COMHAR, Inc.

The Philadelphia FASD-SDT Initiative

Annual Report

September 2011

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(August 1, 2010 – July 31, 2011)
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1. Executive Summary

The goal of the Philadelphia Fetal Alcohol Spectrum Disorders (FASD) - Screening, Diagnosis and Treatment (SDT) initiative is to improve the functioning of children with fetal alcohol spectrum disorders within the service delivery system of COMHAR Inc., using a family-centered approach. The target population for the SDT initiative is children birth to seven years of age receiving early intervention and/or behavioral health services (including outpatient counseling) from COMHAR.

COMHAR's SDT initiative continues to serve children birth to seven years of age across all child-serving programs of the agency. Those programs include children in the three-to-five year old Early Intervention Program, the Behavioral Health and Rehabilitation Services (BHRS) program, and Outpatient Program. All children and families participating in the initiative reside in the City of Philadelphia, and receive early intervention services or behavioral health services from COMHAR.

As with any new initiative, even in option year three (August 1, 2010 – July 31, 2011) the FASD-SDT project continued to be a learning experience for all COMHAR staff, as well as the professional and parent members of the Task Force.

During option year three of the initiative our focus was solely on refining, consolidating and maintaining the important changes we had made to the program throughout option year two**.**

The integration of SDT services into the service delivery system of COMHAR was a continued priority for monitoring and support, as was our continued partnership with the Diagnostic Evaluation Center at St. Christopher's Hospital. The Implementation Work Group (internal staff) and the SDT Task Force (internal and external stakeholders) were consistent, ongoing supports to program functioning.

As a direct result of our continued focus on the issues noted above, we more than doubled the number of children screened for an FASD (over year two figures), moving the initiative closer to meeting its goals of serving all children in the COMHAR system of care, and ensuring that all affected children with an FASD receive the support they need.

2. Key Client Results (See Appendix 1: Reporting Table)

a. Target Population

The target population numbers represent the clients within COMHAR's three to five Early Intervention Program, the Behavioral Health and Rehabilitation Services program, and Outpatient Programs, including the Latino Outpatient Treatment Program. With screening processes now fully integrated within each program, we were able to screen a high percentage of all children entering COMHAR's system of care, as was our stated goal in the last annual report. Screening continues to be voluntary, but parents/guardians are comfortable with the process and rarely decline the offer of screening.

COMHAR continues to serve a significant Latino/Hispanic population, in addition to African Americans and whites. In serving the Latino population, all COMHAR programs and staff work toward being culturally sensitive, in addition to meeting any specific linguistic needs.

b. Screening

The screening data presented in the Reporting Table represents those clients screened during Option Year 3. A total of 142 clients were screened for an FASD (96% of those referred, up from 39%, 66 clients in option year two).

The majority of the clients who met the FASD screening criteria did so due to confirmed prenatal alcohol or drug exposure.

For a variety of reasons, 20 cases were lost to follow up after positive screen and before diagnosis resulting in the cases being exited from the SDT initiative. Reasons for early exiting include: 2 multiple FASD diagnostic evaluation-no shows by the family, 3 loss of contact with the family following the positive screen, and the majority of the remaining cases being exited due to not meeting the FASD diagnostic referral criteria.

There were no clients placed in positive monitor (for children 3 years of age or younger), because the children in this age group at COMHAR are already identified with a developmental delay.

c. Diagnosis

During Option Year 3, the initiative continued to use one Diagnostic Center - the FASD Site Specific Diagnostic Center at St. Christopher's Hospital. COMHAR also continued to apply Northrop Grumman's FASD screening criteria to determine which clients were referred to the FASD Diagnostic Center. However, the FASD Diagnostic Center has their own referral qualifications, regardless of the findings of the COMHAR screening results. This distinction affects the clients who will be evaluated by the FASD Diagnostic Center. For the clients who are

referred to the FASD Diagnostic Center, the Center assesses the client's records to determine if the client meets their referral criteria.

As reported in the Diagnosis section of the Reporting Table, COMHAR referred 30 of 50 clients who screened positive for an FASD diagnostic evaluation. Of the 30 clients referred for an evaluation, six clients received a completed evaluation. All six of the clients who received diagnostic evaluations were diagnosed with an FASD.

d. Intervention Services

Intervention services are currently being provided to eight clients at the time of this report. During year three, COMHAR client-facing staff, program managers, and program supervisors participated in several training opportunities that contributed to their ability to provide FASD-informed interventions.

During year three the Implementation Work Group which consists of the managers and directors from the various programs within COMHAR (Early Intervention, BHRS, and Outpatient) continued to support all aspects of SDT implementation, including the provision of intervention services.

e. Program Description

Population Needs Identified and Addressed

The continued goal of the Philadelphia screening, diagnosis and treatment (SDT) initiative is to improve the functioning of children with fetal alcohol spectrum disorders (FASD) within the service delivery system of COMHAR Inc., using a family-centered approach. The target population for the SDT initiative is children birth/three to seven years of age receiving early intervention and/or behavioral health services (including outpatient counseling) from COMHAR.

During the first year of the project, the service delivery system of COMHAR changed as a result of funder-initiated system changes. This change eliminated the COMHAR early intervention services for children birth-to-three, vastly curtailing the number of children coming into COMHAR who fell within that age range. As a result, the initiative continues to include that population, but will serve fewer children under age three than was originally predicated. As a result of this required system change, children under three will not receive early intervention services from COMHAR, but may still enter the system of care in other child-serving programs. Through their participation in those programs, children birth-to-three will still be eligible to participate in the FASD-SDT initiative.

During year three, the SDT Initiative continued to include children in COMHAR's three-to-five year old Early Intervention Program, BHRS, and Outpatient Program. All children and families participating in the initiative reside in the City of Philadelphia, and receive early intervention services or behavioral health services from COMHAR.

The initial needs assessment conducted at the start of the subcontract process found that child and family needs fell into several areas, including: characteristics of the target population, and the relevant characteristics of COMHAR staff.

Characteristics of the Target Population

- The target population is comprised predominantly of African American, white, and Latino children and families.
- Some Latino families are likely to need Spanish-speaking staff for their service provision.
- Diagnoses of the younger target children vary, including: "unspecified mental retardation," "mental and behavioral problems," "mental problems with learning," and "motor problems with limbs."
- Diagnoses of children in the three-to-seven year range could also include Axis I diagnoses such as Attention Deficit Disorder, or other behavioral disorders.

Characteristics Relevant for COMHAR Staff

- The need for COMHAR staff to be knowledgeable about fetal alcohol spectrum disorders.
- The need for COMHAR staff to have supportive and inclusive attitudes toward working with children and families living with an FASD.
- The need for COMHAR staff to have an understanding of the various stressors with which families with children with special needs may be coping, and how those stressors impact engagement in FASD screening, diagnostic and intervention services.

In year three the initiative continued to meet the needs of children, families, and COMHAR staff. As the project has unfolded, and individual children and their families have received services, the provision of program services has been refined to meet their needs (detailed below in the service delivery section).

Service Delivery Process

Service delivery of the FASD-SDT initiative is being implemented in the local service delivery organization via COMHAR, Inc., an independent community-based service organization that provides voluntary services.

The implementation work group[1] continued to meet on a regular basis to address program-related service-delivery issues as they arose. Integration of screening was accomplished prior to

[1] The Implementation Work Group was convened after year one. It is a group internal to COMHAR comprised of the FASD-SDT Project Director, COMHAR's Director of Children's Services/FASD-SDT Administrative Director, Associate Behavioral Health Director of Outpatient Services, Supervisor of Behavioral Health Services, Clinical Coordinator of BHRS, and the Research and Evaluation Design Support staff person. These programmatic participants were identified specifically to address the full integration of FASD-SDT services into COMHAR's service delivery system, and to address internal needs and challenges of initiative implementation.

year three, but the work group continues to monitor the screening process to ensure continued operation.

Training for all COMHAR staff (intake, implementation work group, intervention-providers) continued with great success in year three. New trainers were added to the roster of those providing training, and training was developed and provided in direct response to staff requests and needs. Staff presence for each training was excellent, and ratings of satisfaction were high. In this arena, the initiative was able to make forward progress, bringing to the staff new knowledge that directly improves their ability to work with children and families around FASD's.

Screening

Prior to year three COMHAR revised its intake procedures for child–serving programs to ensure that all incoming children are offered the FASD screening upon their entry to the COMHAR system of care. This new procedure has significantly increased the number of children being screened, as evidenced by our increase in screening numbers from year one to year three.

All parents of children birth to seven years of age who are new to the COMHAR system of care continue to be invited to receive a child screening for an FASD as part of the program Intake process. A separate referral to the SDT initiative is not needed. Identified Intake staff within each of the three child-serving programs at COMHAR (early intervention 3-5 years of age, behavioral health, and outpatient) have been trained to introduce the SDT screening process, to include important health screening information in the intake process, and to utilize with families the revised Intake and Consent documents that address FASD screening.

Diagnostic Evaluation

The SDT Project Director reviews all completed screening forms and screening photographs. Children who receive a positive screen (meet the FASD screening criteria) are recommended for a diagnostic evaluation by the Project Director. The procedure for referrals is:

- Telephone contact with family informing the parent/guardian the findings of the FASD screening.
- In person visit with family, including an intake for the SDT initiative, description of evaluation procedure, and signing of Consents for Release of Information.
- Requests are made for all available relevant health (behavioral, medical, and educational) information to be submitted to the diagnostic evaluation team.

The SDT Project Director is actively involved in monitoring the scheduling of evaluation appointments with the diagnostic center, case managing the receipt of required documents, and assuring that scheduled evaluation appointments have been completed.

The SDT Project Director and/or Case Manager actively interacts with the Co-Coordinators of the diagnostic center to ensure timely scheduled evaluations and needed records are obtained, as well as actively follows-up with families prior to scheduled appointments to ensure scheduled appointments are kept and that families who require transportation or other supports receive what they need. This follow-up prior to appointments is designed to keep families fully engaged in

each phase of the initiative, and to ensure that any challenges to their participation are addressed in advance and do not become barriers to their participation.

Once the diagnostic evaluation takes place for eligible children, the evaluation team provides the family with a written FASD diagnostic summary of the evaluation, which includes intervention recommendations and strategies. As part of the evaluation procedure, families are asked to sign Consents for Release of Information for all existing service providers involved with the child, as well as COMHAR/the SDT project. The diagnostic center forwards a copy of every completed summary to the SDT Project Director. If new services are recommended, the SDT Project Director and/or Case Manager will ensure that signed consents for the release of information are obtained prior to the making of any referrals on behalf of the family.

Intervention Services

As of year three we now have eight children who have been diagnosed on the FASD spectrum and who are receiving intervention services. The majority of the children who were found with an FASD were diagnosed with neurobehavioral disorder; alcohol exposed.

For all children who receive a completed diagnostic evaluation, the SDT Project Director meets with the parent/guardian to review the FASD diagnostic evaluation report summary and to address any questions/concerns the family may have, as well as discuss next steps in the process. If the child is not found with an FASD but there still are recommended intervention services, the SDT Project Director and/or Case Manager will assist the parent/guardian with locating the intervention services, even though the child is exited from the FASD-SDT initiative because of not being diagnosed with an FASD.

After meeting with the parent/guardian to review the FASD diagnostic evaluation report summary, for those children who are found with an FASD, the SDT Project Director and/or Case Manager begins the process of contacting the family and the providers of all services currently in place to schedule a team meeting. At the same time, the Case Manager collaborates with the Diagnostic Center and the family to ensure that referrals are made to all recommended services not yet in place for the child. Typically the Diagnostic Center serves as the contact for all medically-related services, and the SDT Project Director or Case Manager makes referrals for behavioral-health-related services.

Case Management continues to be provided to the families to ensure that recommended intervention services are provided, that the family and child are actively participating and receiving intervention services, and also to assess and monitor the degree to which the services in place are meeting the child's needs. Anonymous data of the intervention services is submitted to Northrop Grumman on a monthly basis as stipulated by the subcontract.

The SDT Project Director and/or Case Manager share responsibility for monitoring and updating the database regarding the timely completion of service engagement, service delivery, and outcome required assessments.

Staff Training

Staff training has been an integral part of successfully implementing the FASD SDT initiative within COMHAR. During the reporting period, training has been provided in a variety of areas, to respond to several programmatic needs. Importantly, we were able to address many of the training needs that we identified in year two.

1. Screening and intervention staff received trainings, including from national experts [external training]. Topics included: Engagement of families from different cultural backgrounds, sensitivity to language differences, and intervention strategies for children with FASD's.

2. Intake staff received on-going formal and informal support from the FASD-SDT Project Director [internal training].

3. The Work Group members continue to convene their own team meetings, which served as an informal training support for developing programmatic policies and procedures [internal meetings].

4. The Diagnostic Evaluation team and the SDT Project Director participated in all teleconference calls provided by Northrop Grumman.

5. Database training was provided by Northrop Grumman for all staff currently responsible for data entry [external trainers]. No additional training in database entry or management is needed at this time.

Each of the trainings individually, and as a whole package, has provided valuable assistance and support to COMHAR staff and stakeholders. Thus far the training program has satisfied the needs of the COMHAR staff and SDT team members, enabling us to meet the needs of the target population, and successfully implement all three phases of the initiative.

Staff training in database and reporting

Internal staff training in database and reporting was provided when the FASD Assistant (bilingual) was hired during year three. The part time Case Manager position was not filled since program capacity did not warrant the additional support in year three. This position is under consideration for year four, should program capacity continue to increase. Internal ongoing training will be necessary in order to ensure accurate data entry and quality assurance. The Evaluation and Design Consultant will continue to work jointly with the initiative while providing supports to address data quality assurance.

Task Force and Stakeholders

During year three FASD-SDT Task Force members continued to attend meetings and support the COMHAR SDT team (and initiative). Individually, and as a group Task Force participants were particularly helpful in discussing sustainability strategies and options.

As noted above, the ongoing convening of the Implementation Work Group has continued its essential function of addressing the smooth integration of FASD-SDT services into COMHAR's service delivery system, and to address internal needs and challenges of initiative implementation as they arise.

Lessons Learned

Our essential lesson learned during option year three of the SDT initiative has been "persistence." Our team, task force members, and partners continued to persist in the face of significant start-up challenges during year one and early year two. However, we persisted in being flexible, in implementing new efforts, in recruiting the necessary supports within COMHAR, and in meeting each challenge as it arose.

In year we were able to reap the rewards of that persistence, screening twice the number of children than we were able to screen in year two (increasing from 68 to 142 children screened). We identified 50 children within COMHAR's system of care who screened positive for an FASD (up from 42 in year two), and successfully referred 30 of those children for an FASD.

In year three we also were able to have eight children successfully enter the intervention phase of the program – a first for the initiative.

The primary model for our success has been the challenging, but essential integration of the screening process into each of the COMHAR child-serving programs – including the identification, training and on-going support of specific screening and referral staff within each individual program. These staff members liaise consistently and frequently with the SDT Project Director to problem-solve, ensure the timeliness of screening, referrals to the diagnostic center, and on-going contact with families. As noted above, the responsiveness of the Implementation Work Group to program-related issues has also served as an essential support in this model.

Program Changes

Over the three years to-date, the Philadelphia FASD-SDT initiative has been able to facilitate and maintain several changes integral to the success of the initiative.

Change Category	Description of Change
State/local policies and procedures	As a result of the FASD-SDT sub-contract, CBH (Community Behavioral Health - the county funding and referral source, in children's behavioral health) has been referring children who are seven years and younger to COMHAR's BHRS program, so that the children may be screened for a FASD. This change has served as an important exemplar of city-agency integration toward the benefit of FASD screening, diagnosis and intervention services for young children in Philadelphia.
Organizational policies and procedures (agency policy, Task Force, partner agreements)	The screening, assessment and referral for an FASD diagnosis was integrated into the Children's Services Division of COMHAR, which serves children seven years and younger. During Option Year 2, the birth to 3 early intervention program was phased out, due to internal program changes, but the 3 to five early intervention program, the Behavioral Health Rehabilitative Services (BHRS), and the Outpatient programs at COMHAR continued to have children screened for an FASD who were within the target age range of birth through 7 years of age. The Latino Outpatient Program was phased in, and has been an important part of the initiative thus far. The changes implemented towards the latter months of option year two continued to remain in effect during year three – e.g. COMHAR drafted and changed the overall organization's policy regarding behavioral health consents to include a clause for the parent/guardian to consent for their child to receive a FASD screening, more thoroughly including the SDT initiative within the typical flow of COMHAR's Children's services.
Systems integration (intake, screening, case coordination, agency collaboration, internal and external system referrals, diagnostic	**Referrals for Screening and Child Screening** Amongst all child-serving programs, all children continue to be offered screening for a FASD if they are within the target age range of birth through 7 years of age. There were no changes of note in this area during option year three. As noted above in this report, our major focus during year three was to consolidate, maintain, and refine the important changes that were made during option year two (and documented thoroughly in the Option Year Two Annual Report). The work of maintaining existing changes was of major importance in year three. It is all too common for programmatic changes to disappear as staff changes are made, pressures on staff increase, and time goes by. However, the gains made

team/center, etc.)	across the SDT-involved programs were fully maintained, and even enhanced in year three. **Provision of FASD Diagnostic Evaluations** We continued our close integration with the Diagnostic Evaluation Center in option year three, but no significant changes to processes were made.
Service delivery processes (parent engagement, modification of existing case plans or development of new plans, new clinical techniques, case management, etc.)	**Provision of intervention services.** New to year three, we had eight children enter the intervention phase following their diagnostic evaluation. With these children now in the intervention phase, the program was required to follow these children's progress while insuring that recommended services and interventions were being provided. Close follow up and contact with the parents/guardians and interventionists was a priority for the success of the children. **Administration of baseline, exit, and follow-up outcome assessments.** Program procedures dictate that the FASD-SDT Project Director and/or Case Manager follow up with every parent/guardian along every step of the process, regardless if the child is found with an FASD. Case Management is provided for every child in the initiative, from the start of their referral for an FASD screening. Communication with the family is via phone, e-mail, letters, and/or home visits.
Data Systems (integration of program data, centralization, etc.)	New part-time administrative staff was hired and trained internally to use both COMHAR record-keeping systems, and the Northrop Grumman database. This new position has enabled the SDT Project Director to have the time necessary to accommodate the tremendous increase in program census from last year, with its accompanying requirements for screening, record keeping, and case management tasks.
Staffing (new training focuses, refresher training, staffing structures, qualifications for new hires, training for service providers, etc.)	See above, regarding part-time administrative staff person. The continuation of our training program into year three was a major component of success for the initiative this year. As staff became increasingly involved in the initiative, their desire for increased knowledge and skills around FASD's increased. We responded to that challenge by calling in several national experts in FASD. The specific training needs of our staff (such as the need to focus on Latino children and families, in particular) challenged the trainers to craft a program specifically for our staff. This program was highly attended, well-received, and greatly appreciated. The gains made by staff certainly translate to their successful work with children and families on a daily basis.

Appendices

A. Additional Report Measure

	Number Referred for Screening	**% Referred for Screening**	**Total Entering Service**
Total N/% of children/adolescents entering service who are referred for screening	148	96%	142

Appendix B. FASD Diagnosis and Intervention Monthly Report with Crosswalk

	Option Year 2 Between 8/1/2010 and 7/31/2011
I. **Screening**[2]	
1. Clients screened for an FASD	142
2. Clients with a positive FASD screen	50
3. Clients placed in positive monitor (+ monitor)	0
4. Clients moved from positive monitor to positive FASD screen	0
5. Total Number of clients with a positive FASD Screen	50
II. **Diagnosis**	
6. Number of clients referred for diagnosis	30[3]
7. Number of clients with completed diagnostic evaluations	6
8. Number of diagnostic evaluations with written reports completed	6
9. Number of clients diagnosed with an FASD	6
10. Number of clients diagnosed with an FASD and other diagnoses	0
11. Number of clients receiving a diagnosis other than an FASD	0
12. Number of clients not receiving any diagnosis	0
III. **Intervention Services**	
13. Number of clients receiving interventions	8
14. Number reporting as lost to follow up after positive monitor and before positive screen	0

[2] The numbers may not represent the complete number of clients screened due to some of the end of the month numbers for July 2010 rolled over into August 2010 which is the start of Option Year 3.

[3] The numbers may not represent the complete number of clients referred due to some of the end of the month numbers for July 2010 rolled over into August 2011 which is the stat of Option Year 4.

15. Number reporting as lost to follow-up after positive screen and before diagnosis	28[4]
16. Number reporting as lost to follow-up after diagnosis and before intervention	0
17. Number of clients diagnosed and received some intervention services but no longer accessible for services	0

[4] The majority of these numbers reflect clients who were referred for an evaluation, but did not meet the FASD diagnostic center's referral criteria to have a completed evaluation.