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The Role of a Statewide Information and Referral (I&R) System in Enhancing the Access of Children and Their Families to Developmental Programs and Services

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KEY POINTS

- Telephone access points are efficient ''one-stop shopping'' vehicles for accessing timely and appropriate services for children and their families.
- Telephone access points for assistance with developmental or behavioral issues of children (such as Connecticut's *Help Me Grow* program) must be adequately staffed with trained telephone Care Coordinators who are culturally sensitive and have a background in child development.
- A valid and reliable data collection system is essential for documenting families' needs, as well as for identifying gaps in and barriers to the services needed by callers.
- Specialized telephone access points need to be co-located with or have access to a generic information and referral service, to relevant specialized call centers, and have relationships with community-based programs and services.

THE HISTORY AND RATIONALE FOR ESTABLISHING TELEPHONE INFORMATION AND REFERRAL (I&R) SERVICES

During the 1960s, there was substantial growth in the number and complexities of the various health and human service delivery systems. The proliferation of services, guidelines, eligibility criteria, and procedures for applying for assistance often resulted in frustration, lack of follow through by eligible consumers, and non-receipt of needed services. Simultaneously, the United Way of America and the State of Connecticut recognized the need for establishing Information and Referral (I&R) systems, with the goal of serving as a road map to services and offering assistance in accessing appropriate resources in a timely manner. In the mid 1970s, the combination of available federal dollars, the United Way of Connecticut becoming an incorporated entity, and the establishment, by Governor Thomas Meskill, of a State Council on Human Services, served as the multi-layered catalyst for creating Connecticut Infoline, a program of the United Way of Connecticut. In January 1976, with federal Title XX funding matched (three to one) by United Way of Connecticut dollars, Connecticut Infoline became a reality.

The Establishment of Specialized Call Centers with Connecticut Infoline

Connecticut Infoline started as a generic I&R service designed to assist anyone with a health and/or human service issue. In an effort to streamline assistance to callers, each telephone caseworker was able to handle the full range of cases from start to finish. While this required a broad range of substantive knowledge as well as a deep understanding of the various delivery systems, in the 1970s and early 1980s the task was manageable. Over time, a number of internal and external developments caused a rethinking and the thoughtful establishment, within Connecticut Infoline, of specialized call centers, many of which serve as access points to statewide programs. Table 1 summarizes some of the key changes that occurred between 1986 to 2002.

The decision to create specialized call centers was influenced by funders who wanted to have a visible and recognizable access point for their programs. Simultaneously, there was an internal recognition that it was no longer feasible to have telephone casework staff responsible for the full range of issues that callers could present. In 1993, these factors influenced the establishment of *Birth to Three Infoline* as *Infoline's* first maternal and child health (MCH) specialized call center. In 2002, Birth to Three Infoline became the *Child Development Infoline* (CDI), as the call center became the access point for several programs serving children.

CHILD DEVELOPMENT INFOLINE (CDI), THE ACCESS POINT FOR THE *BIRTH TO THREE SYSTEM, CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS (CYSHCNS), PRESCHOOL SPECIAL EDUCATION SERVICES,* AND THE *HELP ME GROW* PROGRAM

While the substantive knowledge required by CDI Care Coordinators (CCs) is consistent for all the programs that are accessed through this call center, their role and responsibilities have greatly expanded. CDI adheres to the same philosophy as the 211 Call Center, that all staff are crossed-trained to manage all calls. There are no *Birth to Three, Preschool Special Education, Children and Youth with Special Health Care Needs (CYSHCNs),* or *Help Me Grow* specialists within the unit. This philosophy

Table 1. Timeline of Expansion Activities within Connecticut Infoline

Date	Activity
1991	*Infoline* meets the federal mandate to serve as the state's point of access for consumers of Maternal and Child Health (MCH) services.
1993	*Birth to Three Infoline* is established as the telephone access point for the State's *Birth to Three System* administered by the Department of Education.
1998	*HUSKY Infoline* is established. Callers receive assistance in applying for and obtaining covered services through the *HUSKY* health insurance program operated by the State Department of Social Services.
1999	Callers can access the general I & R call center by dialing 211.
2002	*Birth to Three Infoline* becomes the *Child Development Infoline* and serves as the access point for the *Birth to Three System, Preschool Special Education Services, Children with Special Health Care Needs*, and the newly established *Help Me Grow* Program through the Children's Trust Fund. (*Help Me Grow* was formerly known as *ChildServ*, which served the city of Hartford.)

is grounded in the original premise of Connecticut Infoline. Whoever answers the telephone should be the caseworker, whenever possible, who stays with the caller until the situation is resolved and the case is closed. Triaging to specialists within a Call Center can add to the confusion that many callers experience while trying to negotiate on their own the maze of services and resources. On a practical level, the more specialized the staff, the more difficult it is to adequately maintain the call center. Vacations, sick time, staff turnover, and time off the phones for staff meetings and trainings can severely compromise the ability to be a fully-functioning call center. While cross training maximizes the number of CCs available to all callers, handling the full range of calls coming into CDI increases the intensity and scope of their work. Regardless of where a case may ultimately be referred, the initial assessment process used with all callers to CDI is consistent and based on the model developed and used by generic I & Rs. The goal of the CC is to determine the child's and her/his family's needs in order to share accurate information, make a timely referral(s), and, if necessary, advocate on behalf of the family. In telephone interviewing, the relationship between caller and interviewer is verbal. There is no eye contact or observation of body language. There are no opportunities to provide positive feedback or offer encouragement by nodding or smiling. While this might appear to limit the interview process, the CCs have honed their listening skills (How does the caller sound? Are there background noises, such as baby crying?) and telephone interviewing techniques, which are based on guidance developed for I&R telephone interviews. Listening is done with attentiveness, questions are asked with sensitivity, confidence is treated with respect, restraint is exercised in imposing personal views on callers, and care is taken to avoid disappointments and uneasiness based on glib and ill-founded statements and promises. The term ''access point to care'' does not adequately describe the important work that is done on behalf of families by the CCs. A successful specialized call center is dependent on knowledgeable, well-trained Care Coordinators who are often the ''glue'' that assists parents in finding the information and/or services needed by their children and families.

From the perspective of the caller, using the telephone as the communication vehicle for seeking help provides her/him with the ability to control how much and when she/he is willing to disclose information about their situation. The skills and compassion of the CC make the caller feel comfortable in sharing information. There are several broad categories of CDI callers. These categories are consistent with other specialized call centers and generic I&R services. For some callers, CDI is the first place that they have sought help for a child about whom they are worried. It may be the first time that they have ever articulated their concerns or fears about their child's development or a behavior problem. In order to help this caller (usually a parent), the CC must make it safe by giving verbal cues of encouragement and not passing judgment, while reassuring the caller that they will work with them in addressing the issue. Other callers have tried to obtain help on their own and come to CDI frustrated, often times angry, and increasingly concerned about the situation for which there does not seem to be any relief. Allowing a caller to ventilate is an important first step in providing a positive experience with CDI and with the program to which a referral is ultimately made. Another challenging type of call occurs when the person calling is very articulate about what they are looking for, but during the course of the interview the CC realizes that what they want is not really what is needed to address or resolve the presenting problem. Helping a caller in this type of situation can be challenging, as there is often resistance to hearing different options.

As the access point for several programs serving children in Connecticut, CDI staff are responsible for making callers feel respected, doing an accurate assessment of the situation, offering reassurance and education, obtaining mutual consensus on the next steps for help, and making appropriate and timely referrals to programs and services. CDI offers a free and confidential access point to the *Birth to Three* system, *Preschool Special Education Services, Children with Special Health Care Needs,* and the *Help Me Grow* program. Between July 2004 and March 2005, CDI staff of 7.5 people handled 7,969 cases. The caseload is anticipated to grow and an increased awareness of CDI is welcomed. However, in order not to compromise quality, an increase in call volume must be balanced by having an adequate number of trained and knowledgeable CCs, including bicultural and bilingual staff.

THE RELATIONSHIP BETWEEN CDI AND *HELP ME GROW*

In July 2002, the *Help Me Grow* program of the Children's Trust Fund began operating with CDI serving as the program's access point. *Help Me Grow*, a statewide expansion of the Hartford-based *ChildServ* program, is

designed to connect families to needed community resources. Unlike the other programs for which CDI serves as the point of contact, *Help Me Grow* is not a self-contained system of services. Once a mutually agreed upon decision is made between the family and CC on services needed, a search for the community-based resources that can meet those needs is performed.

A number of supports are available to assist the CC in finding appropriate resources in a timely manner. As part of the United Way of Connecticut/211 Infoline system, the CCs have access to REFER, a searchable computerized database that consists of a comprehensive inventory of Connecticut's health and human services. REFER includes information on 4,795 providers, 47,200 service sites, and 1,900 support groups. REFER is maintained by a 7 member staff of the Infoline's Information Division and is updated on an ongoing basis. Even the constantly updated REFER database is limited in the provision of timely information, such as whether a program has a waiting list, new eligibility guidelines, change in staff, at the point in time that the information is needed by a family.

Information that the CCs obtain through REFER is supplemented by the *Help Me Grow* child development liaison (CDL) staff, who are the community-based research component of the program. CDLs work with the CCs in locating resources and, in some cases, expediting the referral process. The CDLs are regionally based throughout the state and are active participants in local meetings, networks, and coalitions. The relationships that they establish with local providers enable *Help Me Grow* to identify and access services on both formal and informal bases. The CDLs are an invaluable component of the *Help Me Grow* program. Not only is their information shared with the CCs who, in turn, share it with the families, but the information is also given to Infoline's Information Division for inclusion in the REFER database.

CDI staff also use the knowledge and expertise available in the other call centers of the United Way of Connecticut/ Infoline system, including 211 Infoline, Child Care Infoline, the HUSKY Infoline, and Care 4 Kids. 211 Infoline, the generic I & R component of the system, offers information and referrals on a broad range of services, including basic needs. Staff in the 211 unit are also trained in crisis intervention and, in 1995, Infoline was certified by the American Association of Suicidology. Child Care Infoline helps parents find child care and related services. HUSKY Infoline informs families about health coverage eligibility and benefits of the state's HUSKY program, which consists of Medicaid managed care coverage for income eligible children and their families (HUSKY A) and the newer federal program, State Child Health Insurance Program (SCHIP), for children living in households that are over-income for Medicaid (HUSKY B). The Care 4 Kids call center is the access point for a child care subsidy program that helps low to moderate income families pay for their child care expenses.

Having access to and the support of the CDLs and staff from the other Infoline call centers is essential in order to meet families' full range of needs, many of whom are dealing with a number of problems, concerns, and issues. A hierarchy of need must be identified and addressed by the CCs during the interview process. If a family is confronting an eviction, needs food or heat, or is living in an unstable environment as a result of domestic violence, substance abuse, or homelessness, it is unrealistic to expect them to deal with their child's developmental or behavioral issue until the more pressing needs are addressed. If parents feel that the CCs are interviewing them in a safe and non-judgmental manner, they often disclose information that goes beyond the initial reason of the call. Having the CDLs, their community-based contacts, and staff from Infoline's other call centers available for situations that are beyond the scope of CDI helps to ensure that Infoline offers a seamless system of help, regardless of which call center is initially contacted.

As the CCs work with families, third party referrals, and community-based agencies, they recognize the importance of delivering and securing family-driven care, as families are empowered to be the primary decision maker in the care of their children. When a parent initiates the call to CDI, the first step of family-driven care has taken place. In order for family-driven care to be maintained in cases that start with a third party referral, including those from pediatricians, communication among the referral source, the family, and CDI must be clear and consistent. All third party referrals require that a CDI staff person contact the family. In order for that call to be welcomed by the family, the expectation between the referral source and the family must be clarified. Ideally, third party referral sources should encourage families to be proactive and to initiate the call on their own. In some third party referral situations, when the CC contacts the family and the family either did not hear and/or accept what the referral source told them about CDI, the call is not welcomed and can result in a negative, even threatening, experience for the parents. Third party referral sources must ensure that parents understand and accept a referral to CDI. When this does not happen, despite a CC's best efforts to listen, interview, and help, successfully connecting with the family is in jeopardy. CCs are always available to discuss situations with third party referral sources and together think about the best way to work with different families, even before a referral is made.

Another aspect of the definition of family-driven care is that families have a role in the policies and procedures that govern the care of children. *Help Me Grow*, through CDI, provides some families with a vehicle for influencing policy by inviting them to share their personal situation with policy makers. When families accept the invitation, policymakers are given a unique opportunity to hear first hand from parents about the gaps and barriers they confront in seeking services for their child(ren).

Automated Client Tracking System

The CDI client tracking system has been developed in order to provide the *Help Me Grow* program with client-generated data. The Database of Children (DOC) was developed for tracking all calls except *Birth to Three* cases, which CDI staff data enter directly into a Department of

Mental Retardation database. DOC is based on both the *Birth to Three* and HUSKY Infoline client tracking systems. Demographic information, how the caller heard about CDI, and the presenting concern that are collected in DOC are similar to the information obtained in the *Birth to Three* database. The reason for the call, what action(s) the CC took, where referrals were made, and the outcome of the case are field elements modeled after the HUSKY Infoline client tracking system. The outcome of the case is coded from a system's perspective – did the family receive the needed service(s)?

Coding an outcome with anything other than unknown is dependent on having a follow-up contact with families. CDI's follow-up policy requires that the CCs do three follow-up telephone calls on different days and at different times of the day. If telephone contact is unsuccessful, a letter is sent to the families with referral information and a request to contact CDI. Despite these efforts, follow-up attempts are unsuccessful in a large number of cases, consistent with other call centers' follow-up attempts. Many households that the CCs are unable to reach are the high-risk families who lack phones, have phones that have been disconnected, or have moved and are usually dealing with a host of problems and issues. These are the families that often ''fall through the cracks.''

Reports generated from DOC include demographic information on the callers, information on the primary health provider of the child, how the caller heard about CDI, the presenting concern, the reason(s) for calling, what action(s) the CC took to help the family, where referrals were made and, when known, the case disposition based on whether the family received the services for their child(ren) and family.

LESSONS LEARNED AND NEXT STEPS

Specialized call centers offer an efficient and cost effective access point to services for children with developmental and behavioral issues. The call center must be adequately staffed by trained telephone caseworkers, who have substantive knowledge of child development. The staff must be bilingual and culturally diverse.

In order to meet the full range of needs and concerns of callers to a specialized call center, there must be relationships with a generic I & R and other relevant specialized call centers. When there is one entity responsible for providing a comprehensive, one-stop shopping system within a specified geographic area, such as the United Way of Connecticut/211 Infoline, the framework for that relationship already exists. In situations where there are multiple organizations administering call centers, mutually agreed upon formal (and informal) systems for communication, coordination, and collaboration need to be developed and maintained.

While a searchable computerized inventory of community-based resources is essential, the ability to make appropriate and accessible referrals must go beyond the technology to the personal. Reciprocal relationships between the call center and direct service providers must be cultivated, maintained, and respected. The establishment of regional reciprocal contracts with commonly-used referral sources help to expedite a referral, linking the family quickly and seamlessly to a community resource. Giving CCs the ability to book appointments at the community-based agencies should be explored as a component of the scope of work defined in reciprocal contracts.

There is a precedent for booking appointments through Infoline. In 1989 and 1990, Infoline's South Central regional office served as the Pregnancy HealthLine (PHL) for the New Haven Special Commission on Infant Health. The PHL staff (imbedded within the telephone casework staff) were able to book prenatal care appointments at the two community health centers and two hospitals in the city. Based on an evaluation of the service conducted in 1990 by Cartoof and Carey, ninety percent of the women kept the prenatal care appointment that was made for them by the PHL.

In order to track the work of the call center and, even more importantly, how families fare in seeking mutually-agreed upon services, a client tracking system needs to be developed. All telephone caseworkers must be trained and supported in data entering case information in a consistent manner, to ensure that the reports generated are valid and reliable.

A limitation of a telephone access point is the need for a telephone. Even in this era of the ubiquitous cell phone, many high-risk families lack access to a telephone, therefore limiting their ability to connect with a call center. The next step in the evolution of specialized call centers is adding a home visiting component. This can be done either as an extension of the call center or by contracting with community-based home visiting programs. The ability to visit families in their homes or at other mutually acceptable places in their community would help to identify family needs. This extension of the service would help marginalized families, many of whom are dealing with a plethora of problems, connect to needed services before their situation reaches crisis proportions.

REFERENCE

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