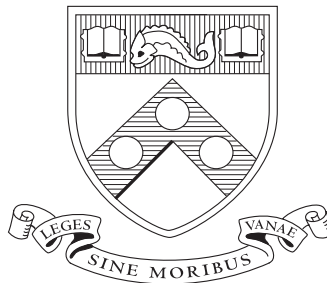


Follow-Up Review of the State's Efforts to Comply with the *Felix* Consent Decree

A Report to the Governor and the Legislature of the State of Hawaii



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OVERVIEW

Follow-Up Review of the State's Efforts to Comply with the Felix Consent Decree

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Summary

By legislative request, the Office of the Auditor contracted with a consultant to undertake a follow-up review of the State's progress in implementing selected recommendations from the Auditor's Report No. 98-20, *Assessment of the State's Efforts Related to the Felix Consent Decree*. The consultant retained was the Center for the Study of Youth Policy, School of Social Work, University of Pennsylvania. Principal consultants for the Center are: Professor Ira M. Schwartz, Dean of the School of Social Work, a prominent scholar and consultant on child welfare and children's mental health; and Professor Richard J. Gelles, Ph.D., Welsh Chair of Child Welfare and Family Violence at the School of Social Work, an internationally recognized researcher and author on the subject of deviant behavior and children. The principal consultants have served as court monitor and/or expert witnesses in education/mental health cases. They also assembled a team with specialized expertise in *Felix* issues.

Findings of the follow-up review

The follow-up review focused on two recommendations from Report No. 98-20. The consultants evaluated the efforts to develop, implement and clarify a working definition of the *Felix* class and the maintenance of effort requirement. The consultants also examined whether funding for carrying out the decree is reported consistently by the Departments of Education and Health. The consultants also compared the State's efforts with those of other jurisdictions and reviewed the literature.

The consultants found that while the departments have made significant progress in establishing a system of care for *Felix* children, a working definition of the *Felix* class has still not been developed. A working definition is an "operational definition" that establishes comprehensive thresholds or boundaries for inclusion or exclusion from a group or category. It is also reliable—different evaluators using the working definition would arrive at the same conclusions. The lack of a working definition results in the departments' system of care that provides open-ended entitlements and inconsistent services, and lacks an ability to ensure that services provided are effective. There is no assurance that appropriate services are being provided to *Felix* class children or that these services result in improved school performance. The consultants also found that there is an appearance of a blurring of roles and responsibilities of the court monitor, a technical assistance panel, and psychologists who diagnose and provide services to children. As a result the system of care lacks independent oversight. All of these factors can contribute to a significantly higher financial burden to the State than necessary.

The consultants conducted a "best practices" review to compare Hawaii's efforts to other efforts nationally. They found that Hawaii's efforts focus on process and providing a continuum of services necessary to have the consent decree lifted. This has resulted in less concern over whether the services provided are effective and least restrictive and whether *Felix* children are actually making progress as a result. Case file reviews showed no ongoing assessment or concern for assessing whether services should be continued, modified or changed.



The consultants concluded that the individualized education program process is flawed. The process places too much responsibility and authority on psychologists to assess conditions and prescribe services at the expense of family and other appropriate agency involvement. Prescribed interventions are based on broad categories of disabilities rather than tailored to individual student needs.

The consultants found that the *Felix*-related costs and services continue to be inconsistently reported. The education department combines *Felix*-related administrative and service costs with other special education costs. The health department combines costs for compliance with the costs of delivery of services. The health department also combines costs for new and experimental services such as Multisystemic Therapy with the costs for traditional mental health services. As a result it is impossible to examine the budgets and determine the cost of core and essential services versus the costs of new, experimental, and non-essential services.

Finally, the consultants also found inconsistent coordination continues between the Department of Education and the Department of Health. The departments also lack the “seamless” management information system required by the consent decree. And neither department was able to quickly and correctly locate, retrieve, and deliver files for review. Personnel problems and the inability to obtain and retain necessary qualified personnel to provide and sustain *Felix*-related services also persist.

Recommendations and Response

The Center recommends that the Legislature consider establishing (1) a working definition for special education eligibility and (2) a credible and independent evaluation entity to evaluate services, programs, and alternatives such as the use of service vouchers to provide services to *Felix* class children. The consultants further recommend that the departments collaborate with the University of Hawaii to effectively address the personnel needs required to provide services to the *Felix* class, and that the departments develop mechanisms to ensure coordination at the agency and individual case level.

A unified response for the Departments of the Attorney General, Education and Health contends that a potentially useful document is flawed because the consultants and the Office of the Auditor are not sufficiently qualified in the areas of education, the Individuals With Disabilities Act, *Felix* class youths, and best practices in children’s mental health. As a result the departments claim that the report contains “many consecutive mistakes.” The response concludes that the consultant’s recommendations would amount to an effort to restrict the State’s ability to comply with the consent decree’s obligations and could result in further contempt of court issues being raised.

The consultants’ rebuttal is included in the report.

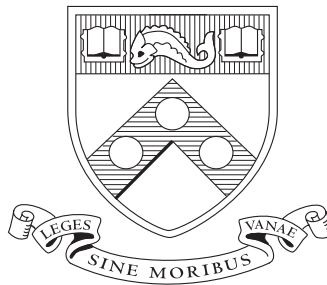
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Submitted by:
THE AUDITOR
STATE OF HAWAII
January 2001

Foreword

This report was prepared pursuant to a request from the Legislature to have an independent consultant with national expertise evaluate the compliance efforts related to the *Felix* consent decree, and on the progress made in implementing selected recommendations from Report 98-20, *Assessment of the State's Efforts Related to the Felix Consent Decree*.

We wish to express our appreciation for the cooperation and assistance extended to us by officials and staff of the Board of Education and the Departments of the Attorney General, Education and Health as well as others providing assistance during the course of this project.

We also wish to thank the Center for the Study of Youth Policy, School of Social Work, University of Pennsylvania that performed the evaluation.

Marion M. Higa
State Auditor

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Chapter 1

Introduction and Background

Pursuant to a request from the Legislature requiring the retention of an independent consultant with national expertise in the areas of the federal Individuals with Disabilities Education Act (IDEA), delivery of children's mental health services, and related litigation in other states, the Office of the Auditor contracted with the Center for the Study of Youth Policy, School of Social Work, University of Pennsylvania. The contractor was asked to perform an evaluation of the Department of Health and the Department of Education's compliance with the *Felix* consent decree from December 1998 to the present and to provide information to the State Legislature and key decision makers on the progress made in implementing selected recommendations from the Auditor's Report No. 98-20, *Assessment of the State's Efforts Related to the Felix Consent Decree*.

The principal consultants representing the contractor for this project are:

Professor Ira M. Schwartz, Dean of the School of Social Work at the University of Pennsylvania. Dean Schwartz is a prominent scholar and consultant in the areas of juvenile and criminal justice, community-based programming, law-related education, child welfare, and children's mental health on international, national and state levels. He also has experience as administrator of federal and local governmental programs and in the private sector. Dean Schwartz has served as a court monitor on child welfare issues, including mental health services.

Professor Richard J. Gelles, Welsh Chair of Child Welfare and Family Violence at the School of Social Work at the University of Pennsylvania. Dr. Gelles is an internationally recognized researcher and author on the subject of deviant behavior and children. He has extensive consulting experience on issues related to child welfare, including numerous assignments to assist with drafting legislation. In that capacity, he has served both houses of Congress, the U.S. Department of Health and Human Services, and numerous state and local agencies.

This report is presented with three appendices:

Appendix A *An Analysis and Review of Case Studies Involving Children Qualifying for Services Under Felix Consent Decree* by Annie Steinberg, MD, a child and adolescent psychiatrist. The analysis and review is an assessment of the services rendered in the State of Hawaii, based on a review of approximately 100 cases.

Appendix B *Definitions of Disabilities* - literature review on issues pertaining to the *Felix* consent decree and discussion of the derivation of definitions underlying the working definition of the *Felix* class.

Appendix C *References* – a bibliography for the titles used in the literature review.

Previous audit report

Report No. 98-20, *Assessment of the State's Efforts Related to the Felix Consent Decree*, issued in December 1999, was the result of an audit responding to a special request of the president of the Senate and the speaker of the House for a comprehensive assessment of the State's efforts and expenditures related to the *Felix v. Waihee* consent decree.

Report No. 98-20 concluded that the State's system of care was inefficient and ineffective as it lacked clarity of means, resources and purpose. Its recommendations included a call for:

1. Aggressive clarification of a working definition of the *Felix* class and maintenance of effort requirements.
2. Reporting of funding for *Felix* services with the same definitions of budget and expenditure terms between departments and from one year to another.
3. Ensuring that quality services are provided consistently and in a coordinated, timely manner.

Objectives

1. Examine and evaluate the development and implementation of the working definition of the *Felix* class and the maintenance of effort required to implement the consent decree and sustain the efforts required by the implementation of the decree.
2. Examine whether all the funding for the implementation of the *Felix* decree is reported consistently by the Department of Health and the Department of Education.

The Center for the Study of Youth Policy also undertook the following tasks:

- Conducted a comprehensive review of the professional literature regarding the provision of educational and mental health services to handicapped children. The literature review examined the

extent to which the State of Hawaii's policies and practices, including the working definition of children who qualify for the "class," compared with other states and what current literature reported as "best practices" in this area. The literature review examined: definitions, diagnoses and assessments, treatment interventions, residential treatments, appropriate outcome and performance measures, and results of process and outcome evaluation research.

- Examined the progress the State is making in meeting the mandates of the consent decree. A specific focus of this examination was to identify particularly constructive and effective efforts that have statewide implications (i.e. are there local efforts that could be used as models for statewide compliance efforts).

This comparison was aimed at identifying "best practices" that can be used in Hawaii to deliver educational and mental health services, as well as improving compliance as required by the *Felix* consent decree.

- Examined and documented the progress the State has made in the specific areas listed in the request for proposals. These areas were also covered in the earlier Office of the Auditor report.

An important component of this examination was to identify whether there continue to be difficulties in clearly identifying the *Felix*-eligible cases. To that extent, this examination specifically focused on the working definition of what constitutes an eligible child.

- Examined the State's plan for meeting the requirements of the consent decree. We identified existing services and the funding for services.

Our initial task was to examine the impact of the Office of the Auditor's report and recommendations and document responses to the recommendations made in the 18 months since the report was completed.

- Examined the procedures in place to conduct process and outcome evaluations of current services and programs and whether such procedures are appropriate, and if so, whether the information they are producing is used by key decision makers.

The above assessment was conducted considering the requirement that interventions and services be the least intrusive and most appropriate. Are these general principles adhered to, and if not, is there a pattern that requires redress?

- Examined the extent to which the Departments of Education and Health are coordinating their efforts at the state level and on each island. In addition, we examined and commented on coordination with other relevant agencies such as child welfare and youth services.

Scope and Methodology

The project commenced the first week of January 2000 and fieldwork was substantially completed in May 2000. However some additional work, primarily monitoring and assessing subsequent events, was performed between May and October 2000. Our staff reviewed documents and correspondence related to compliance with the consent decree and the provision of services to children identified as part of the *Felix* class. Second, we conducted a review of the literature on the provision of educational and mental health services to handicapped children. The literature review focused on identifying working definitions, “best practices,” and evidence-based models of effective intervention for children covered by IDEA and Section 504 (which includes the Hawaii *Felix* class). Thirdly, we met with individuals, officials, and agency administrators in the Department of Health, Department of Education, Department of the Attorney General, Office of Youth Services, Office of the Auditor, and members and staff of the State Legislature. Project staff have also met with school principals and parents of children who are in the *Felix* class. Lastly, Dr. Annie Steinberg, a board-certified pediatrician and child psychiatrist, reviewed case files provided by the Departments of Education and Health. These files included children placed in residential facilities on the mainland as well as children with various levels of special education and mental health needs in Hawaii.

Chapter 2

The State Has No Assurance That Services Provided to *Felix* Children are Appropriate and Effective

This chapter outlines our findings and recommendations from our review and analysis of the State's *Felix* implementation effort, including a review of case files (discussed in detail in Appendix A).

The Departments of Education and Health have made significant progress in establishing a system of care for *Felix* children. However, this effort continues to be impaired by a lack of a working definition of the *Felix* class as well as other problems, including a lack of a best practices approach to providing services. As a result, the State has no assurance that services to *Felix* children are appropriate and effective.

A Working Definition of the *Felix* Class Still Does Not Exist

The State's continued failure to develop a working definition of the *Felix* class has resulted in open-ended entitlements, inconsistent services, and an inability to ensure that services provided are effective. The failure to develop a working definition of the *Felix* class can also result in significant fiscal consequences to the State.

The State has not developed a working definition of the Felix class

The issue of whether the Departments of Education and Health have developed and implemented a working definition of the *Felix* class has been debated for more than five years and was most recently discussed in the Office of the Auditor's Report No. 98-20, *Assessment of the State's Efforts Related to the Felix Consent Decree*. This report detailed concerns about the State's efforts to clarify membership of the *Felix* class and outlined some of the potential consequences, including:

- ineligible children receiving services for which they are not entitled, causing an expanded *Felix* class,
- eligible children not receiving services for which they are entitled,
- difficulties in consistently identifying children whom the system should serve, and
- difficulties in determining whether children receiving *Felix* services are actually eligible for those services.

The Department of Health provided then, and continues to provide the following (taken directly from the *Felix* consent decree) as the working definition of the *Felix* class:

The “Plaintiff class” is “all children and adolescents with disabilities residing in Hawaii, from birth to 20 years of age, who are eligible for and in need of education and mental health services.”

In responding to the findings in Report 98-20, the Office of the *Felix* Consent Decree Operations Manager stated that:

The State has a clear “working” definition of the *Felix* class that was provided in the “Stipulation and Order Modifying the Consent Decree,” filed on January 12, 1998. The decree defines the Plaintiff class as “all children and adolescents with disabilities residing in Hawaii, from birth to 20 years of age, who are eligible for and in need of education and mental health services.”

However, neither the definition provided by the health department nor the explanation offered by the *Felix* operations manager meets the standards for a working definition. Social scientists generally agree that a working definition is an “operational definition” that establishes thresholds or boundaries for inclusion or exclusion from a group or category. The working definition provides procedures for determining which individuals or groups belong inside and outside of the category. It is exhaustive and inclusive in that it identifies all possible members of a class or group and excludes individuals or members who do not belong in a group or category. In addition, a working definition is reliable—different evaluators who use the working definition would arrive at the same conclusions regarding inclusion and exclusion into a group or class. Such a working definition does not exist in Hawaii and has not been developed for use in determining which children belong or do not belong in the *Felix* class.

Thus, we find that there is no working definition and no training of staff in applying a working definition of the *Felix* class. Entry and exit from the *Felix* class is left to the judgment of Individualized Education Program (IEP) teams and case coordinators. However, the principals whom we interviewed uniformly stated that psychologists who evaluate children for whom an IEP has been requested often determine inclusion into the *Felix* class. The principals emphasized that the IEP team may not even determine inclusion in the *Felix* class. This is contrary to what the literature review considers to be “best practices” for special education and mental health services for children.

Problems caused by the lack of a working definition include:

- No assurance that children receiving services meet appropriate criteria for inclusion in the *Felix* class and that services received are effective.
- Over-reliance on psychologist assessments in the IEP process may cause services being provided to ineligible children or services being provided that are not required.

Based on case file reviews and discussions with school principals, we concluded that the lack of a carefully crafted working definition has resulted in a system that is psychologist-driven rather than cooperative and interdisciplinary in nature. Stated differently, the actual working definition in use is whatever any individual psychologist concludes in an evaluation of a child. School personnel, teachers, principals, and even parents are left out of the discussion and decision making that determines the child's diagnosis. Of note is that in the few school complexes that are in compliance with the court monitor's standards measured by Service Testing, the working definition is not left to the evaluation carried out by the psychologist. Service Testing was specifically developed to assess compliance with the terms of the *Felix* consent decree. The working definition is the outcome of a coordinated evaluation that includes parents, psychologists, and school personnel. The literature review on "best practices" also indicates that such cooperative efforts are the most appropriate means of determining which children should receive special education and mental health services and what kind of services they should receive.

Additional important potential problems created by the lack of a working definition include:

- Inability to predict how large the *Felix* class will be.
- Inability to ensure that a "best practices" working definition is being used.
- Inability to ensure that diagnoses are reliably and consistently conducted by IEP teams and/or contracted mental health professionals.
- Inability to predict the appropriate mix of needed services.

Our concerns about the effects of a lack of a working definition are directed at what occurs before the clinical case file is opened and a treatment plan is established. Therefore, Dr. Steinberg's review, *Analysis and Review of Case Studies Involving Children Qualifying for Services Under the Felix Consent Decree (Appendix A)*, would not find any of the

potential problems outlined above. Dr. Steinberg's analysis was concerned with clinical data and did not question whether a child's inclusion in the *Felix* class was based on a "best practices" model.

Open-ended entitlements and inconsistent services may have significant fiscal consequences

The lack of an appropriate working definition has produced the unintended consequence of creating an open-ended entitlement for special education children and children with mental health issues and problems. Mental health and special education services are an entitlement when children are identified as having a disability or special education need. However, nothing in federal law or in the consent decree requires the entitlement to be open-ended. The provision of services must be reasonable. A working definition is necessary to ensure that services provided to *Felix* class children are effective and the least intrusive. With the size of the *Felix* class expanding dramatically, and with estimates of *Felix* class costs approaching \$250 million annually, the Departments of Education and Health are providing more and more services. However, the lack of a working definition means that there is no assurance that the services provided to *Felix* class children are provided to the appropriate children.

This situation could have significant fiscal consequences if the State is providing services for children who are not eligible to receive such services. National estimates indicate that serious emotional disturbances afflict 9 to 13 percent of the country's children and adolescents (see *Analysis and Review of Case Studies Involving Children Qualifying for Services Under the Felix Consent Decree*, Appendix A, page 2). For Hawaii, this means a potential population of 29,000 to 42,000 *Felix* children. Since there are currently only about 11,000 children identified as belonging to the *Felix* class, the importance to state finances of ensuring that eligibility is properly determined should be evident. The lack of a working definition also has important fiscal, social, and emotional consequences for schools, parents, and children. Schools may be overburdened providing services for children not eligible for services. Families may be frustrated in obtaining needed and important services for their children. Also, children may either receive services they do not need or may be blocked from receiving services for which they are entitled and require for educational achievement.

Our investigation shows the State of Hawaii has not established a "best practices" approach for designing and funding programs aimed at achieving compliance with the *Felix* consent decree. A "best practices" approach would set a goal of progress rather than process. Legal definitions, protocols, and paperwork are necessary evils, but educators and lawmakers must not lose sight of the fact that the goal is improving academic achievement levels for students with disabilities or mental health

problems. The consent decree clearly calls for educational and mental health assistance that is effective—not just having the child in the class, but also having the child advance academically.

The Department of Education has developed the Comprehensive Support Services System (CSSS) as a system of care. Our review of case files and discussions with school personnel indicate that the current CSSS system is not using a “best practices” approach and thus, is not meeting the needs of *Felix* class children.

Despite the implications of the recent federal court ruling that Hawaii is in contempt and the new court order of August 2, 2000, in our opinion, means more money and more programs, these are not the appropriate means of achieving compliance with the *Felix* decree. The Departments of Education and Health need to fully implement “best practices” principles and procedures. The State Legislature must set goals and parameters for funding, in order to ensure that students will actually benefit from the programs being created for them. Otherwise, the State is simply opening the floodgates for an open-ended entitlement.

We discuss best practices in more detail below (see page 18).

State lacks assurance that services are effective

The state Departments of Education, Health, and Attorney General demonstrated confusion whether a mandate for effectiveness of services to children exists. This confusion when combined with blurred responsibilities of parties involved with determining compliance with the *Felix* consent decree cause the State to lack assurance that services provided are effective.

The State sees no mandate to ensure that services are effective

The Departments of Education, Health, and Attorney General are not assessing effectiveness of services to *Felix* class children.

The superintendent of education acknowledged that he would like to assess the effectiveness of services provided to *Felix* class children. However, the superintendent contends that the department has devoted so much energy to compliance and provision of services that it has not been able to develop an effort to assess service outcomes.

The deputy attorney general in charge of the *Felix* case dismissed and denied the suggestion that there was a mandate that the Departments of Education and Health and provide effective services to the children in the *Felix* class.

The director of health and the deputy director for the Behavioral Health Administration of the Department of Health initially stated that they

believed that the terms of the consent decree and the benchmarks did not include a mandate to provide effective services to children. However, at a subsequent meeting, both stated that they were concerned about outcomes and effectiveness of services. Nonetheless, they are still not using standard scientific methods to assess outcome. The Service Testing protocol provided by the *Felix* monitor is not a scientifically appropriate protocol to assess outcome and effectiveness. Service Testing is not a reliable and valid measure of individual child progress or outcomes; rather, Service Testing was specifically designed to assess compliance with the terms of this consent decree. As such, it can only assess a school complex's compliance with procedural benchmarks and satisfaction with services and systems of care.

The consent decree does require the provision of effective services. The following items are quoted from the decree:

Item 17:

There must be a reasonable prospect that the services provided in response to a class member's needs will achieve their purpose. The services must be of a type and mix likely to be effective in meeting the class member's needs.

Item 19:

Each IEP, IFSP, or MP will identify the specific steps to be taken by service providers toward meeting the short-term and long-term objectives stated in the program or plan and will include objective criteria to measure a class member's progress toward the goals and objectives of the program or plan.

By the terms of the consent decree, children, parents, and taxpayers are entitled to effective services, as well as services that are least restrictive.

Without an assessment of the effectiveness of services, it will be impossible for the Departments of Education and Health to know how to match diagnoses to services and how to provide the most effective and least restrictive services to *Felix* class children.

The above discussion focuses on "aggregate level" effectiveness—that is, whether a particular intervention or service is more effective than an alternative service. Assessing this type of effectiveness would involve comparing groups of children. Even at the individual level, our review of case files indicates that there is minimal effort to assess progress and effectiveness. Case files include IEP evaluations, service plans, and authorizations for services, but limited progress reports (see Appendix A for a full discussion). In one instance, a child received months of individual therapy without a single progress note included in the file.

There was no evidence as to whether the child had made progress, nor whether the individual therapy would ever end. An analysis of the case files of children placed in residential facilities on the mainland suggests that many of these children are not receiving effective services in the least restrictive environment.

The State needs to clarify overlapping roles and responsibilities that may create an appearance of conflict

The appearance of a blurring of roles and responsibilities of the court monitor, a technical assistance panel, and psychologists who diagnose and provide services to children leads us to conclude that the Legislature should carefully examine these apparent overlapping and conflicting roles, and perhaps, seek assistance and guidance from state and federal courts regarding the appropriate span of authority and responsibility for individuals and panels monitoring compliance efforts with a federal consent decree.

The court monitor and the advisory panel's central role are to assess and measure the State's effort to comply with the terms of the *Felix* consent decree. They also provide technical assistance to the Departments of Education and Health. Here is where a blurring of roles, boundaries, and responsibilities occurs. The court monitor not only established the benchmarks and developed the instrument to measure achievement of the benchmarks, but he apparently also serves as a consultant to the State to help it achieve compliance—that is, comply with his own benchmarks as measured by his own instrument.

During our study, we also learned that a member of the court monitor's advisory panel—someone who is supposed to help evaluate the State's compliance with the consent decree—is a participant in the development of proposals for services to meet the needs of *Felix* class children.

It appeared to us and to many others in Hawaii that the court monitor's oversight role is in conflict with his technical assistance and consultant role. There appears to be no independent individual or panel that is assessing the compliance efforts and is also independent of the activities and pressures of the compliance effort.

A similar blurring occurs with regard to the role of psychologists who provide evaluations for schools. As noted throughout this report, the lack of a clear and consistent working definition for the *Felix* class means that psychologists are the primary determinants for inclusion into the *Felix* class and classification as to what level of services are required. In many communities, the agency with which the psychologist is affiliated then provides the recommended services. Here again, there is no independent oversight or even an independent diagnostic and/or "gatekeeping" function.

From the office of the court monitor to the individual psychologists, there is no independent agent who can be depended upon to reliably and consistently determine who belongs in the *Felix* class and what services are actually required to meet the federal mandates under IDEA and Section 504. With no independent and appropriate oversight, the end result is likely to be an open-ended entitlement.

The Legislature should mandate an independent evaluation capacity

A Center for Service and Program Evaluation should be established in Hawaii. The center should be independent of the agencies and programs to be evaluated—capable of conducting process and outcome evaluations. Funds for such a center should be derived from legislative set-asides that are part of funding for the Departments of Education, Health, and Human Services programs and initiatives. At present neither the Legislature, the Departments of Education and Health, nor the court monitor are able to make evidence-based decisions as to what services are effective, what services are essential, and thus, what services merit funding and which do not. As we noted many times in this report, the greatest emphasis has been on the *process* of compliance rather than the *product* of compliance—that is, the impact of compliance on *Felix* class children. Having evidence on the aggregate and individual effectiveness of services and programs would be a significant resource as all parties assess what is necessary and essential to meet the needs of *Felix* class children. We note the implementation of Multisystemic Therapy (MST) as a benchmark (#50) in the August 2, 2000 court order, and we stress that there is no scientifically acceptable evidence that MST is effective with the *Felix* class population. Here again, evidence collected by a Center for Service and Program Evaluation would help determine whether MST implementation should be funded and should be considered a significant benchmark of compliance.

We recommend the Legislature hold monthly oversight hearings to learn about the progress of compliance with the new court order. The Legislature should also require the center to seek and secure funding from the federal government and appropriate foundations.

The Legislature should consider a statutory definition of the Felix class

We are not aware of any federal legislation or legal precedents that would prevent the Legislature in Hawaii from enacting a “working definition” of the *Felix* class. Below, we have provided an initial draft of a recommended legislative definition. In addition, Appendix B provides a more detailed discussion for the underlying definitions. We recommend that the Legislature confirm that it can enact such legislation.

Whereas the Departments of Education and Health have failed to develop a real working definition during the five years of the consent decree, it is necessary and appropriate for the Legislature to establish the measurable thresholds for inclusion and exclusion into the *Felix* class. Our review indicates that at least one state, Kentucky, has legislated eligibility for special education services. We recommend that the Hawaii State Legislature develop a statutory working definition during the next session, based on the following guidelines:

Eligibility. The *Felix* class includes children age zero to 20, residing in Hawaii, who require special education or mental health services as a result of one or more of the following conditions:

- Learning disabilities such as autism, attention deficit disorder, dyslexia
- Mental retardation
- Emotional and/or behavioral disorders
- Substance abuse problems
- Developmental delays in language and communication skills, cognitive skills, social or emotional development, or adaptive behavior
- Speech/language impairment
- Multiple disabilities—at least one of which falls into one of the previous categories
- Additional thresholds for inclusion into the *Felix* class should be:
 - Abrupt and significant deterioration of school performance (as measured by grades)
 - Obvious decline in the mastery of educational objectives
 - Severe decrease in classification productiveness
 - Sudden inability to master more advanced, complex skills, or to accomplish long-term projects (e.g. semester papers)

Exclusions. As is the case with IDEA regulations, the existence of a disability does not automatically mean that a student is eligible as a member of the *Felix* class. To be eligible, students must have one of the above named disabilities that adversely affects educational performance and necessitates specially designed instruction and/or

mental health services. (Lack of proper instruction in reading and math skills does not qualify a child as disabled.) Children who are disabled but are not part of the *Felix* class include those whose disabilities are limited to one or more of the following:

- Mobility impairment
- Vision impairment
- Hearing impairment
- Epilepsy
- Neurological disorders that require assistive technology but do not impair the intellectual learning process (such as multiple sclerosis, muscular dystrophy, AMS)

Any legislated definition should also specifically note that time-limited emotional disorders, such as “adjustment disorders,” are excluded from the definition.

The legislated definition should also clarify that the mere diagnosis of an emotional or behavioral disorder is insufficient for inclusion into the *Felix* class. Emotional and behavioral disorders must cause a marked degree of impairment in academic performance for inclusion into the class.

A. Exceptions. Children with physical disabilities who also have conditions necessitating special education or mental health services will be classified as *Felix* only with regard to their special education or mental health needs. Assistive technology for physical needs will not be financed by funds provided for *Felix* children.

B. Definitions:

1. “Learning disability” refers to any disorder in one or more of the basic psychological processes involved in understanding or in using language—spoken or written—that may result in an imperfect ability to listen, think, speak, read, write, spell, or do mathematical calculations. This term includes conditions such as perceptual disabilities, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. The term does not include learning problems that are primarily the result of visual, hearing, or motor disabilities; of mental retardation; of emotional disturbance; or of environmental, cultural, or economic disadvantage.

2. “Autism” is a developmental disability significantly affecting verbal and nonverbal communication and social interaction. Specific characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences.
3. “Attention deficit disorder” (a.k.a. attention deficit hyperactivity disorder) is a long-term and pervasive condition causing severe distractibility and impulsiveness in children, making it difficult for them to control behavior and complete assignments. Children with ADD often fail to give close attention to details, make careless mistakes, have difficulty sustaining attention to and completing tasks, do not seem to listen when spoken to directly, fail to follow instructions carefully, act restless or nervous, talk excessively, blurt out answers before hearing the whole question, and have difficulty awaiting their turn. The hyperactivity component may or may not be present.
4. “Dyslexia” is an information processing disorder that hinders a child’s ability to understand and perform tasks related to reading, writing, spelling, math, and sometimes music. Many dyslexics have trouble matching letters to their corresponding sounds. Some common characteristics include the reversal of letters and words (such as reading saw instead of was), and defects in the visual and auditory perception and memory considered necessary for reading.
5. “Mental retardation” means significantly subaverage intellectual functioning, existing concurrently with deficits in adaptive behavior and manifested during the developmental period, which adversely affects a child’s educational performance.
6. “Emotional/behavioral disorder” refers to a condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree that adversely affects a child’s educational performance:
 - An inability to learn that cannot be explained by intellectual, sensory, or health factors.
 - An inability to build or maintain satisfactory interpersonal relationships with peers and teachers.
 - Inappropriate types of behavior or feelings under normal circumstances.

- A general pervasive mood of unhappiness or depression.
- A tendency to develop physical symptoms or fears associated with personal or school problems.

This group of disorders includes schizophrenia. The term does not apply to children whose behavior is associated with visual or auditory disabilities, motor disabilities, mental retardation, specific learning disability; nor to children raised in a disadvantaged environmental or economic situation; nor to children who are socially maladjusted, unless it is determined that they have a clinical emotional disturbance.

7. “Substance abuse problem” is a diagnosed addiction to or chronic abuse of alcohol, narcotics, or other controlled drug, which requires medical treatment and psychological counseling.
8. “Developmental delays” are significant delays diagnosed in language skills, cognitive abilities, gross/fine motor function, social/emotional development, and self-help/adaptive functioning. This term applies to children ages three through nine who exhibit disabilities which cannot be attributed to other disability categories.
9. “Adaptive behavior” refers to the effectiveness with which a student meets the standards of personal independence and social responsibility expected of his or her age and cultural group. There should be a significant positive correlation between the student’s IQ and adaptive behavior.
10. “Speech/language impairment” is reduced ability—whether developmental or acquired—to comprehend or express ideas through spoken, written, or gestured language. This term includes stuttering, impaired articulation, or a voice impairment that adversely affects a child’s educational performance.
11. “Multiple disabilities” refers to physical and/or sensory impairments occurring in combination with each other or concomitantly with other disabling conditions. Children in this category exhibit two or more severe disabilities that are likely to be lifelong, significantly interfere with independent functioning, and may necessitate environmental modifications to enable the individual to participate in school and society. Examples include orthopedically impaired/mentally retarded and hearing impaired/mentally retarded. A specific learning disability and a speech/language impairment do not constitute a multiple disability.

It is important to remember that the most useful working definition is one that combines clinical judgment based on a set of criteria with standardized checklists and tests.

Unfortunately, at present, “best practices” definitions and criteria are not uniform throughout the United States, and it has been suggested that learning disability theory has not advanced to the point of offering clear diagnostic criteria. The common practice is to use comparative scores, those of academic achievement compared to a standardized test. This follows the guidelines set by the Social Security Administration’s definition of “marked impairment” as being an impairment resulting in two standard deviations below the population mean on standardized tests.

Other experts suggest the following operational definition for learning disabilities:

IQ scores equal to or above 80 and one or more of the following: Wide Range Achievement Test (WRAT) reading subset scores at or below the 25th percentile, WRAT arithmetic subset score at or below the 25th percentile, and WRAT reading scores at or above the mean on the Parent or Teacher Questionnaire (Coners Parent and Teacher Rating Scales).

A more common operational definition focuses on the discrepancy between potential (as measured by IQ) and achievement. This definition standard appears to be the one preferred among policy makers and is compatible with current policy of Hawaii’s Department of Education. Scores are calculated by comparing the student’s norm-based IQ scores (e.g. WISC-III) with performance scores (e.g. comparing average grade achievement of the student with a standardized norm-based average for age group), or by comparing IQ to specific achievement scores such as the WRAT test. Care must be taken to employ the test that is appropriate to the individual. Certain communication disorders, for example, will impair a child’s ability to perform optimally on verbal tests. To ensure the establishment of and adherence to standards of assessment and intervention planning for children with disabilities, we recommend that state lawmakers enact legislation dictating these standards.

The State of Hawaii’s working definition for the *Felix* class should be narrower than the IDEA and Section 504 definitions, as the intent of the *Felix* consent decree is clearly related to special education and mental health needs, rather than physical disabilities. For example, a child who is wheelchair-bound is not automatically included in the *Felix* class. However, if this immobility leads to emotional problems that impair his or her intellectual functioning in school, he or she would then be included, but only for the emotional or special education needs. A wheelchair ramp would not be funded through *Felix*, but counseling and special education programs would be.

Lastly, as part of the effort to develop a working definition, the Department of Health and Department of Education should be required to develop the necessary systems and capability to develop and submit multi-year plans that include:

- Estimates of the size of the *Felix* class
- Estimates of the class size by degree of severity of the condition
- Projected costs of services
- Projected new services to be added
- Projected services to be modified
- Projected services to be discontinued
- Projected need for secure beds
- Projected need for mainland placements

Shifting Focus From Procedural Compliance to Best Practices Will Ensure that Compliance Efforts are Properly Planned and Budgeted

The Department of Health, Department of Education, and the *Felix* Monitoring Office are primarily concerned with putting into place a continuum of services for children identified as belonging in the *Felix* class. Together with the Department of the Attorney General, the departments present themselves as being singularly focused on having the consent decree lifted. These two goals have resulted in much less concern over whether the services provided are effective and least restrictive.

Our case file review (see Appendix A) and discussions with school principals are consistent in concluding that children in need of special education services and mental health services are better off now than ten years ago because the State has created a system of care to provide such services. There are more services available according to our case file review and principals' accounts. Case file reviews indicate that the services being delivered are largely appropriate and meet the appropriate standard of care.

There is, however, no ongoing assessment or concern to assess which services are more effective than others, which services need to be strengthened, and which could and should be discontinued in favor of other options or services. Moreover, there is no effort to attempt to provide services that are effective and that use existing resources in the community. These questions will have to be answered as the State of Hawaii strives to sustain the efforts on behalf of the children in the *Felix*

class. (Certainly, the Legislature will need this kind of information in order to continue its support for spending such a large amount of the public's tax dollars.)

The departments can improve services to Felix children by adopting a best practices approach

Our investigation shows the State of Hawaii has not established a “best practices” approach for designing and funding programs aimed at achieving compliance with the *Felix* consent decree. A “best practices” approach would set a goal of progress rather than process. Legal definitions, protocols, and paperwork are necessary evils but educators and lawmakers must not lose sight of the fact that the goal is improving academic achievement levels for students with disabilities or mental health problems. The consent decree clearly calls for educational and mental health assistance that is effective—not just having the child in the class, but also having the child advance academically.

Although the Department of Education has developed the Comprehensive Support Services System (CSSS), our review of case files and discussion with school personnel indicates that the current CSSS system is not using a “best practices” approach and thus, is not meeting the needs of *Felix* class children. Also, unique successful practices used in Hawaii school complexes in compliance with the *Felix* consent decree are not readily adaptable as statewide models.

Despite the implications of a recent federal court ruling that Hawaii is in contempt and must comply with the new court order of August 2, 2000, more money and more programs in our opinion, are not the appropriate means of achieving compliance with the *Felix* decree. The Departments of Education and Health need to fully implement “best practices” principles and procedures. The Legislature must set goals and parameters for funding in order to ensure that students will actually benefit from the programs being created for them. Otherwise, as noted earlier, the State is simply opening the floodgates for an open-ended entitlement.

The Individualized Education Program (IEP) needs to be enhanced and strengthened

Our case reviews indicated that significant progress has been made in recent years with regard to assessing and intervening/treating children with disabilities in Hawaii. However, there were several cases in which the level of care prescribed was inappropriate, and children with a distinct need for individualized approaches were not receiving them. Interventions often were too heavily based on broad formulas for categories of disabilities, rather than being tailored to suit an individual student's particular needs. IEPs often lacked creativity in determining the best approach to educating and treating children.

IDEA states that education of children with disabilities can be made more effective by:

- having high expectations for such children;
- ensuring their access to the general education curriculum to the maximum extent possible;
- strengthening the role of parents and families;
- coordinating IDEA with other school improvement efforts so that special education can become a service rather than a place children are sent;
- supporting high quality intensive personnel development so children are prepared to lead productive independent adult lives;
- providing incentives to whole-school approaches and pre-referral intervention to reduce the need to label children in order to address their learning needs; and
- focusing on teaching and learning while reducing requirements that do not improve educational results.

These points should be the basis for the establishment of an individualized education program (IEP) for children with disabilities. The primary goal of the IEP should be to enable the student to reach his or her potential academically, and to eventually live as independently as possible in adulthood. The IEP begins with assessment of a child's academic performance, behavior, and any disorders or disabilities that may be interfering with a child's achievement level in school. IDEA requires an IEP and collaboration between all relevant professionals and the parents.

The earlier a child with a disability is assessed and accurately diagnosed, the better his or her chances are for improved academic achievement. Children who are merely "undertaught" in reading and writing are not eligible for disability programs. However, by identifying them early as well, they may be offered the appropriate instruction to correct their difficulties, preventing them from being labeled as learning disabled in later years.

In a "best practices" approach—depending on an individual student's situation—the IEP team should include the psychologist, family members, representatives from the Departments of Education and Health, a family pediatrician, a Department of Human Services agent, vocational education instructor, and, when appropriate, a juvenile justice representative. Health care providers such as the family or a pediatric practitioner are rarely involved in such tasks as disposition of planning, coordination of

care, or interagency communications although they can provide critical help to ensure the effective coordination and delivery of care. Where appropriate, the child (or suitable guardian) should be present to represent his or her own interests.

The intervention/treatment plan should be culturally sensitive, child-centered, family-focused, and community-based whenever possible. Family-based interventions are necessary in cases involving domestic violence, physical and/or sexual abuse, alcoholism or addiction in the family, and parental depression.

An integrated system of care (including mental health, social services, education, health care, substance abuse prevention and treatment, vocational and recreational opportunities, and other support services) will lead to better access to treatment, greater continuity of care, and higher client satisfaction. Resources within the community should be utilized to create innovative interventions that enable the student to stay within the family unit or community whenever possible and appropriate. When developing treatment centers and programs in the community, the emphasis should be on “macro” over “micro.” Many agencies narrow their focus when developing programs, which limits the number of clients who can benefit from them. Subspecialty areas should be included within the programs, rather than emphasized as the overall reasons for the programs.

We were informed that the Department of Education’s CSSS is supposed to function in this fashion, but our review of case files and discussion with school personnel indicates that the CSSS is not reaching the ideal of “best practices.” At the highest support levels, psychologists generally have too much of the responsibility for assessing conditions and prescribing treatment. Not only does this practice violate IDEA’s mandate that families and other appropriate individuals and agencies be involved in developing the IEP, but it also leads to undertreatment of certain medical conditions. According to our case review, physiological causes and pharmacological treatment for severe maladies were often not considered when they likely should have been. Our case review discovered, for example, several instances where severe headaches were not addressed beyond inclusion in the case history (see Appendix A).

The IEP should establish specific short-term and long-term educational goals for educational intervention, specify symptoms requiring intervention, and prioritize target symptoms and/or co-morbid conditions. The plan should also provide for periodic reassessment of academic, adaptive, behavioral, social, and communicative skills, as well as the monitoring of the effects of medication.

Interventions for disabilities and mental health disorders should typically include early intervention, education, rehabilitation and ancillary therapies

(e.g. physical, occupational, and language), family support, and other services. Such interventions minimize functional disorders and maximize personal abilities.

Several guidelines for developing an IEP are suggested by researcher J.M. Havey:

- Make decisions based on the needs of the individual child, not “one size fits all.” This includes refraining from having all children with a certain disability in the same setting without considering each case individually, regardless of whether the setting is specialized or mainstreamed.
- The IEP process calls for identification of the special needs of the individual child before a placement decision is made.
- The consideration of individual needs should include the possibility of special “supplementary aids and services.” Those may include resource rooms and itinerant instruction, as well as assistive technology.
- Adhere to procedural guidelines.

It is common for youths to suffer more than one disorder (e.g. serious emotional disabilities in addition to learning disabilities). In fact, the incidence rate of clinical social, emotional, or behavioral problems among students with learning disabilities is up to four times the incidence rate in the population without learning disabilities. Co-morbidity needs to be accurately assessed in order to provide optimal educational and mental health services. (Operational definitions for specific learning disabilities and other disorders are included in the literature review in Appendix B.) In addition, diagnostic evaluations should be performed with consideration that certain communication disorders (e.g. speech/language disorder) may have a physiological or neurological basis, which would alter the prescribed intervention.

For students with serious emotional disabilities, the following three predictors for success in special education programs have been identified:

- enrollment age (the lower the age of identification and enrollment, the higher the chances of success)
- WISC-R verbal IQ not significantly lower than performance IQ; and
- the presence of DSM-III depressive or anxiety disorder.

The use of DSM psychiatric diagnosis has a predictive value, unlike standard behavior checklists, and is considered a more reliable standard baseline for diagnosis. Baseline measures should be employed as standard procedure for identifying and comparing the effects of interventions.

With regard to determining the least restrictive environment (LRE), a delicate balance must be attained. Studies have shown special programs to be more effective than regular classes in improving academic achievement, but detrimental to students' sense of self-concept. In determining the LRE, the team must take into consideration whether a student's behavior will be disruptive to the rest of class to the point of interfering with other students' class work. Policy-makers should establish different levels of restriction according to the degree of behavioral problems. This will allow a better and more efficient distribution of resources among all students with disabilities.

In children with behavioral problems, parents' training and involvement in the IEP is considered essential for a positive outcome. Parents would receive training in behavior modification methods and ancillary therapies. Sustained and continuous programming has proven to be more effective for these youths than episodic intervention, therefore the IEP should include summer programming to avoid regression during the time when school is not in session.

Family members should be encouraged to serve as care coordinators for their child when they are interested and capable. This would be a low- to no-cost intervention that would likely result in improved coordination and quality of care. Continuity of care has been shown to improve diagnostic accuracy and increase patient satisfaction. Turnover of case workers would not be an issue and the parents are likely to be more concerned with monitoring and maintaining their child's continuum of care.

Developing alternatives to out-of-state and residential care placements will improve outcomes

We recommend an independent review of all cases for which residential care in Hawaii or on the mainland are prescribed. It is the education department's policy to wait until a child has failed to improve in at least five local treatment options before placing him or her out of state for treatment. The State of Hawaii has had as many as 105 emotionally disturbed and/or mentally disabled youths placed in out-of-state treatment facilities in recent years (down to 64 as of March 2000); the problem being that intensive services required for severely impaired or troubled youths were not available on the islands.

The Department of Education contends that 63 percent of out-of-state placements are court ordered. However, our experience with juvenile,

family, and dependency courts in numerous jurisdictions is that courts order placements based on recommendations presented to them from caseworkers and agency attorneys. If the report states that there are no reasonable alternatives to residential placement, judges tend to lean toward such an order. Judges tend to not order residential placement when provided with recommendations that offer reasonable and appropriate alternatives.

A special effort is needed by the Legislature and Department of Health to monitor the need for secure beds, either in Hawaii or on the mainland. The Department of Health should assess the feasibility of reducing the number of secure beds for children in the *Felix* class. A report from the *Felix* Monitor's Office suggests that the Departments of Education and Health teams may recommend the intense treatment that has typically been unavailable in Hawaii when that level of care is not absolutely necessary. Our review indicates that case workers appear to be too willing to accept the premise that out-of-state residential treatment is appropriate for some students, when in fact, there is little evidence of benefit from residential treatment. Our case file review indicated that some children were placed in residential care who might have alternatively received intensive crisis services coupled with long-term home based services (see Appendix A). Therapeutic foster care might have also been appropriate for some children placed in residential care. We are aware that in Hawaii, as in other communities, therapeutic foster families are scarce. Thus, the Department of Human Services would have to put special efforts into recruiting therapeutic foster homes. The reliance on residential placement may reduce Department of Human Services efforts to recruit such families.

Here, too, a random trial field evaluation could assess whether there are feasible alternatives to residential care. Such an activity is consistent with the stipulation in the consent decree that services should be the least restrictive. Few of the case records reflected the creative use of such resources as community leaders, extended family, pediatricians, school-based mental health programs, religious or spiritual communities, after-school diversion programs, mentors, creative-expressive interventions, and job training and youth employment programs.

Based on our review of case files and especially discussions with school personnel, there are not enough comprehensive, all encompassing planning meetings to consider local interventions that could meet the needs of the child and family. This underscores the need for emphasizing the "individualization" in the IEP. In addition, community development will counteract the problem of inadequate community-based, family-supportive programs that could be utilized as an alternative to out-of-state placements.

Better wraparound services for children exiting residential care will ease their transition

According to the literature on “best practices,” the IEP should be adapted by age 16 to consider transition to adulthood. Factors for consideration would include instruction, community experience, development of employment skills, and other post-school adult living objectives. Transitional planning is designed to improve a student’s likelihood for employment and independent living. Researchers have found that students making the smoothest transitions to adulthood are those whose parents were closely involved in their IEP. In addition, students who were employed prior to finishing high school were more likely to make a successful transition to post-school life. Our review of case files indicates that this is not being carried out and, was especially prevalent in many cases regarding children who are placed on the mainland.

As indicated earlier, students who receive treatment on the mainland may have difficulty making the transition of returning to the islands. When out-of-state placement is absolutely necessary, special provisions must be made to assist the youth in that respect. One mainland treatment facility, citing the logistical difficulty in including Hawaii parents in meetings regarding the students’ progress, indicated plans to utilize videoconferencing technology. Just as is done with youths who are “aging out” of the system within the State, these mainland video meetings should include representatives of agencies and employment counselors who can offer assistance in finding appropriate situations for youths returning to Hawaii after out-of-state treatment.

Best practices in other states include guidelines for class size and caseload for special education

Policies of other states generally establish a maximum class size of 12 for special education students—smaller size for classes that are integrated with non-disabled students. Guidelines set forth by New York and other states establish the following maximum class sizes:

Non-integrated classes (special education students only):

- For severely disabled students, staff-to-student ratio of one teacher and one educational aide for every five students (with an additional aide when six to nine students are in class, and an additional teacher when students number 10 to 15);
- For students whose needs are moderately intensive, a maximum of eight students with one teacher and at least one paraprofessional aide;

- For students whose needs are highly intensive, a maximum of six are to be placed with one teacher and one paraprofessional aide; and
- For students with severe disabilities (who require mainly habilitation and treatment), a maximum of 12 students with a staff-to-student ratio of 1:3.

Integrated classes (mainstream with some special education students):

- Few states spell out class size guidelines for integrated classes. Iowa designates a maximum of 12 students at the elementary level and 15 at the secondary level.
- In general, it is recommended that the chronological age difference in integrated classes not exceed three years. We are aware that Hawaii recently funded a reduction of class size to 12 for grades K-6 and 15 for grades 7-12. We are also aware of the obvious cost of funding a further reduction to reach levels in other states. We are not recommending that Hawaii fund a further reduction. We present the data on “best practices” regarding class size for the Legislature to consider so that it may consider the cost effectiveness of class size reduction compared to the cost of other interventions that may be required to meet the mandates of the new court order.

Early intervention is the most cost-effective practice dealing with emotional disabilities

The final “best practices” recommendation is that early intervention produces the most cost-effective and effective interventions for children with serious emotional disabilities. As Hawaii continues to develop its continuum of care, it should emphasize efforts for early identification of children with serious emotional disabilities.

Providing service vouchers may help improve effectiveness of services

The Departments of Education and Health should assess the feasibility of providing service vouchers to parents of children in the *Felix* class. The use of service vouchers could assess the effectiveness of actually empowering parents and caretakers who have children in the *Felix* class. Service vouchers would also assess the viability of a market-driven approach to service provision.

Successful programs within the State are not readily adaptable as best practices models

The practices used in school complexes that have achieved satisfactory levels of performance as measured by Service Testing are not easily transferred to school complexes that are not in compliance with the standards measured by Service Testing.

We examined particularly constructive and effective efforts that have statewide implications (i.e. are there local efforts that could be used as a model for statewide compliance efforts?). Unfortunately, the local efforts cannot be used as a model for statewide compliance efforts. Local school complexes that are in compliance are relatively small, serve a homogeneous population of children, and have developed good communications between principals and providers. Complexes that are in compliance have good communication and coordination with the Department of Health, while complexes not in compliance reported to us that they did not have good communications and coordination with the Department of Health. Coordination between school complexes and the Department of Health, particularly regarding “high end” cases, is the most important component of bringing about compliance with the standards set by Service Testing.

Inadequate management controls prevent clear assessments of cost and appropriateness of services provided under the Felix consent decree

Felix-related costs and services continue to be inconsistently reported. As a result, the costs to deliver services cannot be clearly identified. In addition, the failure to separate essential services from new and experimental services makes it difficult to assess the appropriateness of the services that are being provided.

Funding for the implementation of the *Felix* decree is not reported consistently by the Department of Health and the Department of Education

Based on our discussion with the Auditor’s staff, administrators at the Departments of Education and Health, and our own analysis of the budget data provided to us from the Departments of Education and Health, we found no consistency in the manner in which costs are reported. The Department of Education combines costs for administration and services to *Felix* class children with administrative and service costs for other special education children. The Department of Health budget combines costs for compliance with the consent decree with costs associated with delivery of services to the *Felix* class. In addition, the Department of Health includes the costs for new and experimental services, such as Multisystemic Therapy (MST), with the costs for traditional mental health services. Thus, it is impossible to examine the budgets and determine the costs of core and essential services versus the costs of new, experimental, and non-essential services. Such segregation is essential for controlling cost effectiveness of alternative treatment options.

The lack of clear and consistent budgets and expenditures reporting results in a situation in which it is impossible to determine the costs of providing services to the *Felix* class.

Figure 1 represents the number of children in the *Felix* class, according to data from the Department of Education and Department of Health as supplied to us by the Office of the Auditor. Figure 2 represents data on costs provided by the Office of the Court Monitor, derived from maintenance of effort reports submitted by the departments.

Figure 1
***Felix* Class Size, Fiscal Years 1994-2000**

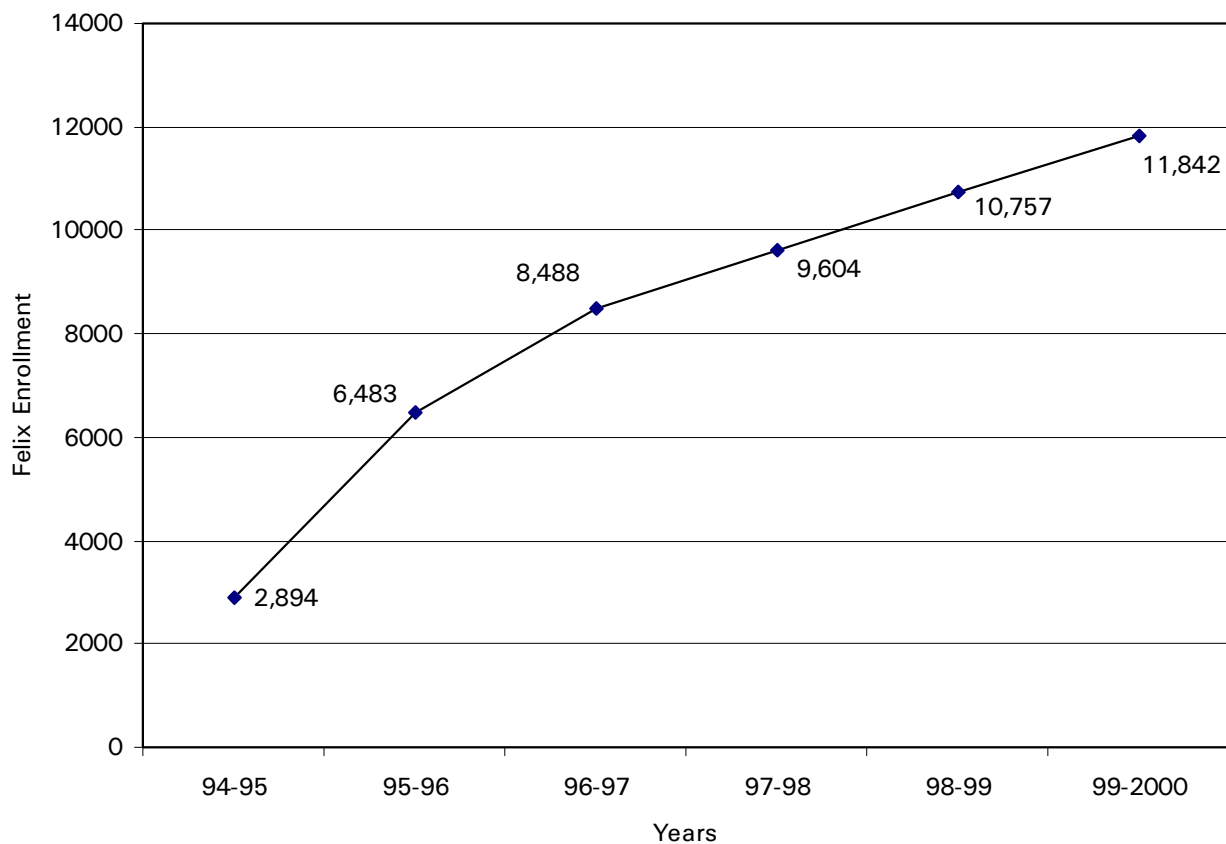
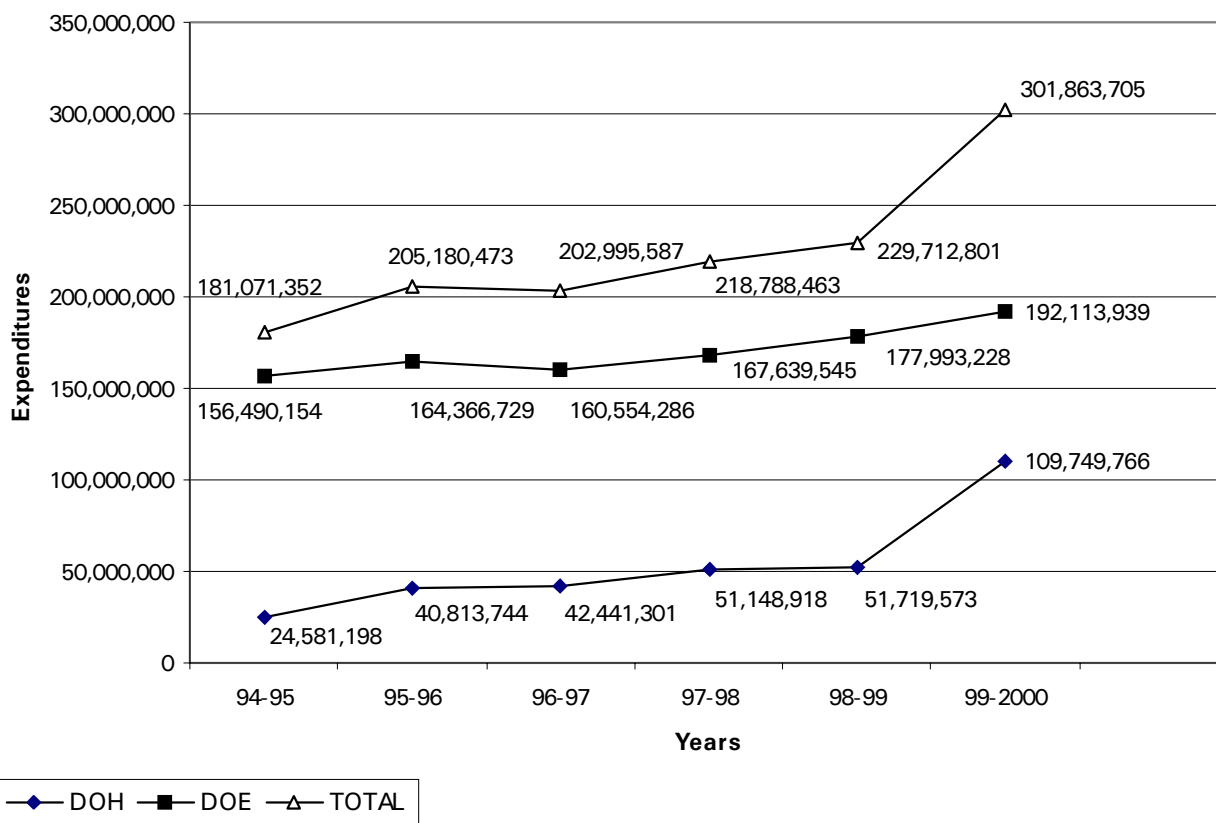


Figure 2
***Felix* Expenditures, Fiscal Years 1994-2000**



NOTE 1: The Department of Education expenditure data included Special Education students as well as students in the *Felix* class but excluded costs of employee benefits.

NOTE 2: Department of Health cost figures included Foster care children, not all of whom are in the *Felix* class and excluded costs of employee benefits.

NOTE 3: Expenditure data for FY1999-2000 were not available.

Core and essential services are not differentiated from new and experimental services

There is no segregation of the costs for establishing and providing services, and for assessing compliance with the decree. Further, there is no segregation of core and essential services from new and experimental services. This results in the impression that all services are essential and must be funded.

An example of this false impression situation is the request to the 2000 legislative session from the Department of Health for an emergency appropriation, which included \$1.2 million for Multisystemic Therapy. MST has been used and rigorously evaluated with juveniles involved in delinquency. It has never been used for sex offenders or other children with the same category of special education or mental health needs as *Felix* class children. The health department implemented MST in January 2000, before the emergency appropriation was approved. By including a funding request for MST in an emergency request, the Department of Health implies that MST is an essential service needed to comply with the terms of the consent decree. MST is an experimental service that is not used by other school districts in the country for IDEA or Section 504 students and thus could not be considered an “essential” service required by the consent decree.

A second example is the decision to place children in residential facilities that are out of state rather than seeking to place children in therapeutic foster homes in Hawaii (this would require recruiting families to serve as therapeutic foster families). There is no scientific evidence that residential placement is superior, in terms of outcome, to therapeutic foster placement. Granted, therapeutic foster families would have to be recruited in Hawaii, but it appears that the choice was made to use residential placement as opposed to recruiting and using therapeutic foster families.

Our interviews with department officials and school administrators indicated that evidence-based models for selecting and implementing services were not in use in Hawaii.

The Departments of Education and Health Continue to Experience Coordinating Effort Difficulties

An interagency management information system is not in place

The coordination for the delivery of *Felix*-related services between the Departments of Education and Health continues to be inconsistent. There is evidence of good coordination at the state level and in some school complexes. However, in other complexes and different departmental levels, the communication and coordination is lacking. As a result, the departments continue to experience problems in effectively delivering needed services.

As of June 30, 2000, the Departments of Education and Health did not have a “seamless” management information system (MIS) as required by the terms of the consent decree. A representative of the Department of Education in January 2000 informed us that the department’s MIS would not be operational by June 30, 2000.

The Department of Education continues to be in the process of developing a MIS system. The Department of Health claims to have an appropriate system on hand. However, our experience in attempting to secure sample case files indicates to us that a smoothly functioning MIS system does not exist in either agency. The department daily changed its estimates of the number of children currently on the mainland that were scheduled to be returned to a newly constructed residential facility. The Departments of Education and Health were not able to quickly and correctly locate sample files, retrieve the files, and deliver them for our review. Neither department was able to deliver simple descriptive data about the size of the *Felix* class or the budget expenses for each fiscal year of the consent decree.

Coordination problems persist

We found evidence of good coordination between the Departments of Education and Health at the state level, and evidence that good coordination between these agencies exists in the complexes that are in compliance with the *Felix* decree. However, we also discovered instances of lack of communication and coordination for some key programs and activities. During the course of our work, a proposal was developed by the Department of Education to provide an intensive residential treatment program in four youth correctional centers (the juvenile detention center in Honolulu, the Hawaii Youth Correctional Facility (HYCF), and the HYCF Canoe House, and Olomana Youth Center). While the proposal may have merit and be designed to improve services or better answer unmet needs, the director of the Office of Youth Services (the state youth corrections agency) had no knowledge of it until he received a written draft. The director also reported that the Family Court was unaware that such a proposal had been developed until it surfaced in writing, even though the Family Court in Honolulu administers the juvenile detention center. We also learned of other examples of programs being developed in one agency that were unknown to relevant state agencies, such as the construction of a residential facility in Pearl City.

The analysis of the sample of case files provided to us also revealed a similar absence of coordinated planning and implementation of services. Apart from the Departments of Education and Health, there was often little or no documentation about or from agencies that had custody or jurisdiction over *Felix* class cases. It was also unclear from many of the case files reviewed, the number and types of services that a child or family might be receiving from all of the various agencies involved in a particular case, and who had ultimate responsibility for managing and coordinating the services.

***Personnel problems
continue to make the
maintenance of effort
problematic***

We interviewed a number of school principals, counselors, teachers, and agency administrators in Hawaii, and they all voiced concern about personnel problems and the inability of their school, school complex, and the State to maintain the needed effort to provide services to *Felix* eligible children. This concern was echoed in the consent decree issued by the federal district court in June 2000. School personnel in particular were concerned about the lack of key personnel, especially school psychologists and speech therapists, and about the heavy workload imposed by the mandate to provide services as well as the lack of personnel to provide mandated services.

The Department of Health has been creative in adding case coordinators to the system of care. However, the system still has too few important specialists, including sufficient school psychologists and speech therapists. Principals report that they are experiencing significant turnover among key personnel. The lack of personnel creates a vicious circle in which case loads and workloads are high, prompting personnel to leave their positions, creating even higher workloads and even more turnover. Such turnover reduces productivity and increases the cost of the system of care.

Perhaps the most difficult task facing Hawaii is the shortage of trained mental health and special education personnel to meet the needs of the more than 10,000 children already in the *Felix* class. Past and current efforts have not produced a workforce large enough and stable enough to meet the *Felix* class' need for services. In addition, turnover negatively impacts continuity of care. Continuity of care has been shown to be a low to no cost intervention that improves diagnostic accuracy, quality of care, and patient satisfaction.

This problem is not unique to Hawaii or to the area of special education. Personnel shortages have always been a limiting factor in meeting social service and mental health needs in the community. There is no single or simple means to address this problem.

The Departments of Education and Health can expand their efforts beyond the stipulations of the August 2, 2000 court order regarding recruitment and retention of teachers, and work with the University of Hawaii to develop loan forgiveness and tuition remission programs as recruitment incentives for the training of necessary personnel—with the requirement that the beneficiaries work in the state for a certain period of time. In our experience, the use of national recruitment firms is useful in the short run in filling positions, but such recruitment efforts are not cost-effective in the long term. Also, incentives should be developed to identify and encourage undergraduate students from Hawaii attending colleges and universities on the mainland to return and work with *Felix* cases.

The State of Hawaii should develop an indigenous capacity to recruit and retain critical personnel. The Legislature could fund stipends for school psychologists and other professionals on the mainland to support field placements in Hawaii schools and mental health agencies. The Legislature and the University of Hawaii could also fund exchange programs and internships that would fund undergraduate students from the mainland to spend one or more semesters at the University of Hawaii studying and working in the areas of speech pathology, school psychology, and other needed specialization. The Legislature can also fund scholarships for high school juniors and seniors who are interested in pursuing careers in critical areas. Such a program could fund summer study between the junior and senior year, between the senior year and enrollment at the University of Hawaii, and then provide scholarship support for college and graduate school.

Recommendations

1. The Legislature should consider establishing a statutory working definition for special education eligibility.
2. The Departments of Education and Health should adopt a best practices approach for designing and funding programs.
3. The State of Hawaii should establish a credible and independent capacity to evaluate services and programs provided to children in Hawaii. Such a capacity should be mandated by legislation.
4. The Departments of Education and Health should assess the feasibility of providing service vouchers to parents of children in the *Felix* class.
5. An independent evaluator, such as the Center for Service and Program Evaluation, proposed above, should assess the use of service vouchers, and the service voucher program should be established using a random assignment procedure, so that appropriate evaluations can be carried out.
6. The Departments of Education and Health should collaborate with the University of Hawaii to address the personnel needs required to provide adequate and effective services to children in the *Felix* Class.
7. The Departments of Education and Health must develop mechanisms that will ensure that coordination and cooperation take place at the state and local levels with other entities such as the Hawaii Office of Youth Services, the Department of Human Services and the Judiciary (e.g. Family Court). The same is true at the individual case level.

Conclusions

The situation in Hawaii regarding compliance with the *Felix* consent decree has been fluid and dynamic during the five months we conducted our fieldwork and the subsequent five months leading to the final draft of this report. A few weeks after we completed fieldwork, the federal judge found the State in contempt. Before the final draft of the report was completed, the judge issued a stipulation approving the monitor's recommendations and order.

We offer the following final observations and opinions based on our study and review of the August 2, 2000 court order.

The court order includes more than 140 recommendations, benchmarks, and deadlines. To date, the State has had difficulty meeting deadlines. More importantly, state officials have, in our opinion, been unrealistic about the progress they were making. Administrators and attorneys assured us in Spring 2000 that because they had made progress in meeting the stipulations of the consent decree, the decree would be lifted June 30, 2000. This did not occur. The State was found in contempt and a new order with new benchmarks and deadline was issued. The Legislature would be advised to be skeptical about whether the State can meet the new deadlines and benchmarks, and should closely monitor progress in meeting benchmarks. The consequences of not meeting the benchmarks and deadlines this time may be *grave*. If the State does not comply with these benchmarks and deadlines, the court will likely give the monitor more power, including expenditure of funds, hiring of personnel, etc. From our position, we see the beginning of a process of more and more power being shifted from the executive branch of government and its agencies to the court and court officers. In short, the State is moving closer to being in *de jure* receivership and may now actually be in *de facto* receivership. Item 130 (page 19) of the court monitor's July 14, 2000 "*Monitor's Recommendations for Achieving and Sustaining Compliance with IDEA and a Functional System of Care as Specified in the Felix v. Cayetano Decree*" clearly indicates this can occur. In our opinion, failure to comply with the current order could result in policy, management, and fiscal authority regarding the *Felix* case to be shifted to the federal court and more specifically to the monitor.

Our reading of the court order indicates that it will be in effect until the State is in full compliance. We pointed out to those whom we met as early as January 2000 that the history of similar class action suits in many other states is that the states are under court order, monitoring, and special masters for many years. Those whom we met believed we were "Cassandras." Nonetheless, the Legislature would be wise to be skeptical about assertions that the State will be free of the court order in matter of a year or two.

The court monitor's July 14, 2000 recommendations further state that not all leaders in the schools, including Department of Education personnel, are committed to implementing the court order. Given that the education department has had six years to educate school personnel as to the importance of the *Felix* case, we are concerned that school personnel and administrators, and education department staff themselves, are not yet committed. Beyond the benchmarks, the Legislature needs to be concerned about how the department will communicate to its staff the importance of complying with the court order.

As noted above, we remain concerned about the implementation and recommended expansion of MST. Again, we feel it important for the Legislature to know that there is no credible evidence that MST works with a mental health population. We do agree with the monitor regarding his observation that children are being recommended by the treatment teams to more restricted services than children need. We also agree with the monitor's statement that children are being referred to therapists and seem to be getting "unfocused therapy." We also agree that attention deficit hyperactivity disorder (ADHD) diagnosed children could benefit from medications. Our case file reviews came to the same conclusions.

Appendix A

**Analysis and Review of Case Studies
Involving Children Qualifying for Services Under
Felix Consent Decree**

June 2, 2000
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Context of Review

With the *Felix* Consent Decree approval in October of 1994, it was mandated that a system of care be instituted in Hawaii for a class of children that satisfy either IDEA or Section 504 of the Rehabilitation Act of 1973. Because some of the criteria were specified therein, the plaintiff class was described only as:

...all children and adolescents with disabilities residing in Hawaii, from birth to 20 years of age who are eligible for and in need of education and mental health services.

While this definition appears exceptionally broad and does not lend itself easily to the development of inclusion/exclusion criteria, it appears to honor the principles of the original statutes, which continually undergo revision as case law evolves. For example, IDEA does not ensure an optimal education—only a free, appropriate, and adequate education program. Judges clearly prefer “usefulness and adequacy” to “best practices and ideal outcome.” Mental health services per se are not an entitlement, but it is mandated that children should have full access to mental health services regardless of disability status. Mental health services become an entitlement only when the child is identified as having a disability, and if the emotional or behavioral disorder presents a barrier to learning. These standards are the relevant context of the chart reviews.

Felix does establish the expectation that services will be provided in the least restrictive setting, and that a culturally competent, child- and adolescent-centered, family-focused, and community-based coordinated system of care will be implemented. There is the expectation that all services will embody CASSP principles. Understood in this context, *Felix* is designed to ensure the implementation of a federally mandated system of care for children and adolescents who are residents of the State of Hawaii and who are eligible for and in need of special education and/or mental health services. There is the assumption that eligibility criteria will be considered with the principle of reasonableness and even-handedness, but the process to define the eligibility with respect to reasonableness is ongoing. These considerations are incorporated in the assessment of services rendered in the State of Hawaii.

Findings

Overall, this record review did not reveal excessive or abusive use either of the working definition for inclusion in the class or treatment services. The children and adolescents whose charts were reviewed did not lack criteria for disability nor for inclusion in special education. The services they received were largely appropriate (see comments below) and would meet the standard of care. Many of the cases reviewed demonstrated considerable improvement in the availability and delivery of services around 1996, documented additionally with the increased coordination of various services. Services which were simply not available in the mid-1990s were often available several years later, or consultants were retained to assist the children, adolescents, and families. It was clear from this review that **significant progress had been made in the implementation of a system of care for children with mental health and special education needs over the course of the past five years.**

In an effort to understand probable prevalence of children who might meet the criteria of the *Felix* class, we can utilize the recent Surgeon General's Report on Mental Health, which acknowledged that about 6 to 9 million children and adolescents have "serious emotional disturbances," accounting for 9% to 13% of all children. Given that this prevalence reflects the most severe mental health disorders and does not include any other disabilities which pose significant barriers to learning, this prevalence rate applied to the 1999 KIDS COUNT Hawaii data (approximately 326,000 children and adolescents under the age of 19 in the state) suggests that the approximately **10,000 *Felix* class enrollees most likely reflect an under-recognition and under-inclusion** in the class receiving necessary services at this time. Given the likelihood that **this class will continue to grow in the next decade**, the following recommendations and observations are offered, based on the review of the records and the recognition of areas for improvement and innovation.

The children and adolescents of Hawaii need access to mental health and special education services, and they will **need to be provided at reduced cost through the innovative and efficient use of resources within the community**. This will require a visionary—a leader who will gather information, generate priorities and ideas, develop a community-based strategy, and generate the support of community members to implement the approach. The current paradigm for intervention appears to be reactive, diagnosis-dependent, and formulaic (*e.g.* sexually aggressive youth with little response to residential treatment on a generic unit are moved to a facility in North Carolina, and family members are transported there for treatment sessions). Few of the records reflected the creative use of resources such as community leaders or members, extended family, school-based mental health programs, the religious or spiritual community, after school diversion programs, mentors, creative-expressive interventions, and job training and youth employment programs.

Currently, the conceptual approach, while meeting the standard of care in most respects, appears to lack innovation or creativity, serving to harm the children who are most in need of an individualized approach to receiving services in the least restrictive environment. Rather than consolidating categorical programs and integrating efforts in an effort to preserve and build mental health services, many professionals and agencies appear to have accentuated this problem by responding to narrowly targeted initiatives and building service delivery systems in subspecialty areas—adolescents who have disorders such as sexually aggressive behaviors and substance abuse. Regardless of the system within which it is based, there is a dearth of generic community and strength-based, family-friendly programs with significant family leadership in its governance. Beyond the dearth of innovation, there is limited evidence base to the interventions utilized.

For example, professionals appear to accept the premise that out-of-state residential treatment is optimal for some youths, such as those with severe oppositional defiance or aggressiveness. (In fact, there is little evidence of the efficacy of inpatient or residential treatment.) There is little evidence of interagency planning meetings or case conferences to explore treatment options and to develop a strategy that meets the needs of the child and family, while building capability within the state. **Sending a child or adolescent out of Hawaii is neither proactive in building community networks and linkages, nor is it cost-effective.** These youths will return to the state years later feeling alienated, and without community connections, employment or the necessary transitions to adulthood. Furthermore, a reliance on a remote external agency to 'fix' the youth, make recommendations regarding length of treatment, design outcome measures (*e.g.* "needs to develop

‘victim empathy’ before discharge”), is problematic in terms of capacity building as well as cultural and contextual sensitivity and relevance. There appears to be no basis for long-term out-of-state placement, and no evidence base that it is superior to a carefully crafted and supervised rehabilitation or vocational training program with respect to outcome. Out-of-state services, bereft of cultural context for many of these youths and their families, is far from being the least restrictive setting.

Another area of poorly conceived human resource utilization is **the automatic use of non-family members and previously uninvolved professionals for the coordination of care**. While care coordinators often play a prominent role in service coordination, some families who received treatment were both capable of and motivated to coordinate their own services, and should have been supported in doing so. Service vouchers and other creative interventions can empower families to retain control and make choices that will yield the best compliance and outcome. **Health care providers such as the family or pediatric practitioner were rarely involved in such tasks as disposition planning, coordination of care, or interagency communications**. This reduced the coordination of care, particularly for those children with medical issues in need of further diagnostic or therapeutic interventions for which the health care provider was well positioned to provide both coordination and continuity of care. Improving the continuity of care is a low- to no-cost intervention which will immediately result in improved coordination and quality of care. Continuity of care is associated with increased diagnostic accuracy, as well as patient satisfaction. Chart reviews demonstrated significant turnover of providers, particularly (and paradoxically) care coordinators.

While evaluating practitioners most often recommended individual and family therapy, care coordination, and therapeutic staff support in more severe situations, **there was little effort to tailor a treatment program to the child’s and family’s needs** (e.g. group therapy with other adolescents struggling with such issues as identity and separation/individuation). While it is widely recognized that family support and education lead to improved family satisfaction, reduced stress, increase in parenting skills, and improved outcomes for children, there was little evidence that family support and learning, family support networks, family coaches/advocates were being utilized. Family members trained as staff members, computer supported family based learning, teleconferencing, and family-responsive initiatives should be incorporated as services come together. Families will likely wish to see creative, expressive arts and mentoring programs responsive to the needs of their community’s children. Public/private partnerships and external funding sources could be sought to build capacities within neighborhoods and communities. Furthermore, **there was little use of the community’s natural supports** (e.g. extended family, community elders, the pediatrician).

The general approach appears to be psychologist-driven rather than interdisciplinary in nature. Psychologists appeared to be utilized to diagnose psychiatric conditions. Assessments most often appeared to be thorough and frequent. However, while medical symptoms and conditions were often noted, there was no recommendation for follow-up diagnostic evaluations or treatment. For example, several children had persistent, severe headaches which were never addressed beyond inclusion in the history. **The possibility of a physiological cause was almost completely overlooked**, and psychopharmacological interventions were infrequent, although the psychologists freely made such diagnoses as major depressive disorder, which would normally require medication. This does not appear to be concordant with the dramatically changed landscape for children’s mental health services due to the confluence of several factors. The “decade of the brain” has witnessed the

increased use of psychotropic medications and further development of biological psychiatry. Advances in psychopharmacology have led to many breakthrough treatments, particularly in mood disorders among adults. Psychotropic medications are now used with children as well (although extrapolation of safety and efficacy data from adults is not always valid). **Many of the *Felix* class children would have benefited from the earlier consideration of medications, but did not, because of the psychologist's paradigm or limited knowledge base.**

Furthermore, given that the primary care provider is often very involved in the assessment and treatment of the behavioral/emotional problem or disability affecting education, close collaboration with the pediatric care provider needs to be incorporated in a meaningful way. There were few mentions of the primary care provider or of the child and adolescent psychiatrist. **Contracting therapists often appeared to function in a vacuum, with some coordination and communication with school staff, but little with primary care providers, specialty care physicians, child protective services, juvenile justice, and vocational rehabilitation.**

It is important to note that until several years ago, there were only three child psychiatrists at the University of Hawaii Medical Center, whereas there are now 16 attending child and adolescent psychiatrists serving as medical directors for all of the family guidance centers (previously only one had a medical presence) and traveling within all of the islands. There is a new triple board certification program which graduated the first trainee last July. This program will certainly enhance collaboration between pediatricians and child psychiatrists. New graduates are native Hawaiians and recipients of payback programs from the Department of Health, ensuring community service work in Hawaii.

The general treatment approach was neither family-driven nor child-centered. Family-driven does not mean responsive to a family's increasingly urgent requests for help, but rather an overall philosophy—including consumer-driven innovative behavioral health models based in accessible community settings and a strength based approach to family-centered care. To implement this approach, family leadership would need to be included on the governance boards of institutions, community based services, and advisory boards of the service delivery systems. Families would help design the optimal services, including family support services such as child support and broad support at work. Family-based interventions are needed to provide interventions in domestic violence, physical and sexual abuse, family alcoholism and addiction, and parental depression.

There also appeared to be little innovation in the inclusion and empowerment of the child in his/her treatment team and IEP evaluation team, with the presumed exception of those few children reviewed who had either a child advocate or a guardian *ad litem*. **In no single case was the child or adolescent's opinion solicited, utilized, and documented as a key factor in the decision-making process** (including children who were separated from their families and moved out-of-state).

A system of care model holds promise for children with special needs, but the *Felix* class has not benefited from the integration of mental health, special education, and other health and social services. The system of care model was proposed by Stroul and Friedman (1986) and refined by Kutash and Rivera (1996). This model encompasses coordination of multiple services to meet the needs of children and adolescents with mental health problems while remaining at home and in their

communities to preserve the family unit. The components within a system of care include mental health, social services, education, health care, substance abuse prevention and treatment, vocational and recreational opportunities and “operational services” (support services, such as case management, support groups, legal aid that enable the entire system to operate). “System of Care” studies show that integrated systems provide better access to treatment, greater continuity of care, and higher client satisfaction. The members of this class did not appear to benefit from coordination with the Department of Human Services, and children involved with child protection appeared to fare the worst with respect to outcomes and off-island placements (despite foster parents’ efforts to have their foster children return prior to ‘aging out’).

The Department of Human Services appeared to be the most consistently absent member at the table, with vocational rehabilitation being a close second. It was unclear how and why this has evolved, particularly given the critical nature of these two systems in ensuring the child’s safety and ultimate contribution to the community. While the *Felix* class does not address the responsibility of the Department of Human Services, the lack of collaboration and participation in the treatment process will sabotage any efforts made by the Departments of Health and Education with these most seriously impaired youths. Senior administration of these agencies will need to activate this critical involvement and remedy this situation promptly.

Juvenile Justice was an invisible participant in major decisions on behalf of the youths who are involved with the law. Often, there is little documentation of the legal proceedings or deliberations that move a child into the *Felix* class when he/she previously was not identified as such (*e.g.* sexually aggressive youth). It is doubtful that the mental health provider or special educator has shared information with the judge or received information regarding the possible consequences of the youth’s behaviors. This limits the development of diversionary programs or culturally attuned alternative sentencing. While coordination with juvenile justice may improve with the addition of two full-time child psychiatrists at the Youth Study Center, this problem appears more systemic in nature and would likely require a substantial intervention to alter the paradigm.

Because child psychiatric disorders are recurrent, chronic, and affect child and family functioning, they should be expected to require higher health care utilization. Behavioral health care should be required to demonstrate coordination and a system of care as described in the *Felix* consent decree. Agencies that respond to financial incentives to designate rather than assume responsibility for necessary care should anticipate penalties. It is unclear if unnecessary cost-shifting will occur with the recent discrimination of low-end and high-end cases—a seemingly arbitrary designation. Privatization of many intervention services may have addressed the need to increase the availability of providers, but it may also serve to limit the implementation of systemic change and innovation in service delivery. **Funding streams for children’s mental health issues should be united, along with a consolidated—rather than categorical—system of care.** The inclusion of only the Departments of Health and Education in the *Felix* Consent Decree does not maximally support the cooperation and collaboration of the Departments of Human Services, Juvenile Justice, and the Office of Vocational Rehabilitation in the effort to coordinate and develop a system of care.

While special enabling programs must be a component of a system of care for complex and distinct sub-populations (*e.g.* children with severe and persistent emotional/behavioral problems, multiply-

disabled children with psychiatric disorders, children in foster care, or children of parents with serious mental illness or substance abuse disorders), policy efforts should recognize different levels of solutions for those children who have minimal, moderate, and severe problems. With an improved system of care for severely affected children, resources can be better distributed to less affected children. **While the system is not completely hijacked by the high severity members of the class currently, it will become so increasingly, as these class members are the ones who ultimately utilize services maximally.** The community at large would benefit from public health interventions to increase awareness and decrease the stigma associated with mental health problems and barriers to learning. **This public health campaign will facilitate the development of services in state and reduce the pressure to remove the child from the island.**

School-based centers appear to be an untapped potential setting in which to reduce barriers to learning, provide access to mental health care to children, and foster the development of a system of care. There was no evidence of the existence of a comprehensive approach to integrate programs or place them within a system of care or continuum of interventions addressing behavioral, learning, and emotional problems that affect development and learning. The use of the school as a community and family center was also not evident in this review.

There is limited evidence regarding the effectiveness of mental health and special education services in the State of Hawaii. Studying the interventions utilized in Hawaii in real-life settings is essential. Measures of function, outcome, quality, readiness for change, parental and family function, satisfaction with services, systems coordination, vocational outcome, and disability status need to be developed to fully capture the complexity of the factors that affect children's mental health and educational outcomes. **Research on the cost-effectiveness of children's mental health and special education programs is also needed to analyze costs in terms of long-term outcomes, impact on other systems of care (e.g. juvenile justice and foster care) and effects on other populations.** Long-term studies would assist in developing a culturally relevant evidence base for decision-making, and clarify the extent to which early and competent mental health and special education interventions prevent or reduce adult mental health problems, unemployment or underemployment, and persistent disability.

Appendix B

DEFINITIONS OF DISABILITIES
Literature Review on Issues Pertaining
to the
***Felix* Consent Decree**

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The Individuals with Disabilities in Education Act (IDEA) is related to children who are “identified” as having a disability, whereas under Section 504 of the Rehabilitation Act of 1973, a child may just be “regarded” as disabled (Schacht and Hanson, 1999).

OPERATIONAL DEFINITIONS

The legal definitions proposed by Federal legislation are somewhat obscure, and tend to emphasize the distinctiveness of disabilities from each other. However, existing research tends to suggest the co-morbidity of various disabilities on the one hand, and the difficulty of setting clear criteria for various disabilities on the other. For example, Kavale and Colleagues (1991) argue that the poor state of learning disabilities theory prohibits the development of meaningful operational definitions.

Thus, this discussion attempts to synthesize the literature on operational definitions, while emphasizing practices best fitting policy decisions. Though such practices are far from being “best practices,” in terms of representing the conceptual and methodological complexity of these issues, they are best for setting up clear and feasible operational definitions in service of policy decisions. In other words, until research in the field crystallizes to provide better theoretical and operational understanding of the relationships between various disabilities and their identification, the current definitional practices, though admittedly arbitrary, are the best that are available in order to serve this population of children. For most, if not all, operational definitions, the common practice is to use comparative scores, comparing between academic achievement and some standardized average score. Given the lack of clear legal definitions, such practices follow the guidelines set up by federal authorities, such as the Social Security Administration’s definition of marked impairment as an impairment resulting in two standard deviations below the population mean on standardized measures (Schacht and Hanson, 1999).

Learning Disabilities

The definition of Learning Disabilities (LD) has been contested vehemently on theoretical and conceptual bases for more than 10 years (Hammill, Leigh, McNutt and Larsen, 1990; Swanson, 1991). Several problems are related to the attempt to define learning disabilities, as they are not a homogeneous group of disabilities. The definition issued by the National Joint Committee for Learning Disabilities (NJCLD) in 1981 (Hammill et al, 1987) states:

“Learning disabilities” is a generic term that refers to a heterogeneous group of disorders manifested by significant difficulties in the acquisition and use of listening, speaking, reading, writing, reasoning or mathematical abilities. These disorders are intrinsic to the individual and presumed to be due to central nervous system dysfunction. (Hammill et al, 1987).

Towards An Operational Definition of Learning Disabilities

Swanson (1991) suggests that a realistic approach to the operationalization of learning disabilities would be to restrict such definitions in terms of a narrow range of operations. Morrisson and Siegel (1991) suggest the following definition for learning disabilities:

IQ scores equal to or above 80 and one or more of the following:

1. Wide Range Achievement Test (WRAT) reading subset scores equal to or below the 25th percentile
2. WRAT arithmetic subset score equal or below the 25th percentile and WRAT reading scores equal to or above the mean on the Parent or Teacher Questionnaire (Coners Parent and Teacher Rating Scales).

Swanson (1991) comments that such a definition captures three high incidence disorders within learning abilities: reading, arithmetic and attention.

A more common type of operational definition focuses on the discrepancy between potential (as measured by IQ) and achievement. Mercer, King-Sears and Mercer (1990), report that 86% of the states require some sort of discrepancy test, although there is variability between states in terms of both the magnitude of discrepancy and the tests used for establishing the discrepancy. Thus this type of operational definition seems to be the one preferred by policy makers, and is compatible with current policy of the Department of Education of Hawaii (MacMillan, Gresham and Bocian, 1998; Gronna, Jenkins and Chin-Chance, 1998). Such scores are calculated by comparing the potential of the student, using norm-based IQ scores (e.g. WISC-III) with performance scores (such as comparing average grade achievement of the student with a standardized norm-based average for age-group); or specific achievement scores such as the WRAT test (Swanson, 1991).

Outcomes and Best Practices for Learning Disabilities

While most states have some clear operational definition of learning disabilities, based on discrepancy scores (Mercer, King-Sears and Mercer, 1990), it appears that one may find discrepancy between that definition and the one actually practiced by specific schools. In a study carried out in California by MacMillan, Gresham and Bocian (1998), more than half the students defined as learning disabled by the schools did not reach the discrepancy level (22 points) between IQ and WRAT-R, as defined by state regulations. Examining the students defined as learning disabled by the schools, the researchers discovered that schools based their definition of learning disability on low absolute achievement rather than by using norm-based tests. Furthermore, for children who showed a discrepancy of more than 22 points, but were not defined as learning disabled, it was found that those students had relatively high levels of school achievement, despite exhibiting the required 22-point discrepancy. In other words, those students were achieving higher than classmates, but still operating below full potential.

Since the enactment of IDEA, there has been an enormous acceleration of the number of children defined as having a learning disability. In the academic years 1976-77 and 1992-93, the number of children identified and served as learning disabled increased by 198%, while the number of children identified and served as mentally retarded has decreased by 41%. Overall, more than 52% of the children with disabilities served under IDEA are defined as learning disabled (MacMillan, Gresham & Bocian, 1998). MacMillan and colleagues recounted interviews with school personnel that may explain the discrepancy. From the point of view of services available, there was no advantage to identifying students as Mentally Retarded, while the label of Learning Disabled was more acceptable for students and parents alike.

SERIOUS EMOTIONAL DISABILITY/EMOTIONAL-BEHAVIORAL DISTURBANCE

Emotional/Behavioral Disabilities (defined under IDEA as Serious Emotional Disabilities), include myriad emotional disturbances and mental health conditions that may occur in one of three functional areas: emotional, behavioral or interpersonal. Essentially, all psychiatric disorders that have their onset during school-age years may be included. These include: Tourette's syndrome, schizophrenia and other psychotic disorders, major depressive disorder, dysthymic disorder, bipolar disorder, cyclothymic disorder, panic disorder, social phobia, obsessive-compulsive disorder, post-traumatic stress disorder, acute stress and adjustment disorder, generalized anxiety disorder, somatization disorder, pain disorder, hypochondriasis, body dysmorphic disorder, dissociative disorder, anorexia nervosa/bulimia, and impulse-control disorder. Aside from those, the definition may include mental disorders due to general medical conditions, substance-related disorders, sexual and gender identity disorders, personality disorders, and a variety of less severe disorders such as social maladjustment. Not all those disorders are necessarily part of the IDEA definition, as will be discussed below.

Serious Emotional Disabilities (SED) may exist concomitantly with other disabilities, such as learning disabilities, mental retardation and autism. There is growing evidence that the co-morbidity of SED with learning disabilities is quite high, and national organizations and coalitions such as NCJLD (National Joint Committee on Learning Disabilities) and the NMHSEC (National Mental Health and Special Education Coalition) have incorporated the possibilities into their respective definitions of Learning Disabilities and Serious Emotional disorders.

Summarizing extensive studies, Rock, Fessler and Church (1997), found that between 24% and 52% of children with learning disabilities have clinical social, emotional, or behavioral problems. This incidence rate is up to four times the incidence rate for the population without learning disabilities. Learning disabilities or severe learning problems among students with SED are estimated between 38% and 75% (Rock, Fessler, and Church, 1997). The Fifteenth Annual Report to Congress on the Implementation of IDEA (1993, cf. Rock, Fessler and Church, 1997) found that a substantial number of students initially classified with SED were being reclassified as having learning disabilities. One

reason for the practice of reclassification is the discouraging wording of IDEA towards comorbidity of disabilities (see below). Whatever the reason, “the reclassification may be further indication for the overlapping symptoms of those two categories, and/or problems with identification procedures resulting from Federal legislation” (Rock, Fessler, and Church, 1997).

Towards an Operational Definition of Serious Emotional Disability

IDEA specifies the need to construct an Individualized Educational Program (IEP) for children with Serious Emotional Disability or disturbance (SED), to the extent that such a disturbance impacts the educational achievement of the child. However, both the definition of SED and the relationship between SED and educational achievement are highly unspecified and vague.

The definition specifies the following (Wordich, Stobo and Trca, 1998):

1. *(SED) means a condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree that adversely affects a child's educational performance:*
 - a. *An inability to learn that cannot be explained by intellectual, sensory or health factors*
 - b. *An inability to build or maintain satisfactory interpersonal relationships with peers and teachers*
 - c. *Inappropriate types of behavior or feelings under normal circumstances*
 - d. *A general pervasive mood of unhappiness or depression*
 - e. *A tendency to develop physical symptoms or fears associated with personal or school problems*
2. *The term (SED) includes schizophrenia*
3. *The term does not apply to children who are socially maladjusted, unless it is determined that they have a serious emotional disability*

Thus the law refers to three areas of disturbance—emotional, behavioral or interpersonal.

The IDEA law indicates that serious emotional disturbance must be present for a long period of time. Such a definition excludes time-limited emotional disorders such as “adjustment disorders” and similar maladjustment problems (Schacht and Hanson, 1999). Furthermore, in order to be eligible under IDEA, the emotional disturbance should cause a marked degree of impairment to academic achievement, and may not be caused by intellectual, sensory or health factors, and should be more than a mere social maladjustment. Therefore, a mere diagnosis of emotional or behavioral disorder is not enough for entitlement under IDEA, and courts tended to be suspicious towards clinical diagnoses conducted for non-academic reasons (Schacht and Hanson, 1999).

Two possible loopholes emerge from the above restrictions. First, by defining a disruptive child as “maladjusted,” schools may forfeit the rights of children with emotional disturbances. However, in litigation emanating from such practices, courts tended to recognize the possibility of such abuse of the law, and rule in favor of the plaintiffs. Second, students whose misbehavior is judged to be unrelated to their poor academic achievement, as well as misbehaving students whose academic performance does not suffer enough to classify them as subaverage (e.g. a student whose score falls from two standard deviations above the population mean to one standard deviation above), are considered ineligible under state regulations.

Schacht and Hanson (1999) suggest that in order to measure “marked degree of impairment” to ability, one could rely on the Social Security Administration’s regulations which define “marked degree of impairment” as functioning two standard deviations below the population mean on standardized measures. Such a definition would be in line with the definitions used for other types of disabilities, as discussed above. However, as stated in the previous paragraph, this may lead to some cases of misuse and abuse of the definition.

However, others have contended that such a definition may not be sufficient in order to serve all the deserving population. Wordich, Stobo and Trca (1998) suggest the use of three sets of criteria in order to capture a wider population of children with SED that could “fall between the cracks” otherwise:

- as used for learning disorders, discrepancy between potential and achievement as measured by regression scores or norm-based scores on standardized instruments
- for students that may not show an obvious discrepancy between achievement and potential, failure to continue to master the curriculum may indicate a learning problem that may emanate from emotional/behavioral disorder. They suggest the following to identify those students:
 1. abrupt and significant deterioration in report card marks
 2. obvious decline in the mastery of educational objectives
 3. severe decrease in classification productiveness
 4. sudden inability to master more advanced, complex skills, or to accomplish long term projects (e.g. semester term paper)
- chronic absence from school, which may indicate the onset of a major emotional or behavioral problem, and may result in the students not being tested, and not having any current and verifiable records of this very criteria

Outcomes and Best Practices for Students with Serious Emotional Disability

Students with SED show the least positive outcomes of all disabilities groups (Lichtenstein, 1988; Rock, Fessler and Church, 1997; Stington, Frank and Carson, 1990). These students tend to fail more often, be placed in restrictive settings, and drop out of school.

They have significant difficulty with employment, as compared to students with other disabilities. Like learning disabilities, this category covers a wide range of disabilities.

Special Education for SED students

Comparing successful and unsuccessful outcomes of students with SED in special education classes, Mattison, Spitznagel and Felix (1998) have found three predictors of success:

- enrollment age
- WISC-R verbal IQ not significantly lower than performance IQ
- the presence of DSM-III depressive or anxiety disorder.

The results of the study point to several intervention applications. First, the lower the age of identification and enrollment, the higher the chances of success with the student. Current practices emphasize delaying the labeling of the student, leading to delay in identification and enrollment in special classes. However, the longer the delay in identification, the higher the chances of dropout of SED students, and the higher the chances of the problem becoming chronic and more resistant to intervention.

Certain students with conduct disorders, who are usually excluded from SED special education intervention, appear to benefit from that intervention. Excluding them automatically prevents them from receiving potential benefits. Thus, the overall clinical picture should be considered before such a decision is made. Students with depressive and anxiety disorders appear to have better chances of benefiting from SED programming. Low verbal IQ for students with SED may indicate possible co-morbidity with reading and language disorders. Early recognition and intervention could be remedial for students who have also psychiatric disorders.

The use of DSM psychiatric diagnosis has a predictive value and should therefore be considered as standard baseline for diagnosis. This is contrasted with the low level of predictability found for standard behavior checklists. The use of baseline measures as standard procedure for identifying and comparing the effects of interventions should be adopted. That would enable the practitioners in the field to adopt and change interventions on a periodic basis, and fit the best intervention to the child.

Schneider and Leroux (1994) conducted a meta-analysis of interventions with pupils with behavioral disorders. A meta-analysis is a technique for reviewing and comparing studies in a rigorous way.

In conducting meta-analysis, the reviewer must clearly indicate sources of studies (i.e. the sample) and the methods used for summarizing them. The statistics reported in the original studies are converted—no matter which statistical strategy was used in the original study—into standard common unit known as the effect-size

estimate. In this way, the effect size of one study can be compared with others, even if the studies have different sample sized, used different instrumentation, and so on. (Schneider and Laroux, 1994)

Although the original intent was to compare the effects of various interventions, issues of strategy or treatment technique were dropped from the analysis for lack of sufficient data. Three dependent variables (outcomes) were defined—academic achievement, behavior change, and self-concept.

Overall, the majority of studies have found special programs to be more effective than regular classes in promoting academic achievement, while comparisons between special programs were inconclusive. Similar positive results are reported for the effects of resource rooms as compared to regular classes on the behavioral improvement of students, and for special-school settings as compared to special classes. On the other hand, studies on the effects of more restricted settings on self-concept had the opposite effect. In other words, while more restrictive settings were found to be more helpful for educational achievement and behavioral improvement, they had a negative effect on the students' self-concept.

The results are based on short-term follow-up, lasting from six months to a year. Some of the studies reviewed attempted long-term follow up on the students, but were inconclusive and greatly varied across locations and programs. However, only a few interventions appear to achieve total reintegration of SED students after several years.

Post-School Planning and Outcomes

IDEA calls for an Individualized Educational Program. The IEP should include a statement of needed transition services beginning no later than age 16, and at age 14 when appropriate. The legislation adopted and expanded the concept of transition services (Will, 1984) to include such components as instruction, community experience, development of employment, and other post-school adult living objectives such as acquisition of daily living skills and functional vocational evaluation when appropriate.

On a national level, research has shown that 40.7% of young adults who were identified as SED students were competitively employed two years after leaving school. That number tended to increase to 47.4% three to five years after leaving school. However, this increase still leaves more than 50% of this population with no steady employment. Furthermore, within two years of finishing school, less than 12% were living independently, although that increased to 40.2% in a three-to-five year follow-up (Blackorby and Wagner, 1996). These results indicate this population's need for an extended period of time to achieve independence, and the low levels of success in transitional services (more than 50% unemployed five years after leaving school, and close to 60% living with parents or other dependent setting).

Examining post-school outcomes for students with emotional disturbances, Sample (1998) found parents' involvement in their children's educational planning to be a positive

predictor of postsecondary education and steady work. The other predictor of successful integration into the work world was involvement in paid employment previous to finishing school. The results indicate the need for higher involvement of parents in the child's educational program, a demand that is consistent with the insistence of IDEA on parents' involvement in IEP. It also indicates that for those students who do not plan on continuing their education, active involvement in paid employment while in school may be a positive predictor of later employment prospects.

COMMUNICATION DISORDERS AND SPEECH/LANGUAGE IMPAIRMENTS

Speech/Language Impairments (SLI), also known as Communication Disorders (CD), tend to overlap with learning disorders. In 1980, the American Speech Language Hearing Association (ASHA) stated:

A language disorder is the abnormal acquisition, comprehension or expression of spoken or written language. The disorder may involve all, one or some of the phonologic, morphologic, semantic, syntactic, or pragmatic components of the linguistic system. Individuals with language disorders frequently have problems in sentence processing or in abstracting information meaningfully for storage and retrieval from short- and long-term memory (Cf. Kamhi, 1998).

Two years later, the definition changed somewhat to include any symbol system:

A language disorder is the impairment or deviant development of comprehension and/or of a spoken, written and/or other symbol system..." (Cf.: Schoenbrodt, Kumin, and Sloan, 1997)

As Schoenbrodt and her colleagues point out, such a definition is conceptually correlated and overlapping with existing definitions of learning disabilities. Furthermore, a major number of the students diagnosed with learning disabilities are reported to have language problems, and many of the defining characteristics of learning disabilities are basically communication problems.

Towards an Operational Definition of Communication Disorders

The conceptual definitions for language and speech disorders are problematic for operationalization, not only because of their overlap with Learning Disabilities definitions, but also because of their lack of exclusion and inclusion criteria. Kamhi (1998) reports that common exclusionary criteria should involve ruling out mental deficiency, hearing loss, severe emotional disturbance, oral/motor dysfunction and frank neurological deficits as the primary cause of the language impairment. Many researchers require that children defined as SLI will perform within one standard deviation of the mean on a measure of nonverbal intelligence. (The focus on nonverbal rather than verbal is derived from the fact that SLI may affect children's performance on verbal IQ tests). Non-verbal intelligence tests include the Leiter International Performance Scale, the Columbia Mental Maturity Scale,

the test of Non Verbal Intelligence, the performance portion of Wechsler Preschool and Primary Scale of Intelligence (WWPSI), or the Wechsler Intelligence Scale for Children-Revised (WISC-R). However, in most cases, clinicians only need to demonstrate that a child's language abilities are deficient by using some type of discrepancy-based criteria (Kamhi, 1998).

Discrepancy based criteria for SLI include such exclusionary definitions as having the child's overall language age at least 12 months lower than the chronological age or nonverbal mental age—whichever is lower (Kamhi, 1998). However, such criteria have their own problems, the most serious of which is that a child whose language disabilities are not sufficiently discrepant will be denied eligibility for services. Such an approach emphasizes the idea that cognitive abilities are primary and determining language abilities. That approach contradicts research findings that show that cognitive prerequisites are neither sufficient nor necessary for language development (Kamhi, 1998). Furthermore, research has shown the instability of such measures in determining the linguistic abilities of children. For example, Cole and colleagues (1992) found that between 70% and 90% of a group of young children (ages 3-7) changed from non-eligible to eligible during an eight-month period. The type of test used was also crucial—13% of non-eligible changed to eligible depending on the type of test used. Based on such findings, Fey (1996) called for all children who have age-referenced delays (which are identified by a speech-language pathologist as having language impairment that may predict future life-functioning complications) to be defined as eligible for services.

Outcomes and Best Practices for Communication Disorders

Mental Retardation

Mental retardation is not a single trait, but rather a heterogeneous condition defined by significantly subaverage intellectual and adaptive functioning, and onset before adulthood. Using appropriate education, based on principles of normalization, persons with MR usually live, work and are educated in the community (Szymanski and King, 1999).

The widely accepted definition of mental retardation is the definition proposed by the American Association on Mental Retardation (AAMR) in 1992, which states:

Mental retardation refers to substantial limitations in present functioning. It is characterized by significantly subaverage functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self care, home living, social skills, community use, self direction, health and safety, functional academics, leisure, and work. Mental retardation manifests before age 18.

(American Association on Mental Retardation, 1992)

Mental retardation may co-exist with many other types of disabilities, as primary or secondary definition, including autism and other pervasive developmental disorders,

learning disabilities, and emotional/behavioral disorders (Harrison-Elder, 1996; Fredericks and Williams, 1998; Polloway et al, 1997; Volkmar et al, 1999). The operationalization of that definition will be discussed below.

Autistic Disorder and Other Pervasive Developmental Disorders

Autism and pervasive developmental disorders are neuropsychiatric disorders characterized by patterns of delay and deviance in the development of social, communicative, and cognitive skills (Volkmar et al, 1999). These conditions differ from primary mental retardation and from other specific developmental disorders (such as language development) in that the developmental and behavioral problems are observed in multiple areas, are highly distinctive, and are not a simple manifestation of a developmental delay (Volkmar et al, 1999). These disorders may be co-morbid with mental retardation, learning disability, or serious emotional disability or disturbance (Harrison-Elder, 1996; Fredericks and Williams, 1998; Polloway et al, 1997; Volkmar et al, 1999).

Towards an Operational Definition of Mental Retardation, Autism and Developmental Disabilities

Mental Retardation

Based on the definition advanced by the AAMR, diagnosis of mental retardation is based on three criteria:

1. subaverage intellectual functioning, based on IQ scores of 70 points or below (75 points in some states)
2. subaverage functioning in at least two areas (based on standardized tests or checklists), including communication, self care, home living, social skills, community use, self direction, health and safety, functional academics, leisure, and work
3. onset before age 18

Autistic Disorder and Other Pervasive Developmental Disorders

In order to diagnose autistic disorder and other pervasive developmental disorders, clinical judgment based on a set of criteria is usually combined with standardized checklists and tests. Furthermore, the clinician uses family history and individual history in order to ascertain a differential diagnosis of autism.

The diagnosis requires disturbances in each of three domains: social interaction, communication and play, and restricted interests in activities. By definition, the onset is by age three. Symptoms of social disturbance include marked impairment in nonverbal behaviors in social interaction, failure to develop peer relations as appropriate to developmental level, lack of seeking to share enjoyment or interests, and lack of social or emotional reciprocity. Impairment in communication skills includes a delay or total lack of spoken language (without an attempt to compensate thorough other means) or a marked difficulty in the ability to sustain or initiate conversation, stereotyped and repetitive (or idiosyncratic) language, and lack of make-believe or social play as appropriate to developmental level. The onset before age three is determined by whether or not the individual had abnormal or delayed functioning in the areas of social interaction, social use

of language, or symbolic or imaginative play by that time. Delay or abnormality in any one area is typical and sufficient for diagnosis. If a child meets the behavioral criteria for autism but does not meet the onset criteria, a diagnosis of atypical autism is made. The diagnosis of autistic disorder is not made if the disorder is better explained by association with Rett's disorder or Childhood Disintegrative Disorder (Volkmar et al, 1999).

Rett's Disorder

Rett's disorder is different than autism, in that the child shows a brief period of normal development followed by decelerated head growth, loss of purposeful hand movement, and development of severe psychomotor retardation. Onset is usually at the latter half of the first year of life. To date, it has been observed only in females (Volkmar et al, 1999).

Childhood Disintegrative Disorder

Childhood Disintegrative Disorder (CDD) is characterized by a period of at least two years of normal development. This is followed by marked deterioration and significant loss of at least two skills in the areas of receptive or expressive language, social skills, toilet skills, play or motor skills. Also there is the development of abnormal functioning in at least two of the areas of behavioral disturbance observed in autism: social relatedness, language/communication, restricted interests and activities. The onset is highly distinctive and serves a central diagnostic feature. It develops after a prolonged period of several years characterized by normal development, defined by the DSM-IV as at least two years. Onset is typically between ages 3 and 4. CDD clearly resembles autism in clinical features (Volkmar et al, 1999).

Asperger's Disorder

Though included in the DSM-IV in the class of Pervasive Developmental Disorders (PDD), Asperger's disorder is controversial in clinical and research circles (Volkmar, et al, 1999). There is no apparent delay in development in the first years of life. The DSM-IV defines Asperger's disorder as the presence of the same qualitative impairment in social interaction observed in autism, but with a lack of clinically significant general delay in language or cognitive or adaptive behavior early in life. However, it is possible that subsequent pragmatic skills may be impaired (Volkmar et al, 1999).

Pervasive Developmental Disorder Not Otherwise Specified (Atypical Autism)

This term refers to sub-threshold cases where there is marked impairment of social interaction, communication, and or stereotyped behavior patterns of interest, but where full features of autism in each of these domains or another explicitly defined PDD are not met. (Volkmar et al, 1999).

Differential Diagnosis

The following differential indicators are based on Volkmar et al (1999). For more detail and specific guidelines, the reader should consult the cited article or the DSM-IV.

Autistic Disorder

Consideration of the various PDDs, mental retardation not associated with PDD, specific developmental disorders (e.g. language disorders), and early onset of psychosis.

Childhood Disintegrative Disorder

Prolonged period of normal development followed by regression in multiple areas and the development of autistic-like features.

Rett's Disorder

Very early growth and development is normal, but is followed by deceleration in head growth, development of mental retardation, and unusual hand washing stereotypes.

Asperger's Disorder

Early development is apparently normal. Social deficits become more prominent as the child enters preschool and is exposed to peers.

Pervasive Developmental Disorder Not Otherwise Specified (Atypical Autism)

Criteria for any of the other PDDs are not met, but the child has problems with social interaction and other areas consistent with diagnosis of PDD.

Outcomes and Best Practices for Mental Retardation

The treatment plan for severe developmental disorders should target specific educational goals and educational intervention, outline symptoms requiring intervention, and prioritize target symptoms and/or co-morbid conditions. The plan should also provide for monitoring of multiple domains of functioning (including behavioral adjustment, adaptive skills, academic skills, social/communicative skills, and social interaction with family members and peers) and the monitoring of medication for efficacy and side effects (Volkmar, et al, 1999).

Interventions should include early intervention, education, rehabilitation and ancillary therapies (physical therapy, occupational therapy and language therapy), family support, and other services. Such interventions minimize functional retardation and maximize personal abilities. Further, medical care and treatment and prevention of psychosocial dysfunction are helpful in order to avoid medical complications and minimize the effects of co-morbid mental illnesses (Szymanski and King, 1999). Such interventions should be considered individually according to the holistic diagnosis of the individual.

Currently, services to mentally retarded persons are based on inclusion and "normalization"—enabling them to live as normally (independently) as possible (Szymanski and King, 1999). Based on the IDEA legislation, the parents have a right to participate in development of the IEP, and inclusion of children in age-appropriate classrooms. However, such attempts may create major challenges to local schools, due to behavior problems that may co-exist with MR (Szymanski and King, 1999). It should be noted that IDEA does not mandate inclusion in regular classes. Rather, it requires an Individualized

Educational Program, least restrictive setting (based on the needs of the individual child and resources available), and collaboration in the planning of the IEP between all relevant professionals and the parents.

Behavioral problems may be dealt with through the use of behavior modification and other behavioral techniques. The use of such interventions should be considered individually, and in light of current knowledge about efficiency and efficacy of interventions. Parents' training and involvement in the IEP is essential for successful outcomes. Such training may include behavior modification techniques and parent/sibling support groups. Possible ancillary services that may be required include speech/language therapy, occupational therapy, and physical therapy. It is important to note that for those types of disorders, sustained and continuous programming is more effective than episodic programming. Thus the IEP may include summer programming in order to avoid regression due to periodic absence of services (Volkmar et al, 1999).

Szymanski and King (1999) cite research findings that indicate that placement in the community rather than institutions may be harmful to the mentally retarded population. For example, Kastner et al (1993) found that mortality rates for mentally retarded individuals in the community were higher than for those placed in residential institutions. The emphasis should be on the creation of a continuum of care, in which different levels of restrictive care exist, and the correct level of restriction and intervention will be determined according to the specific needs of the child (Luce et al, 1992). Those kinds of considerations are common to all types of developmental disabilities, including mental retardation, autism and PDD.

VISION IMPAIRMENT AND BLINDNESS

The legal definition of blindness is "the ability to see only the largest symbol on a standard Snellen eye chart, at twenty feet, with the better eye, corrected if applicable (with glasses or contact lenses), or restricted visual field of twenty degrees or less... tunnel vision, regardless of central visual acuity" (Bishop, 1987). Though the legal definition of visual blindness is quite clear and measurable, the definition of visual impairment is not so. The IDEA legislation defines "visual disability" as "a visual impairment which, even with correction, adversely affects a child's educational performance." That definition emphasizes the functionality of vision rather than specific measurable criteria. The implication of such a definition is that it is possible to suffer visual impairment that will not harm the functional learning or education of an individual.

Towards an Operational Definition of Vision Impairment and Blindness

Most states use functional definitions in order to determine eligibility of visually impaired students for services. Functional definition identifies a student as eligible for services by implementing an evaluation carried out by a "professional who is a certified teacher of students with visual disabilities, or by an orientation and mobility instructor" (Erin and

Koenig, 1997). Though some states still use clinical tests for such evaluations, based on acuity measures, those tests are less flexible in allowing the inclusion or exclusion of students according to individual needs (Erin and Koenig, 1997).

Outcomes and Best Practices for Vision Impairment and Blindness

Inclusion of blind and visually disabled students in regular classrooms has a long history, dating back to 1900. However, in order to successfully handle the experience of inclusion, visually impaired students need to acquire certain skills. As Bina (1999) writes, “The inclusion movement has not eliminated the need for specialized schools for blind students. In fact, to a large extent it has increased the need for specialized services to enable children with visual disabilities to succeed in regular classes.”

Referrals to special schools may serve several purposes (Bina, 1999). They may be short time referrals for:

- placements in an on-campus program for students who have difficulty achieving academically in the regular classroom and who need more intensive and individualized instruction than is locally available
- summer school enrichment or compensatory skill training
- consultative outreach services

Placements in special schools may arise from lack of local services. Currently, only 33 universities in the US offer pre-service training programs for teachers of the visually disabled—with about 200 graduates every year. Thus demand for certified teachers for the visually impaired is much higher than supply, and many school districts find themselves without qualified personnel. The high attrition rate of specialists in that field also depletes the supply of qualified teachers (Bina, 1999).

Further complication may arise from the co-morbidity of visual disability with learning disability. Being identified as visually impaired may mask a co-existence of other disabilities with similar symptoms such as learning disabilities (Erin and Koenig, 1997). Summarizing extensive literature, Erin and Koenig indicate that between 14% and 65% of students with visual disabilities also have learning disabilities. The visual disability creates major complications when trying to assess learning disabilities for this group of children. Modifications should be made to standardized tools, including the use of different time limits for IQ tests, the use of Braille text and so on. However, all of those modifications can render standardized tests invalid, and cast doubt on the ability to come to definite conclusion.

HEARING IMPAIRMENT AND DEAFNESS

The federal definition for deafness is “hearing impairment that is so severe that the child is impaired in processing linguistic information through hearing, with or without amplification, which adversely effects educational performance.” The condition “hard of hearing” is

defined as “a hearing impairment, whether permanent or fluctuating, which adversely affects a child’s educational performance, but which is not included under the definition of deaf.” Those definitions do not specify a measurement of degree of hearing loss. That lack of specificity results in large disparity and variation among states in the way they define deafness and the term “hard of hearing,” as will be discussed below.

Towards an Operational Definition of Hearing Impairment and Deafness

Deafness and hearing impairment are among the least well-defined categories of disabilities served under IDEA. A comparison of state definitions used across states (Bienenstock and Vernon, 1994) has revealed an enormous variation and discrepancy among different states and the federal definition. While states used a wide range of definitions to describe hearing loss, the situation is further complicated by some states using only one definition for the two conditions of deafness and “hard of hearing,” while others follow the federal lead and separate the two. Bienenstock and Vernon (1994) have found that 24 states, including Hawaii, are using requirements that are similar or the same as the federal guidelines, while the other 26 states and the District of Columbia had different eligibility requirements, such as varying degrees of hearing loss.

Among states that consider the degree of hearing loss, standards begin with auditory deficits as small as 20 decibels. Some states use a single decibel cutoff point for eligibility. Those states do not separate the hard of hearing from the deaf. Rather, all students with that degree of loss or more are considered to be eligible. To summarize, the field of deafness and hearing loss is characterized by lack of consensual operational definition of hearing impairment and deafness, and by lack of sufficient research on that subject.

Outcomes and Best Practices for Hearing Impairment and Deafness

The major issue plaguing the field of education for the hearing impaired and deaf is the issue of whether to include such students in the regular classroom, or have special facilities or classes for them. Supporters of inclusion cite evidence that inclusion facilitates academic and social learning, while resisters claim that such inclusion is harmful to the development of the deaf or hard of hearing child. According to that point of view, deaf and hearing impaired children are supposed to learn to function in a non-hearing environment; and inclusion in a regular classroom may exacerbate their social development, be insensitive to their differences from regular children and may also hinder the learning of the hearing children in the class, due to the extra attention given to the hard of hearing students by the teacher (Afzali-Normani, 1995; Salem and Fell, 1988).

Furstenberg and Doyal (1994) examined the relationship between personal characteristics, as measured by the Teacher Report Form (TRF) of the Child Behavior Checklist. The TRF examines a list of problem behaviors as rated by the teacher, as well as outcomes on the Performance Checklist for Hearing Impairment, which examines hearing impaired students’ progress toward outcome expectations. The two instruments proved to be negatively correlated, indicating that there was a positive correlation between student’s progress and

lack of emotional/behavioral problems. Examining the possible difference between students in mainstream class settings and students in special education has shown no difference in emotional/behavioral problems. However, the performance of students in the mainstream classes was higher on issues such as language, use of hearing, productivity and interpersonal skills. The authors do not indicate that the processes led to placement in mainstream or special education classes. Thus no causal conclusions may be achieved, since those results may be the product of issues like co-morbidity of hearing impairment with other disabilities, such as learning disabilities or developmental disabilities (Davis and Bullis, 1990).

In a study that examined inclusion practices in the State of Kansas, Afzali-Normani (1995) found that full inclusion had a favorable impact when deaf and hard-of-hearing students received social encouragement (such as teachers and fellow students learning basic sign language); when teachers and parents supported the program; and when a full range of services was available. Those findings support the dictum of IDEA for having a full continuum of services available for students, having the parents involved in the IEP, and creating an individualized educational plan (rather than having a “one size fits all” approach).

INCLUSION VS. RESIDENTIAL CARE

Residential care is used mostly for students with severe developmental disabilities/mental retardation (DD/MR), and in certain cases severe emotional or behavioral disorders (EBD). The wording of IDEA is somewhat confusing when it comes to issues of residential care and inclusion in the general classroom. IDEA emphasizes “free appropriate public education” (FAPE) and “least restrictive environment” (LRE) to the maximum extent possible. However, there is no clear definition of “appropriate” or “least restrictive.” However, IDEA mandates the creation of a “continuum of care,” which stipulates the use of more restrictive and less restrictive placements. Thus there is an inherent contradiction between the emphasis on integrating disabled children into the mainstream educational system and the need for more restrictive settings for some of the children (Havey, 1998). The solution may be found in the enforced requirement of Individual Educational Plans. IEP guidelines call for a personalized educational plan that takes into consideration all possible options, while trying for the least restrictive setting possible.

Analyzing federal court decisions in lawsuits related to IDEA and Section 504, Havey (1998) found that—although in most cases the courts supported the parents’ position (which overall was against restrictive settings)—the courts did emphasize the need for considering all available possibilities, rather than the restrictiveness of the setting. Thus, following due process in planning an IEP is the key for placement decisions. Schools should be aware that IDEA calls for a direct participation of parents in planning an IEP, as well as parental access to all records related to their child (and not only “relevant records” as some previous legislation has specified). Several guidelines are suggested by Havey (1998):

- Make decisions based on the needs of the individual child, no “one size fits all.” This includes refraining from having all children with a certain disability in the same setting without considering each case individually, regardless of whether the setting is specialized or mainstreamed.
- The IEP process calls for identification of the special needs of the individual child before a placement decision is made.
- The consideration of individual needs should include the possibility of special “supplementary aids and services.” Those may include resource rooms and itinerant instruction, as well as assistive technology.
- Adherence to procedural guidelines.

When planning the IEP, one should be aware that in addition to the school, other agencies may be involved with the child—especially in cases involving emotional/behavioral disturbance (EBD), which is referred to by IDEA as serious emotional disturbance (SED). These other agencies may include mental health agencies and juvenile courts, which may be responsible for placing the child in alternative programs. Such placement does not necessarily release the school system from responsibility for planning an IEP (Robertson et al, 1998).

Appendix C

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Responses of the Affected Agencies

Comments on Agency Responses

We transmitted drafts of this report to the Department of Education, the Board of Education, the Department of the Attorney General, and the Department of Health on January 2, 2001, inviting them to comment on the consultant's recommendations. A copy of the transmittal letter to the Department of Education is included as Attachment 2. The Board of Education chose not to respond and the other affected agencies elected to prepare and submit a unified response, part of which is included as Attachment 3. The entire response with its attachments is on file at our office. Our consultants' comments on the departments' response is included as Attachment 1.

The departments' response stated that the report had the potential of being a helpful document but that this potential was lost due to a lack of understanding of the relevant federal laws and the consent decree on the part of the consultants and our office. The agencies expressed support for the creation of a recommended independent evaluation center but in view of the present lack of such an organization has contracted with the University for Hawaii's Social Science Research Institute to serve as an independent evaluator of the Multisystemic Therapy program.

The agencies disagreed with the consultants' conclusion that the State does not have a working definition and with the recommendation for establishing a statutory definition for the *Felix* class. The agencies contend that the proposed working definition and statutory definition would conflict with federal law and the supremacy clause of the United States Constitution.

The respondents state that the concern about the issue of best practices is not clear but contend that with the intense focus on empirically supported treatments by the health department's Child and Adolescent Mental Health Division the finding is not supportable. The responding agencies also took issue with the contention that service testing scores showed no significant progress.

The consultants' comments relating to a lack of scientifically acceptable evidence for the effectiveness of Multisystemic Therapy for the *Felix* population are criticized with the agencies pointing to what they regard as considerable evidence for potential viability.

The agencies do not agree with the consultants' concern about the lack of assessments of service effectiveness, citing numerous efforts in the area.

However, the response acknowledges the inability to use available data because of the still pending implementation of an Integrated Management Information System.

The agencies reject the recommendation for a voucher system, stating that a sufficient supply of services is a prerequisite for the success of vouchers, positing that “the consultants are utilizing a mainland thinking not applicable to Hawai‘i.” It must be noted that Hawaii is by far not the only state with a shortage of qualified providers.

The response to the consultants’ criticism of a lack of uniformity of budget information points out that the Department of Education created EDN150 and the Department of Health has used a consistent format for two years. This response did not, however, respond to the point that there is no segregation of core and experimental services, creating the impression that all services must be funded.

The consultants reviewed the unified response of the affected agencies and concluded that the response did not provide substantive or significant corrections to the draft report or substantive or empirical evidence to support the agencies’ claims of inaccuracies and incorrect conclusions. The consultants stand by the findings of their report.