Thus, adaptations in test administration and interpretation have been necessary as neurodevelopmental services have been provided to this population.

Although it might seem that the problem is related to the unavailability of test instruments in languages other than English, the bilingual issue is actually much more complex. Many children in this program are not truly bilingual, but are “transitionally lingual.” These children are raised in a home where the primary language is not English, but the parents may be attempting to learn English as a second language. As the children reach school age, they are placed into mainstream classrooms where instruction is provided in English, although they may receive some support through instruction in English as a Second Language. By the end of the primary school years, social transactions may be conducted easily in either English or in the native language. However, there is substantial variability in the degree to which children become fluent in both written and spoken forms in both languages. Some of our preliminary research on this topic suggests that bilingual children who indicate a preference for English will tend to score approximately two thirds of a standard deviation lower on verbal intelligence measures than on performance measures. This pattern is not observed in children who are monolingual (Armstrong, Levy, Pegelow, & Simpson-Robinson, 1996). Measures that integrate language-based skills must, therefore, be interpreted on the basis of an assessment of the contribution of bilingualism to how a child understands, learns, and attributes meaning to information and stimuli. Careful attention to these issues, and how they influence interpretations about performance in individual children across time, has become a core feature of the integrated neurodevelopmental program with children infected with HIV. A growing issue that has not been previously addressed is trilingualism, where children are simultaneously exposed to a primary language, to English, and to some other secondary language. Multilingualism is a growing phenomenon in the pediatric HIV population, particularly for children whose biologic family is bilingual, but whose foster or adoptive
placement following the death of a mother is in a home where a third language is spoken. Whether exposure to multiple language systems is an enhancement of language development, or a barrier to systematic development of verbal abilities, is a question that has not yet been answered.

**Summary**

The model of integrated clinical care of children with HIV that we have described currently focuses heavily on neuropsychological assessment and school-based consultation and intervention. Since the inception of this program in 1993, 347 children have been evaluated at least once, and 158 have received multiple, repeated evaluations. The median number of evaluations per child is 3. Of this group, 32 (9.2%) had global cognitive functioning (e.g., FSIQ) in the 75–80 range, and 141 (40.6%) had global cognitive functioning below 75. Thus, nearly 50% of this sample had global intellectual functioning in the borderline to impaired range, and most were subsequently referred for either formal special education or significant tutorial assistance. This underscores the extent of the difficulty experienced by children with HIV and the extensive need for early identification and coordinated services to address their needs.

This level of clinical activity has been made possible because medical care of children infected with HIV has dramatically improved the length and quality of long-term survival with the disease. Inclusion of pediatric psychology services within this primary care model has come about largely through negotiation and integration of these services within the primary care medical network. This integration has required the development and maintenance of professional relationships with individuals of multiple disciplines and backgrounds. It has required a substantial ongoing educational effort. The setting and population have presented a number of challenges, but we have described steps to reduce or eliminate the impact of these factors on the outcome of providing neurodevelopmental services within a primary care model. It has not been our intention to propose that ours is the ideal model for providing services of this nature. However, it is a model that integrates pediatric psychology services in a primary care program, that is accepted by physicians, other health care professionals, parents, and children, and that has facilitated assessment and intervention services for a large number of children who would not have had access to such services in any other environment. The test of this model is whether or not it can be generalized to other settings, with different parameters, in serving this diverse population.

**Acknowledgments**

This work was supported in part by NIH grants 2-U01-756006, R01-AI-23524, and N01-HB47111. We thank Gwendolyn B. Scott, MD, Charles Mitchell, MD, Celia Hutto, MD, Caryl L. Gay, PhD, David Lasko, Jacqueline D. Levy, Sabina Coranado, PsyD, Lee Reeback, PsyD, and Richard Burton for their assistance in the development of the program reported here.

*Received July 3, 1998; revisions received December 16, 1998; accepted January 7, 1999*

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