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AUTHOR King, Christopher T.
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ABSTRACT

Researchers evaluated On the Right Track, which works to prevent secondary conditions for Texans with disabilities. The three main goals are: science (knowledge concerning the magnitude and severity of disabilities and secondary conditions); service (promoting healthy lifestyles by increasing awareness of the need for preventing secondary conditions among consumers, providers, and policymakers); and leadership (strengthening the Texas Department of Health's [TDH's] leadership role in understanding and preventing secondary conditions associated with disabilities in the learning domain). Evaluation activities addressed process and implementation aspects. Researchers reviewed project documents and interviewed current and former project staff, TDH staff, key people at specific sites, and Southwest Texas State University researchers. The first 3 years were not totally successful in terms of the three goals. There were continuing contracting and staff turnover problems at all levels, shifts in project focus, and difficulties securing required approvals. The science goal was most problematic. Most of the research components had not succeeded as science projects by year 3. Service and leadership activities were more successful. A Web site became operational and accessible, and most promotional activities had occurred. Staff made substantial progress in bolstering the agency's leadership position in the disability policy area. (Contains 18 references.) (SM)

Year Three Evaluation: *On the Right Track*

Christopher T. King

February 2001

Ray Marshall Center for the
Study of Human Resources



Lyndon B. Johnson School of Public Affairs
The University of Texas at Austin
3001 Lake Austin Blvd., Suite 3.200 Austin, TX 78703 (512) 471-7891

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Executive Summary

Researchers at the Ray Marshall Center for the Study of Human Resources contracted with the Texas Department of Health (TDH) to evaluate its *On the Right Track* Project, a project funded by the Centers for Disease Control and Prevention to address the prevention of secondary conditions for persons with disabilities in Texas. In addition to the Evaluation goal that the Ray Marshall Center is addressing, the project has three main goals: Science, Service and Leadership. The Science goal addresses knowledge concerning the magnitude and severity of disabilities and secondary conditions. The Service goal is concerned with promoting healthy lifestyles for people with disabilities in Texas by increasing the awareness of the need for preventing secondary conditions within the learning domain among consumers, providers and policy makers. The Leadership goal relates to strengthening TDH's leadership role in understanding and preventing secondary conditions that are associated with disabilities in the learning domain. Ultimately, *On the Right Track* seeks to improve learning, achievement, and overall quality of life in people with disabilities in Texas.

The evaluation of Year 3 *On the Right Track* activities primarily addressed process and implementation aspects of the project. Researchers reviewed project documents and conducted structured interviews with current and former *On the Right Track* and related staff at TDH, as well as key individuals with sites in Bell and Harris County and researchers at Southwest Texas State University.

The first three years of the *On the Right Track* implementation have not been a complete success in terms of its three major (non-Evaluation) goals and associated objectives. There have been continuing contracting and staff turnover problems at all levels, shifts in project focus, and difficulties with securing the required IRB approvals, among others. The Science goal has been the most problematical. While the BRFSS data analysis conducted by Southwest Texas State University researchers proceeded largely on schedule, none of the other component efforts, including the Houston/telemedicine and Bell County family-centered planning projects, had succeeded as Science projects by the end of Year 3. However, many important accomplishments

have been logged in this time. Activities under the Service and Leadership goals were carried out with greater success.

Under the Service goal, the *On the Right Track* website was operational and highly accessible by year's end, and most of the related promotional activities had occurred as well. Project staff also made substantial progress in bolstering the agency's leadership position in the disability policy area. TDH accomplished these goals working closely with and through key *On the Right Track* partners, especially the Southwest Texas State University research team in San Marcos. It also enjoyed a boost of energy and expertise with the addition of the Central Texas Network for Children with Special Needs located in Bell County. *On the Right Track* has now largely been reoriented as a capacity- and systems-building project as CDC had originally intended and has begun to focus on integrating its CDC-funded activities within TDH and the larger disability prevention umbrella as part of the post-grant transition.

In Year 4, the Ray Marshall Center will work closely with TDH and its partner staff to evaluate the effectiveness of family-centered planning training in Temple for trainers, family members, educators and health care providers and to develop an evaluation approach that can capture and measure progress on the important systems- and capacity-building dimensions of the project.

INTRODUCTION

Researchers at the Ray Marshall Center for the Study of Human Resources, a research unit of the Lyndon B. Johnson School of Public Affairs at the University of Texas at Austin, contracted with the Texas Department of Health (TDH) to evaluate its *On the Right Track* Project, a project funded by the Centers for Disease Control and Prevention (CDC). The Ray Marshall Center prepared an earlier *On the Right Track* evaluation report as well, a retrospective look at its year-two activities (Betsinger and King 1999). An evaluation of the first year of the project was prepared by a research team from the University of Texas at Austin's University Affiliated Program (UAP 1998).

On the Right Track Overview

Staff at TDH designed *On the Right Track* primarily to address the prevention of secondary conditions for persons with disabilities in Texas. The project grew out of earlier work by the Texas legislature that highlighted gaps in services and information available to Texans with disabilities that TDH staff subsequently used in designing the project. Beyond the goal of evaluating the project, which the Ray Marshall Center is addressing, the project has three main goals: Science, Service and Leadership (Texas Department of Health 1998, pp. 20-25). The Science goal addresses knowledge concerning the magnitude and severity of disabilities and secondary conditions. The Science goal is one that Texas has chosen to emphasize. When it issued the request for proposals, CDC was primarily seeking to fund projects geared towards service provision and capacity building. The Service goal is concerned with promoting healthy lifestyles for people with disabilities in Texas by increasing the awareness of the need for preventing secondary conditions within the learning domain among consumers, providers and policy makers. The Leadership goal relates to strengthening TDH's leadership role in understanding and preventing secondary conditions that are associated with disabilities in the learning domain. While the mix of project activities and partners have changed over its three years of implementation, the project's goals have remained largely the

same. Ultimately, *On the Right Track* seeks to improve learning, achievement, and overall quality of life in people with disabilities in Texas (TDH, “*On the Right Track*” *Blueprint for Action*, p. 1).

TDH staff expect the following benefits to result from the *On the Right Track* Project (TDH 1997, pp. 31-32):

- Improved ability by the state to collect and analyze available data from various organizations related to secondary effects of disabilities on learning;
- Increased understanding of disabilities in Texas and their impact on individuals;
- Determination of the incidence and prevalence of secondary disabilities in the learning domain and their associated conditions and protective factors;
- Training of physicians, nurse practitioners, managed care organization medical directors, and care coordinators in the early identification of disabilities in children; and
- Implementation of effective health promotion and technical assistance activities for consumers, family members, service providers, state agency staff, and policy makers on the prevention of secondary conditions.

Year 3 Evaluation Approach and Emphases

The Ray Marshall Center’s evaluation of Year 3 *On the Right Track* activities has primarily addressed process and implementation aspects of the project. Researchers have reviewed project documents extensively, including project reports from the various partners, reports prepared under the project, website and promotional materials, etc. They also conducted numerous structured interviews with current and former *On the Right Track* and related staff at TDH, as well as key individuals with the Bell and Harris County sites and Southwest Texas State University researchers. A complete list of evaluation interviews is provided in Appendix A.

TDH and Ray Marshall Center staff jointly decided that, while progress on all aspects of the project should be documented, Year 3 evaluation activities should emphasize progress made in the following areas, largely reflecting the shift taking place in the *On the Right Track* activities:

- The Central Texas Network for Children with Special Health Care Needs project in Temple/Bell County on family-centered planning;

- Southwest Texas State University's efforts on statewide strategic planning and systems change; and
- TDH's *On the Right Track* website and health promotion materials.

Organization of the Text

The second section of the report offers an overview of key features of the *On the Right Track* Project. The third section reviews implementation progress in Year 3, with emphasis on the three areas mentioned above. The fourth section discusses various challenges and opportunities encountered during Year 3, as well as a series of lessons learned. The fifth section provides concluding observations and several recommendations for improvement. The final section summarizes Year 4 evaluation plans.

KEY ON THE RIGHT TRACK PROJECT FEATURES

The *On the Right Track* project addresses the prevention of secondary conditions for persons with disabilities in Texas through improving learning, achievement, and overall quality of life in people with disabilities. It has been funded since July 1997, pursuant to a request for proposals issued by the Centers for Disease Control and Prevention. The impetus for the project was widespread recognition that 1) services for individuals with disabilities and their families were both *limited* and *fragmented*, and that 2) there were significant service *gaps*, especially for children with disabilities who were 'aging-out' of services provided to very young (0-3 year old) children by the Texas Interagency Council on Early Childhood Intervention (ECI) but had yet to reach school age (i.e., the learning domain). Rather than approach this broad-based effort as a traditional top-down, state-controlled initiative, TDH opted to pursue a highly collaborative approach that engaged relevant state agencies as well as a series of local partners. Following research on the families of children with disabilities by nationally recognized experts Dr. Mary McCarthy at UAP, Dr. Carl Durst and others, TDH staff also adopted a family-centered health planning model as the basis for their service-related activities. A strong family-centered approach is especially important in a field with highly fragmented services, since it relies on empowered consumers — including

families, but also educators and health care providers — to drive and improve service delivery over time.

Each of the *On the Right Track* project's main goals contains several objectives and sets of activities designed to accomplish them. These goals and their revised objectives for Year 3 are as follows (TDH 2000):

Goal 1: Science—To address the magnitude and severity of disabilities and secondary conditions.

Objective 1.1 Implement the Harris County/Houston pilot research project to study the impact of telemedicine on the involvement of health care providers in the educational setting for more comprehensive and effective assessment and planning and to document the prevention of secondary conditions and risk/protective factors in children/people aged 3-22 with disabilities.

Objective 1.2 Implement the Bell County/Temple pilot research project to test the Family-Centered Planning Intervention method in elementary-aged school children with disabilities and to document their associated secondary conditions and risk/protective factors.

Objective 1.3 Collaborate with other state agencies and organizations providing services to people with disabilities to review and analyze existing data sets to identify the nature and extent of disabilities and associated secondary conditions within the learning domain in people of all ages.

Objective 1.4 Conduct Behavioral Risk Factor Surveillance System (BRFSS) survey to determine the severity of learning domain disabilities and secondary conditions in Texas and in Harris County.

Objective 1.5 Sustain condition-specific injury surveillance activities.

Goal 2: Service—To promote healthy lifestyles for people with disabilities in Texas by increasing the awareness of the need to prevent secondary conditions within the learning domain among consumers, providers and policy makers.

Objective 2.1 Complete and promote the *On the Right Track* website for the education and training of Texas health care providers, educators, and consumers on awareness of and knowledge about the prevention of secondary conditions, the principles of the Texas Strategic Plan for the Prevention of Secondary Conditions, and strategies for the prevention of secondary conditions in the learning domain.

Objective 2.2 Produce broad-based health promotion materials specified in the Strategic Plan to educate consumers, family members, and service providers on the prevention of secondary conditions in the learning domain.

Goal 3: Leadership—To strengthen the leadership role of the Texas Department of Health in the understanding and prevention of secondary conditions associated with disabilities in the learning domain.

Objective 3.1 Distribute the State Strategic Plan for the Prevention of Secondary Conditions in the learning domain in collaboration with other states agencies and disability service/advocacy organizations, to promote healthy lifestyles among people with disabilities and increase awareness of prevention of secondary conditions among consumers, service providers, and policy makers.

Objective 3.2 Increase the visibility of the *On the Right Track* Advisory Committee (ORTAC) and the Texas Office for the Prevention of Developmental Disabilities (TOP) through establishing effective partnerships with consumers, state agencies, and disability service/advocacy organizations to promote healthy lifestyles through the prevention of secondary conditions.

YEAR 3 PROJECT IMPLEMENTATION

Before noting the milestones that were surpassed in Year 3 (July 1999 to June 2000) of *On the Right Track* implementation, it is worth noting that this year constituted

yet another year of transition in many respects. First, as discussed below, there was considerable staff turnover at the state and local level, including almost complete replacement of *On the Right Track* project staff at TDH in the second half of the year. Second, continuing difficulties with seeking and securing the requisite Institutional Review Board (IRB) approvals led to a marked shift in emphasis in the project overall, from a balance of science through research on individual subjects, service and leadership to a focus almost exclusively on service and leadership. One TDH staff member explained that they had dropped the idea of doing research "... in favor of making a practical service-type contribution." It is worth noting that this shift represents a return to the original focus of the CDC request for proposals, which had been service provision and capacity building, not research, *per se*. Some of the local pilots (e.g., Harris County/Houston) ceased to participate in funded project activities altogether, even though there are indications that the desired activities continue to some extent *without* project support. And, third, even within the local pilot projects still underway there were continuing modifications in scope, orientation and activities (e.g., Bell County/Temple).

Science

Objective 1.1 under the Science goal was tied to implementing the Harris County/Houston pilot research project to study the impact of telemedicine on health care provider involvement in an educational setting — i.e., the T. H. Rogers Education Center within the Houston Independent School District (ISD) with the active participation of the Baylor College of Medicine — for more comprehensive and effective assessment and planning and to document the prevention of secondary conditions and risk/protective factors in children/people aged 3-22 with disabilities. None of the scheduled activities under this objective were successfully carried out in Year 3:

- IRB approvals were to have been secured from Houston ISD, the Texas Department of Health and the Baylor College of Medicine, but despite considerable time and effort invested, only one of the IRB approvals (TDH) was secured for the Harris County project in Year 3. Baylor College of Medicine performed its initial review and suggested changes before subsequently relocating their IRB approval process out of state. As a result, the requisite approvals for this project were not secured from the Office for Human Research Protections at the National Institutes of Health (NIH).

- All of the remaining project activities — including collecting and analyzing data and conducting focus groups with telemedicine project participants in Houston — were contingent upon securing IRB approvals.

On the Right Track staff at TDH have been disappointed with their lack of success in securing IRB approvals for this and other facets of the project, as well as with high levels of staff turnover in Houston. TDH staff characterize these events as having "... contributed to the virtual shut-down of activities on this project" (TDH 2000, p. 1). T. H. Rogers Education Center, a unique Houston ISD educational entity that serves students with disabilities and other groups, had an energetic principal who had been one of the driving forces behind the telemedicine project. Several months into Year 3, this individual left for another position. New principal, Linda Anderson, is viewed as a leader in her own right, but understandably had her hands full in her new job without taking on an ancillary telemedicine project that has had its share of problems over several years.

Despite these problems, there are encouraging indications that Baylor College and Houston ISD staff may continue to work towards providing telemedicine services for disabled students in Houston, but without CDC funding. In addition, TDH has proposed that the partners, i.e., TDH, Baylor College of Medicine, Texas Children's Hospital and Houston ISD, "... focus their energy on conducting and participating in training to improve communication and the practice of family-centered care and planning among family members, educators, and health care providers to ultimately enable understanding and implementation of prevention strategies and reduce the incidence of secondary disabilities of children at T. H. Rogers School" (TDH 2000, p. 2). The planned training will involve both didactic and practicum training in family-centered care and planning, as well as the use of supportive technology — i.e., telemedicine — to improve service delivery to children with disabilities and their families.

The second Objective (1.2) under the Science goal pertained to implementing the Bell County/Temple pilot research project to test the Family-Centered Planning Intervention Method in elementary-aged school children with disabilities and to document their associated secondary conditions and risk/protective factors. This project fared much better than the one in Houston and will continue into Year 4, although it too

encountered its share of IRB approval problems. Key scheduled activities for the Bell County project and their status in Year 3 include:

- IRB approvals were to have been secured from Temple ISD, Scott and White Clinic, and TDH, and assurance letters submitted to NIH for their approval. IRB committees at Scott and White and TDH both suggested minor changes and, at year's end, were reviewing a project manuscript that had been revised to reflect these changes. These changes are not likely to be addressed fully in Year 4; at this stage in the project, CDC would not fund additional research activities.
- In mid-January 2000, TDH signed a contract with the Central Texas Network for Children with Special Needs, a grass-roots, non-profit, community-based organization serving Bell County, to recruit, select and train facilitators (termed "trainers" by the Central Texas Network) on family-centered care.
- The Central Texas Network hired a lead trainer and six team trainers from the Bell County area in January 2000.
- Trainers participated in training in family-centered care and support provided by UAP on January 17-19, 2000, and again on February 21-23, 2000, in Austin, as well as two days of additional training in family-centered care and permanency planning provided in June 2000 by Reena Wagle, TDH project coordinator for the federally funded *Texas Family Supports Initiative*. These activities occurred late in Year 3 in large part due to delays in negotiating specific project activities between TDH, Scott and White, and the Central Texas Network, along with the aforementioned problem of staff turnover.
- All of the remaining activities, including initiating Family-Centered, Collaborative Planning interventions, TDH provision of ongoing technical support and conducting participant focus groups in Temple, also were delayed into Year 4. Moreover, the Central Texas Network may approach the interventions more from a *person-oriented* rather than a family-oriented viewpoint.
- Central Texas Network staff, with TDH approval, utilized unexpended Year 3 project balances to purchase some \$27,000 worth of equipment in readiness for Year 4 implementation.

While the Central Texas Network was not satisfied with the initial training provided, feeling it was too generic and conceptual to be of use in their work and dealing with software that proved less than useful, they were pleased with subsequent training that was provided them. The Central Texas Network's trainers will "... focus their activities on developing training materials on family-centered care and planning and

offering facilitation of family-centered care and planning in the Bell County area” (TDH 2000, p. 2).

Another set of activities under the Science goal is tied to Objective 1.3 that is concerned with collaborating with other state agencies and organizations providing services to people with disabilities to review and analyze existing data sets to identify the nature and extent of disabilities and associated secondary conditions within the learning domain. TDH staff made limited progress towards achieving this objective, as follows:

- As reported to CDC during their staff visit to Austin in early January 2000, TDH staff continued their efforts to collect and analyze numerous, potentially relevant data sets to determine the nature and extent of disabilities and secondary conditions in the learning domain, including: the Public Education Information Management System (or PEIMS) data from the Texas Education Agency; data from the Texas Department of Mental Health and Mental Retardation; Medicaid data from the Texas Department of Human Services; and data from TDH’s Chronically Ill and Disabled Children’s Services Program. No reports were produced.
- TDH staff efforts to collect relevant state-level information from the Social Security Administration (SSA) were largely unsuccessful and have been discontinued. After repeated attempts, SSA eventually referred TDH staff to an SSA website that did not contain the desired data. No reports were produced from this activity.
- TDH staff made initial progress towards developing a planned Quality of Life (QoL) Survey for persons with disabilities, reviewing and cataloging existing QoL surveys and questions. This information was presented to CDC staff in early January during their project visit to Austin. No further progress was made from January through June 2000, however, due to *On the Right Track* and other staff turnover and increased workload demands.

Science objective 1.4 calls for conducting a Behavioral Risk Factor Surveillance System (BRFSS) survey to determine the severity of learning domain disabilities and secondary conditions in Texas. This objective was largely achieved. Plans called for Module 16 data (pertaining to adults with disabilities) to be collected and analyzed for both 1998 and 1999. This set of activities are being carried out jointly by TDH BRFSS staff (securing, checking and cleaning the data sets) and Dr. Charles Johnson, chair of the Department of Health Research at Southwest Texas State University.

- The 1998 BRFSS data were received and analyzed by Dr. Johnson, resulting in the June 2000 report, *Texas BRFSS, 1998 – Module 16, Quality of Life*. This report is a descriptive “snapshot” of adults with disabilities only. Cell sizes were too small to support statistical inference or meaningful disaggregation by such factors as age, ethnicity, or geographic region, according to Dr. Johnson. Copies of this report were distributed to ORTAC and TOP members who requested them.
- The 1999 BRFSS data were initially received in mid-April 2000 by Ken Condon, the director of TDH’s BRFSS office. The data set had several errors that were subsequently corrected in the final data set provided in late April. Algorithms for setting up the 1999 data tables required revision due to file specification changes between years, and staff reductions in the state BRFSS office also slowed down 1999 data processing. The 1999 BRFSS Module 16 tables were provided to the *On the Right Track* staff in mid-June 2000. Dr. Johnson will be analyzing the 1999 data — and merging data across 1998 and 1999 to increase cell sizes — in Year 4.

While BRFSS-related activities took place largely as planned, there are continuing issues about the ‘goodness of fit’ between these data and the primary focus of the *On the Right Track* project as Texas has implemented it. The BRFSS Module 16 survey required by CDC of all projects only gathers data on adults and does not allow for linkages between these and data for their children or others with disabilities in the learning domain. Nor do the data permit the identification of the source of the original disability, although some are relatively obvious. All projects were required to include the BRFSS Module 16 adult-oriented survey as a condition of receiving CDC funding. TDH was fully aware of this when it decided to focus its efforts largely on children with disabilities in the learning domain.

The final Science objective (1.5) concerns TDH efforts to sustain condition-specific injury surveillance activities including those for spinal cord, traumatic brain injury (TBI) and submersion injuries statewide. Most of the scheduled activities for this objective were largely completed in Year 3, as statewide surveillance continued. TDH completed the following analyses and reports as scheduled in Year 3:

- An analysis of 1998 submersion injury data with charts has been loaded onto TDH’s Bureau of Epidemiology website (www.tdh.state.tx.us.us/injury).
- The 1998 annual report on drownings in Texas swimming pools.
- The 1998 annual report on spinal injuries.

- The 1997 annual report on traumatic brain injuries, which is completed and has been loaded onto the *On the Right Track* website; 1998 TBI data have not yet been analyzed.
- A report on changes in Texas law and reporting requirements for TBI was submitted to CDC in late 1999.

Additional TBI-related activities will also be taking place in the future, building on the efforts of *On the Right Track*, but funded by a grant to the Texas Health and Human Services Commission (HHSC) from the federal Health Research Services Administration. TDH's Children with Special Health Care Needs (CSHCN) Division, within the Bureau of Children's Health, will co-administer the grant with HHSC and use the funds to enhance services provided to persons with TBI and their families. These activities will be coordinated with TBI-related efforts in the *On the Right Track* project.

On the Right Track made substantial progress on only three of its five Science objectives. The Harris County telemedicine project (objective 1.1) has been discontinued in so far as CDH funding is concerned, though the local organizations may continue to provide the desired services with other sources of support. The Central Texas Network is now positioned to implement the Bell County family-centered planning project (objective 1.2) in Year 4, but as a service not a research initiative. TDH staff made limited progress in completing the data collaboration activities under objective 1.3, but were largely successful in conducting the BRFSS analyses under objective 1.4. The agency's efforts on injury surveillance data collection and reporting under objective 1.5 were completed as planned. Overall, some of the more discrete *On the Right Track* Science objectives were completed by TDH staff, while others (e.g., Bell County) were transformed into service-oriented projects. Few of the research activities will continue into Year 4. De-emphasizing research (i.e., Science) activities essentially brings Texas' project for CDC more in line with other states' efforts and is more consistent with the priority accorded service provision and capacity-building in the original 1997 CDC procurement.

Service

The second major goal of the *On the Right Track* project is comprised of two objectives that are related to promoting healthy lifestyles for those with disabilities by increasing awareness and preventing secondary conditions. The Service goal received a great deal of emphasis and attention from *On the Right Track* staff at TDH in Year 3, in part reflecting their inability to complete many of the project's Science activities. The first Service objective (2.1) calls for TDH to complete and promote a website for the education and training of Texas health care providers, educators, and consumers on the prevention of secondary conditions, the principles of the *Texas Strategic Plan for the Prevention of Secondary Conditions*, and strategies for the prevention of secondary conditions in the learning domain. The website was clearly seen as the primary education and training vehicle for the project.

Considerable progress was made in designing, testing, launching and promoting the *On the Right Track* website in Year 3. The website was initially available for viewing in March, and was officially launched in May 2000. (Appendix B provides copies of selected pages downloaded from the website as of August 23, 2000.) Ida Miller, who joined the project staff in late January, now has primary responsibility for website and related health promotion activities. Miller and the *On the Right Track* staff worked collaboratively on the website effort with key partners, including contractor Database City (on website design), Southwest Texas State University (on website content), ORTAC members, fifteen TDH staff identified by the TDH webmaster, and several community representatives, among others. Key features of the website include resource links designed to cut consumer search time for related TDH and national data, disability education and training materials, and other resources; pages specifically tailored to the needs of its primary customers (i.e., families and individuals with disabilities, educators, employers, and health care providers); and certification of its accessibility to those with disabilities (i.e., BOBBY certification). Progress on the website in Year 3 is indicated by the following (TDH 2000, pp. 3-5):

- Website design contractor Database City created the initial website design, revised it in response to TDH comments and made it available for initial viewing on March 1, 2000.
- Beta testing began on March 3, 2000, on a version of the website that had been further edited by Database City.
- The various partners mentioned above spent ten days beta testing the website, providing insightful comments and suggestions for modifications, most of which were incorporated into the final design.
- The website was officially launched in May 2000.

Whether *On the Right Track*'s website will be able to meet the lofty expectations created for it remains to be seen. Year 4 and subsequent post-grant experience will provide the test. The site appears to be easy to locate and access. The website is BOBBY-approved, which means that it meets the accessibility criteria established by the Center for Applied Special Technology (CAST).¹ TDH project staff are currently working on making the site accessible to deaf as well as blind and visually impaired consumers. For example, one effort being explored is the creation of video-streaming in American Sign Language. They are also working with researchers at the University of Washington to create a Spanish version. Given the heavy web-emphasis for promoting *On the Right Track*, project staff have expressed concerns about whether web-based approaches are effective at reaching their key consumer populations. Finally, the *Strategic Plan* is not yet available on the website as had been planned, nor are Southwest Texas State University's various reports for the project (e.g., the BRFSS analysis).

The second Service objective (2.2) directs TDH to produce broad-based health promotion materials to educate consumers, family members, and service providers on the prevention of secondary conditions in the learning domain. Southwest Texas State University Professor Kathy Selber and intern Jennifer Mallow worked closely with Ida Miller and *On the Right Track* staff on the content of these materials. The staff's intent

¹ To become Bobby-approved, a website must provide text equivalents for all images and multimedia; ensure that all information conveyed with is also available without color; identify headers for data tables and make line-by-line reading sensible for layout tables; provide summaries of graphs and charts; and provide alternative content for features (e.g., applets or plug-ins) that may not be supported; among others. See the CAST website: www.cast.org/bobby/.

was to avoid creating materials from scratch but to rely instead on existing materials where possible. Especially given the high staff turnover on the project, considerable progress was made in creating, assembling and disseminating promotional materials in Year 3, as the following examples demonstrate (TDH 2000, pp. 4-9):

- TDH staff devoted considerable time and effort to informing potential customers of the website's availability and promoting its use, including designing postcards to send out advertising the site (late April 2000), promoting the website at various meetings (e.g., ORTAC) and conferences (e.g., the Texas Respite Network's conference) since March, and preparing listserv and email address lists for promotional purposes.
- Jennifer Mallow, the social work intern from Southwest Texas State University who is joining the *On the Right Track* staff, prepared an article reviewing the literature on family-centered planning that has been now been prepared as a brochure for distribution to consumers in Year 4.
- Two Fetal Alcohol Syndrome brochures that were prepared and distributed in a previous grant cycle by TOP are being reviewed for re-printing and distribution in Year 4 by TDH's Division of Women's Health; by May 2000, about 2,000 copies of each brochure had been distributed from warehouse stock in response to provider requests.
- In late 1999, Dr. Lesa Walker administered a knowledge, attitudes, and practice survey to "key informants," including ORTAC and TOP members, the Fetal Alcohol Syndrome Consortium, the Texas Autism Council, the Texas Traumatic Brain Injuries Board, The Down Syndrome Congress and others. This survey concerned family-centered care and planning and special health care needs. An article based on the survey is being prepared.
- An *On the Right Track* brochure was prepared for distribution.
- Preparation of a *Statewide Catalog of Resources for People with Disabilities* was on hold at the end of Year 3, apparently as a result of TDH's reorganization, but the agency is considering contracting with a private vendor to make the database available on the web.
- Southwest Texas State University staff developed a prototype PowerPoint presentation ("*On the Right Track: Exploring the Occurrence of Secondary Conditions in Texas*") based on the focus group research conducted by Dr. Mary McCarthy, training coordinator at UAP. This presentation was piloted at the Bexar County Case Management Coalition's March 15, 2000 meeting.

Finally, a number of Year 3 promotional activities appear to have derived from the *Caring For Infants and Toddlers* (CFIT) project that was funded in Year 1 of *On the*

Right Track. These activities were carried out by the Texas Interagency Council on Early Childhood Intervention (ECI) and may only be indirectly or partly attributed to *On the Right Track*, but they do show evidence of ‘leveraging’ in the short run, since the initial work was funded by the project. Included in these activities were a series of meetings and the preparation of various promotional materials and brochures for pediatricians, health care providers, nurses, and others; and videoconferences. *On the Right Track* staff view these efforts by ECI as “... a good example of the capacity building process generated by the grant” (TDH 2000, p. 8).

It is noteworthy that, according to staff, TDH is relying heavily on the web as the main promotional vehicle for *On the Right Track*. Clearly, the above list also includes other activities that are not web-based. Whether the web is the most effective promotional strategy for *all* of the target consumer audiences is an empirical issue that can be resolved in the future.

What remains for Year 4 is to get the Strategic Plan up on the *On the Right Track* website and to carry through with related marketing and promotional activities. Since *On the Right Track* is in its fourth and final year of CDC funding, it would make sense for staff to develop a detailed transition plan to ensure that worthwhile efforts emerging from this project are integrated with post-grant plans and activities within TDH, as well as other relevant health and human services agencies, e.g., Texas HHSC’s I&R Network.

Leadership

On the Right Track’s Leadership goal seeks to strengthen TDH leadership in understanding and preventing secondary conditions in the learning domain among people with disabilities. The first of two objectives (3.1) under the Leadership goal concerns the distribution of the State Strategic Plan for the Prevention of Secondary Conditions in the learning domain in collaboration with other states agencies and disability service/advocacy organizations. Key Year 3 accomplishments under this objective include:

- The format and content of the Strategic Plan for the Prevention of Secondary Conditions were revised in order to meet broader audience needs. The simplified, 5-

page Strategic Plan, entitled "*On the Right Track*" *Blueprint for Action to Learning, Achievement and Improve Quality of Life for People with Disabilities*, was completed but not loaded onto the *On the Right Track* website by the end of Year 3.

- Copies of the *Blueprint* and other reports prepared by Southwest Texas State University researchers (e.g., the BRFSS analysis) were distributed to all interested ORTAC and TOP members.
- Southwest Texas State University Professor Kathy Selber began presenting the Strategic Plan to various interagency meetings to educate and inform them about it and to solicit their cooperation in mapping statewide activities for *On the Right Track*. The following agencies and organizations were contacted, among others: Texas HHSC, Texas Commission for the Deaf and Hard of Hearing, Texas Interagency Council on Early Childhood Intervention, and Texas DHS. In addition, brochures about the Strategic Plan were "... drafted and reviewed for reading level, clarity of content, and layout by the DHS Health Educators committee and will be printed soon" (TDH 2000, p. 9).
- Meetings were conducted with advocacy groups, state agencies, and others to identify services provided that support the Strategic Plan. Researchers from Southwest Texas State University conducted these 'stakeholder meetings' (focus groups) with *parents* in Dallas (May 6th), Belton (May 16th), and San Antonio (May 20th); and with *providers* in San Marcos (May 19th) and Del Valle near Austin (May 22nd). Each meeting centered on a single question: "What does 'secondary condition' mean to you?" A total of 118 individuals participated in these focus groups which also featured presentations and group discussions on strategic planning themes. Southwest Texas State University researcher Virginia Rondero is analyzing the content of these focus group meetings to identify key themes and outcomes using qualitative data analysis (NU*DIST™) software. Her analysis began in mid-June 2000 and continues in Year 4.²
- In late May 2000 following completion of the focus groups, *On the Right Track* materials, including informational brochures, an annotated bibliography of reading resources, and health promotional materials were distributed to focus group participants.
- Dr. Mary McCarthy, whose work forms the basis for important parts of *On the Right Track's* approach, made several key presentations including a privately funded talk at Southwest Texas State University on April 12, 2000 entitled "Family Centered Health Care: A Consumer-driven Model for Delivering Services," to approximately 250 people, including agency staff, community parent group members, provider representatives, and students.
- Dr. Selber and her staff at Southwest Texas State University began mapping Strategic Plan activities in early 2000 using Geographic Information System (GIS) software as

² The Southwest Texas State University team had considerable experience with securing IRB approvals and also had an IRB exemption for their focus group research, allowing them to "sail through" the process.

well as simple matrices. This work included educating the various agencies and community organizations about *On the Right Track*. Draft maps were submitted to TDH for review early in Year 4. Detailed analyses have not been completed.

- Southwest Texas State University researchers also collaborated with TDH strategic planners and others, including those preparing Texas HHSC's Coordinated Strategic Plan (CSP), to promote integrated principles for the prevention of secondary conditions across agencies.

The second Leadership objective (3.2) seeks to increase the visibility of ORTAC and TOP through establishing effective partnerships with consumers, state agencies, and disability service/advocacy organizations. Key activities and accomplishments under this objective include:

- ORTAC was reconstituted in Year 3; ORTAC members are also on the CSHCN Advisory Council.
- The 22-member ORTAC conducted regular meetings during Year 3, convening in December 1999, March 2000, and early June 2000. In addition, ORTAC members were engaged in the project as "key informants," responding to the TDH survey on family-centered care and planning in the Admissions, Review and Dismissal (ARD) process in schools.
- TDH staff also met with the Director of Austin's Pilot Parent Program, a program that assists the parents of children with disabilities in the ARD and Individual Education Plan development processes to discuss *On the Right Track* activities and learn about other state and local resources for parent assistance and training.

On the Right Track project staff characterize working with ORTAC and TOP as "preaching to the choir." Their members are 'true-believers' regarding the need to prevent secondary conditions for those with disabilities. A key issue for both ORTAC and TOP members is that they are not only committed but *over*-committed: they are described as juggling so many related tasks simultaneously that it is difficult for them to engage these issues for very long. This is a classic phenomenon, certainly not one confined to disability prevention circles.

CHALLENGES, OPPORTUNITIES AND LESSONS

A number of challenges, opportunities and lessons can be identified from the *On the Right Track* project. These are discussed in this section.

Challenges

The challenges identified for the project are a mix of present and future. They have been grouped into four broad categories: administration; model; measurement; and transition. Some of the challenges discussed here were also highlighted in earlier evaluation reports (e.g., Betsinger and King 1999), and all of them have been recognized by TDH and its project partners.

Administration. Several administrative challenges were apparent in Year 3, some of which continue into Year 4 and beyond. First, there were serious difficulties with staff turnover both with the TDH's *On the Right Track* staff, which experienced almost complete turnover in Year 3 including its director, and with some of its partners, especially the Harris County telemedicine project, which lost its key player, the T. H. Rogers principal. For TDH, this may be part of a larger state employee compensation problem: a recent report by the State Auditor's Office documents eroding compensation for state employees, a growing public/private compensation gap and increased state employee turnover, among other dimensions of the problem (State Auditor's Office 2000). These problems are most severe in Austin where state agencies are in direct competition with large high-tech employers offering higher pay, signing bonuses and stock options. However, since the former project director left for a better-paying position within TDH, this may simply reflect a staff person pursuing the most effective way of moving up the career ladder in state employment. Whatever the root cause of the problem, staff turnover in key positions made it even more difficult for *On the Right Track* to complete its scheduled activities and achieve its objectives. For much of Year 3, staff were in transition at the state and local project level (in Harris and Bell Counties), with a resulting loss of focus and momentum.

Second, continuing difficulties with securing IRB approvals not only presented challenges to the research-based components of the effort, but also appear to have been largely responsible for discontinuing them and shifting the project's focus from Science to Service and Leadership, a focus that is actually more consistent with CDC's priorities under the 1997 procurement. IRB problems were evident early in the project (see Betsinger and King 1999) but never successfully addressed for the project as a whole. The Southwest Texas State University research team obtained IRB approval for their Science-related activities; they also had the benefit of a proven track record of success with IRB approval, as well as an IRB exemption for conducting their focus groups. Moreover, two of the projects enjoyed blanket approval to use their own IRB approval processes under. None of the other Science-oriented projects were able to resolve their IRB problems. While such problems may be more common with multi-institution research projects, many of those involved in the project, from CDC to research partners to local project staff, felt that TDH would have been well served to hire 'outside talent' with a proven IRB track record at the outset of the project.³ It is unlikely that most of the project's Science goals and objectives can be accomplished in the time remaining.

Third, TDH and several of its state partners — and probably most organizations of any size, public or private, for that matter — were either beginning or in the midst of significant agency reorganizations during the past year. Restructuring, substantial resorting of roles and responsibilities, has become the rule rather than the exception in recent decades. Reorganization has a very real downside, however, including temporary loss of focus and long-term loss of institutional memory among key staff, among others. Staff from several of the partners at the state and local level alluded to ongoing and impending reorganization as presenting significant challenges to the project. At times, it became difficult to secure commitments from key entities: they were unclear who could make the necessary commitment. TDH's own restructuring has its staff concerned about a successful transition of *On the Right Track* activities within the larger organization. These concerns arose and were dealt with partly in Year 3; they will need to be addressed more fully in Year 4.

³ Several individuals observed that the agency lacked sufficient familiarity and experience with the IRB

Finally, as mentioned in the previous section, the key individuals committed to the prevention of secondary conditions for those with disabilities, notably those on ORTAC and TOP, are too few in number and committed in too many directions within their agencies. This is likely to be a long-term administrative (and programmatic) challenge in this field.

Model. Several aspects of the *On the Right Track* model present challenges as well. First, the very scope and breadth of the project has been a challenge in Year 3 and in the prior years of implementation. The local partners admire the staff's commitment to accomplishing so many important deeds in the three key project goals, but they also question the project's ability to deliver on its promise with time, energy and resources spread so thinly. To some extent, this challenge may be resolving itself, as the Science-related activities have diminished and TDH staff have begun focusing intently on building and reinforcing capacity and ensuring a successful transition in Year 4 and the post-grant period. Again, this renewed emphasis on service provision and capacity-building better reflects CDC's original intent in funding these projects.

Second, one of the central features of the model is its reliance on collaboration among the partners to plan and carry out the activities and to achieve goals and objectives. But, collaboration is staff and resource intensive. With modest resources, goals that range from Service to Leadership, and complex, multi-faceted activities requiring the coordinated efforts of several critical partners, *On the Right Track* has faced very serious challenges in each year of implementation. Year 3 was no exception. The challenges stand out in sharpest relief for the Science goal, where most of the activities simply have been shut down in favor of pursuing the more attainable Service and Leadership goals.

Third, heavy reliance on the project website — and on broad-based TDH websites in the post-grant period— as the vehicle for educating consumers and preventing secondary conditions in the learning domain also presents challenges as discussed briefly above. The verdict is still out concerning the efficacy of this strategy, especially for the

process and that their IRB submissions were of "very low quality," featuring numerous inconsistencies and problems with question design, such that securing IRB approval was unlikely.

families who are seeking services. It is highly likely that educators and health care providers will do well relying primarily on web-based information. Families may be an entirely different story. More research needs to be done on these issues with an eye to the present and anticipated future developments. Existing barriers to access even in the rural communities and *colonias* of the state may not be very serious just a few short years from now given the strides Texas is making on this front and recent requirements the Federal Communications Commission has placed on telecommunication companies to bring electronic services into residences.

Finally, as the Central Texas Network staff pointed out, the requisite training for its participation in *On the Right Track* has been scheduled and provided in relatively large “chunks,” each requiring several days participation away from home. While this is a typical approach to providing staff training in many state agencies, it is not appropriate or effective either for the parents of children with disabilities or for part-time workers serving as facilitator/trainers in the Central Texas family-centered health care initiative. Future training sessions need to be broken down into smaller “bites” so that these groups can more easily and effectively digest them.

Measurement. To the extent that *On the Right Track* has become more oriented towards system- and capacity-building — through both its Service and Leadership activities — and less focused on research in support of its Science goal, simply documenting its accomplishments and gauging its success become real challenges. This is a challenge for addressing the Evaluation goal that the Ray Marshall Center research team must confront during Year 4. Measurement issues are much more easily handled in the context of discrete activities and services, e.g., provision, participation, outcomes, impacts, benefits and costs. There is far greater ambiguity and uncertainty when the emphasis is on capacity and systems issues.

Transition. A final challenge that has been discussed earlier is the transition from a CDC-funded, stand-alone project to sets of activities that are fully integrated into TDH and other agencies’ ongoing efforts on behalf of those with disabilities and related consumer groups, i.e., health care providers, educators, researchers, and employers. There are many dimensions to the transition challenge, including integrating the project

website into TDH's common website, while ensuring that it is maintained in timely fashion, translated into Spanish and fully accessible to those with disabilities (e.g., video-streaming with American Sign Language);⁴ and making sure that the family-centered health care planning activities are picked up by TDH and its partner agencies, among others.

One of the long-term problems facing not only those with disabilities, but also those who educate, train, employ, and design and provide services to them is the problem of incidence. Persons with disabilities comprise approximately one-fifth of the population, a share that is expected to grow as our population ages. Those with sensory disabilities (e.g., blindness, low-vision, hearing) represent much smaller shares. Yet, mass markets garner most of the Nation's attention and resources. While the Americans with Disabilities Act has bolstered the clout of many disability groups, families and individuals over the past decade and have even helped to create and organize markets for such services, there are still problems to be addressed. Fortunately, new technologies, marketing techniques, and production methods are making it possible for markets to more easily address the needs of such 'niche' markets. This may help with *On the Right Track's* transition.

In addition, many of the activities that comprise *On the Right Track* are inherently strategic and collaborative in nature. Ensuring that these activities become an integral part of the efforts by TDH, HHSC and other state and local entities is another important challenge to a successful transition over time.

Opportunities

Where there are challenges, there are usually also opportunities. Opportunities relevant to the *On the Right Track* project come in various forms. Three are discussed here: new partners; leveraging; judicial and legislative mandates; and technology.

New Partners. Year 3 has seen a marked increase in commitment to success on many of *On the Right Track's* goals and objectives. Many of the evaluation interviews

⁴ For example, see Andrew Park, "Disabled find many barriers online," *Austin American-Statesman*, September 3, 2000, p. A1.

were qualitatively different from the prior years; project discussions were peppered with terms like “energy,” “momentum,” “commitment,” and “excitement.” One important explanation for this shift from earlier years is simply that there was an infusion of “new blood” to the project. Both the Southwest Texas State University and Central Texas Network teams brought considerable energy, specialized expertise and commitment to the project in Year 3, as well as their own wide networks of contacts in this field. The principal researchers/leaders for each of these organizations are acknowledged leaders with highly practical skills that *On the Right Track* has needed to succeed.

The contributions of these new partners, along with the growing cohesion and focus of the TDH project staff, are likely to be too late to save the Science (research) aspects of *On the Right Track*, but they may be just what is required for capacity- and systems-building, as well as for ensuring a successful transition in Year 4 and beyond. These partners are networkers by nature and appear to be thoroughly connected and committed to the very areas that are necessary for carrying out these important tasks.

Leveraging. A related opportunity might best be referred to as leveraging. The project’s reliance on a collaborative approach to services through various partners creates opportunities to leverage services provided with CDC grant-funding both in the present and the future. Several examples of both were suggested in Year 3. There are indications that the Houston partners are continuing to pursue telemedicine in Houston ISD’s T. H. Rogers’ School this year, despite their apparent withdrawal from the project.⁵ In addition, Southwest Texas State University researchers reported that they were able to incorporate numerous non-grant-funded articles and presentations by noted experts (e.g., Dr. McCarthy) into their activities on behalf of the project. Finally, the promotion of C-FIT by the Texas Interagency Council on Early Childhood Intervention in Year 4 suggests that there may also been a longer-term payoff from efforts that were initially funded in Year 1. This too is a less obvious form of leveraging.

Judicial and Legislative Mandates. Court and legal mandates often are viewed by administrators as challenges or barriers to be overcome, but in the case of disability policies and services, they are more typically listed as opportunities. Two mandates

⁵ Whether this is fully attributable to *On the Right Track*’s funding and efforts is not known.

present opportunities for *On the Right Track*. First, in June 1999, the U. S. Supreme Court ruled in *Olmstead v L.C. & E.W* that the state of Georgia could not continue to segregate women residing in a state psychiatric hospital long after the agency's own professionals had recommended their transfer to community care. *Olmstead* further bolsters the need for training in family-centered planning. The *Olmstead* decision may provide some of the necessary backing for the transition to the post-grant period. Second, Texas Senate Bill 1563 mandated in 1999 that all state agencies (and universities) address customer satisfaction, in part by conducting customer surveys. This mandate may reinforce the need for research on TDH's website and whether it is working well for all of its major consumer groups, including the families of those with disabilities.

Technology. The final opportunity stems from technology. Many experts now argue that what has been feared as a 'digital divide' may in fact be reduced to little more than a 'digital ditch' in just a few short years. The technology making this happen is in part the development of the television as the basis for Internet access. As one expert recently asked: "You don't worry about a 'TV divide' do you?" While many poor families may approach the Internet with trepidation, if at all, when the computer is the main vehicle available, they are not likely to be daunted by their TV sets. If the shift from computers to TV screens for Internet access occurs in the next few years as many predict, then the *On the Right Track* (and its successor) website must be much more concerned with content than modality.

Lessons Learned

Numerous lessons also emerged in Year 3 of the project. Many of these lessons are not unique to the *On the Right Track* project. Among these lessons, listed in no particular order, are the following:

- Collaboration is very staff-time and resource intensive.
- Securing IRB approval for human subjects research is a critical and specialized skill. Success requires both considerable preparation and follow-up work. Agencies should rely on experts with proven track records for assistance in securing IRB approvals.

- Data collection and reporting of secondary conditions is poorly done, but the same can be said of primary conditions that are poorly measured to start with. Progress on measuring secondary conditions will likely go hand in hand with improvements in the measurement of primary conditions.
- Website creation and maintenance is best implemented by a team process that requires many varied skills.
- Health promotion for *On the Right Track* occurs through activities other than those explicitly designed with promotion in mind. Activities carried out by staff at Southwest Texas State and the Central Texas Network contributed to the promotional aspects of the project as well.
- Every aspect of the disability area is fragmented and poorly supported, including services and data collection and reporting, as well as disability research. Researchers in this area need to collaborate and be engaged in the process along with planners and administrators if their work is to contribute to improved practice.
- Family-centered training should be provided in smaller, more accessible ‘bites,’ not in such large ‘chunks’ if it is to be both accessible and effective, especially for the families of those with disabilities but also for those working in the field.

CONCLUDING OBSERVATIONS AND RECOMMENDATIONS

Overall, the first three years of the *On the Right Track* implementation have not been a complete success in terms of its three major (non-Evaluation) goals and associated objectives. There have been continuing contracting and staff turnover problems at all levels, shifts in project focus, difficulties with securing the required IRB approvals in a very complex, multi-layered, iterative approval process, and others as well. Of the three project goals (excluding Evaluation), the Science goal has been the most problematical. CDC’s original priorities, and their initial resistance to funding research activities over service provision and capacity-building, appear to have been borne out by subsequent experience in Texas. While the BRFSS data analysis proceeded largely on schedule, none of the other Science-related efforts (e.g., the Houston/telemedicine project) had succeeded by the end of Year 3. However, many important accomplishments have been logged in this time. Activities under the Service and Leadership goals were carried out with greater success.

Under the Service goal, the *On the Right Track* website was operational and highly accessible by year's end, and most of the related promotional activities had occurred as well. Project staff had also made substantial progress in bolstering the agency's leadership position in the disability policy area. TDH has accomplished these goals working closely with and through key *On the Right Track* partners, especially the Southwest Texas State University research team in San Marcos. It also enjoyed a boost of energy and expertise with the addition of the Central Texas Network for Children with Special Needs located in Bell County. In fact, the *On the Right Track* project has now largely been reoriented as a capacity- and systems-building project as CDC had originally intended and has begun to focus on integrating its CDC-funded activities within TDH and the larger disability prevention umbrella as part of the post-grant transition.

Recommendations

Several recommendations are offered here, both to foster improvements in continuing *On the Right Track* project as well as to foster subsequent success in disability prevention following grant completion at the end of Year 4. Many of these recommendations emerged during evaluation interviews conducted with partners at all levels.

Recommendation # 1—Website and Related Promotional Activities. Taking advantage of the opportunity presented by the legislative mandate to conduct customer satisfaction surveys and the partners' continuing commitment to improvement, TDH should conduct a well structured survey to determine how well the current approach and mix of website and other promotional efforts is working and how it could be improved.

Recommendation #2—Transition Planning. TDH should build upon the efforts it now has underway to ensure that *On the Right Track's* successes, especially in system- and capacity-building, continue into Year 4 and beyond. Key steps that could be taken to implement this recommendation include:

- Engaging the staff and leadership from TDH and key state agencies, as well as its local partners in the creation of a concrete, highly collaborative transition plan.

- Engaging employer and business associations in the development and subsequent implementation of this plan. Employers are more keenly aware of the value of investing in every potential student and worker now than they ever have been before. Several years of skill shortages have heightened their awareness considerably. Moreover, a number of the new high-tech entrepreneurs have taken a very proprietary interest in this field.
- Building the transition plan around strategically selected individuals and organizations. One of the lessons learned during the project was that people matter. Key individuals and organizations can play a major role in ensuring a successful transition. It would make sense to begin investing well to secure their services now before the project is in its last months.
- Promoting the transition plan with the same level of effort as the *Blueprint*, the state strategic plan.

Recommendation #3—Participatory Research. TDH and the *On the Right Track* staff should adopt a more participatory model for future research projects of this type. One of the disappointments with the project was its lack of success on achieving its Science/research goals and objectives. TDH should engage its research partners, as well as the families affected by the research, at every stage of the process. Adopting a more participatory research approach might not have solved its IRB approval problems, but it might have surfaced hidden ‘talent’ who might well have done so.

Recommendation #4—Resource Allocation. TDH and *On the Right Track* should review the current budget and its allocation among components and projects, including evaluation, to ensure that it is putting its money in the right places to achieve its remaining goals and a successful post-CDC transition. Given the change in the project’s orientation to systems- and capacity-building, it may be that even fewer dollars should be spent on Science (research) and Evaluation in Year 4.

YEAR 4 EVALUATION PLANS

In Year 4, the Ray Marshall Center will be completing its responsibilities under the *On the Right Track’s* Evaluation Goal. To accomplish this, our research team will work closely with TDH and its partner staff to:

- Develop and refine a methodology to evaluate the effectiveness of family-centered planning training in Temple for trainers, family members, educators and health care providers.
- Develop an evaluation approach that can capture and measure progress on the important systems- and capacity-building dimensions of the project.

Our Year 4 activities will largely focus on family-centered planning training, on systems- and capacity-building activities and their effectiveness, and on TDH's health promotion activities, especially its website.

References

- Betsinger, Alicia M. and Christopher T. King (1999). *Year Two Evaluation: On the Right Track*, Austin: Ray Marshall Center for the Study of Human Resources, Lyndon B. Johnson School of Public Affairs, The University of Texas at Austin. August.
- Center for Applied Special Technology website: <http://www.cast.org/bobby/>
- Centers for Disease Control and Prevention [n.d.]. *Disability and Health Project Profiles: Health Promotion for Persons with Disabilities and the Prevention of Secondary Conditions—State Capacity Projects, Research Grants, National Limb Loss Information Center*, Based on Project Submissions to CDC. October.
- O’Shea, Daniel P., Alicia M. Betsinger, and Christopher T. King (1998). *The Value of a Comprehensive Texas Information and Referral Network*, Austin: Center for the Study of Human Resources, Lyndon B. Johnson School of Public Affairs, The University of Texas at Austin. December.
- O’Shea, Daniel P., Leah Kegler, and Christopher T. King (2000). *The Value of a Comprehensive Texas Information and Referral Network: August 2000 Update*, Austin: Center for the Study of Human Resources, Lyndon B. Johnson School of Public Affairs, The University of Texas at Austin. August.
- Park, Andrew, “Disabled find many barriers online,” *Austin American-Statesman*, September 3, 2000, p. A1.
- [Southwest Texas State University] (2000). *On the Right Track: Exploring the Occurrence of Secondary Conditions and the Experience of Disability*, Walter Richter Institute of Social Work Research, College of Health Professions, Department of Social Work, Southwest Texas State University, July.
- [Southwest Texas State University] (2000). *On the Right Track: Health Promotion Report*, Walter Richter Institute of Social Work Research, College of Health Professions, Department of Social Work, Southwest Texas State University, July.
- [Southwest Texas State University] (2000). *On the Right Track: A Roadmap for Texas*, Walter Richter Institute of Social Work Research, College of Health Professions, Department of Social Work, Southwest Texas State University, October.
- [Southwest Texas State University] (2000). *Texas BRFSS, Behavioral Risk Factor Surveillance System, 1998 – Module 16 Quality of Life*, Report Prepared by Department of Health Services Research, Southwest Texas State University, June.

Texas Department of Health [n.d.]. *"On the Right Track" Blueprint for Action to Improve Learning, Achievement, and Quality of Life in People with Disabilities in Texas.*

_____ (1997). *On the Right Track Grant Application: Preventing Secondary Disabilities in Texas*, Austin: TDH. July 1.

_____ (1999). *On the Right Track Continuation Application*, Austin: TDH.

_____ (2000). *On the Right Track Year 3 Revised Budget and Workplan*, Austin: TDH. January.

_____ (1998). *Project Workplan: Goals, Objectives, Activities, Schedule, and Staff*, Austin: TDH.

Texas Department of Health, *On the Right Track Project website:*
<http://www.tdh.state.tx.us/disability/>

[Texas] State Auditor's Office (2000). *A Biennial Report on Recommended Changes in Total Compensation for State Employees*, Austin: SAO Report No. 00-711, June.

University Affiliated Program (1998). *Year One On the Right Track Project Evaluation*, Austin: UAP.

APPENDIX A:
On the Right Track Evaluation Interviews

On the Right Track Evaluation Interviews

In-person interview with On the Right Track Program Specialist, Peggy Gullede, Texas Department of Health, Austin, TX, October 18, 1999, by Alicia Betsinger, Research Associate, Ray Marshall Center.

In-person interview with On the Right Track Project Director, Dr. Hallie Duke, Texas Department of Health, Austin, TX, November 1999, by Christopher T. King, Director, Ray Marshall Center.

In-person interview with Director of Systems Development in the Division of Children with Special Health Care Needs, Bureau of Children's Health, Lesa Walker, M.D., and On the Right Track Project Director, Linda Jones, Texas Department of Health, Austin, Texas, June 8, 2000, by Christopher T. King, Director, Ray Marshall Center.

In-person interview with Associate Commissioner Lesa Walker, M.D., On the Right Track Project Director, Linda Jones and Communications Specialist, Ida Miller, Texas Department of Health, Austin, Texas, July 19, 2000, by Christopher T. King, Director, Ray Marshall Center.

In-person interview with Southwest Texas State University Social Work Professor Katherine Selber, Ph.D., and Lecturer Virginia Rondero, Austin, Texas, August 9, 2000, by Christopher T. King, Director, Ray Marshall Center.

In-person interview with Dr. Lucinda Harman, President, Combridge and Board Chair, Central Texas Network for Children with Special Needs, Belton, Texas, August 10, 2000, by Christopher T. King, Director, Ray Marshall Center.

In-person interview with On the Right Track Project Director Linda Jones and Program Specialist Ida Miller, Texas Department of Health, Austin, Texas, August 16, 2000, by Christopher T. King, Director, Ray Marshall Center.

Telephone interview with Southwest Texas State University Professor and Chair,
Department of Health Services and Research, Charles Johnson, Ph.D., August 25,
2000, by Christopher T. King, Director, Ray Marshall Center.

Telephone interview with Houston Independent School District Assistant Superintendent
Harriet Arvey, September 5, 2000, by Christopher T. King, Director, Ray
Marshall Center.

Telephone interview with Texas University Affiliated Program Training Coordinator Dr.
Mary G. McCarthy, February 12, 2001, by Christopher T. King, Director, Ray
Marshall Center.

APPENDIX B:
Selected *On the Right Track* Website Materials



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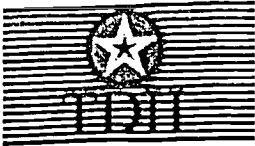
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Bureau of Children's Health
Division of Children with Special Health Care Needs
Texas Department of Health
1100 W. 49th St., Austin, TX 78756
(512) 458-7111 ext. 3046
Fax: (512) 458-7238

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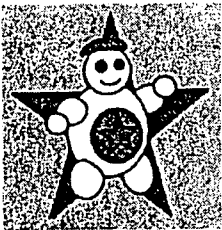
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Introduction to the Adults with Disabilities Page

This section is designed for adults with special health care needs. Individuals with a disability have shared with us that they need information about how to stay healthy and maintain the highest quality of life possible. We have focused on the use of family-centered planning as a tool for attaining the highest quality of life possible. We also have focused on the use of information as a technique to staying healthy. We have included information on topics that may be helpful and interesting to you.

This area of the website will continue to grow and develop. Help us determine the topics that are needed. To suggest a specific topic or website, click on the E-MAIL ORT icon. As we learn of topics through your requests, we will research them and add the information to this website.

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Methods of Communication

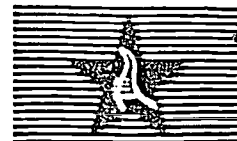
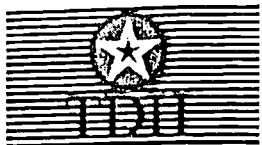
Interacting with Professionals

On the Right Track advocates for health care to be delivered using a team approach known as person or family-centered planning. There are many approaches to person-centered planning, but they all emphasize the individual as an equal participant in the health care team. For the person with a disability to be an equal participant, certain values must be present in the health professionals as well as in the person. Below are some sources of information on person-centered planning and interacting with health professionals.

for further information on interacting with health professionals link to:

[Fact Sheet: Person-Centered Planning](#) A fact sheet created by the American Association of Mental Retardation.

[A Parent's Guide to Doctors, Disabilities, and the Family](#) A document that is written for parents of children with disabilities to help in the selection of a physician and to help in the development of an ongoing relationship. Although it is written for parents, the information is helpful for adults seeking their own



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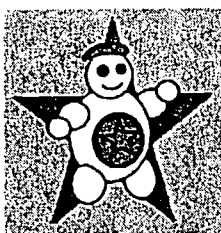
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INTRODUCTION TO THE FAMILY PAGE

This section is designed for families of children with special health care needs. Families have shared with us that if they had more information they would be better able to make decisions and to meet the needs of their children. We have focused on the use of information as a tool for staying healthy. We also have focused on the use of family-centered planning as a tool for attaining the highest quality of life possible. We have included information on topics that may be helpful and interesting to you.

The web is an excellent source of information. New sites are being added daily. As we learn of topics that people are requesting, we will research the subjects and add the information to this website.

If you would like us to add information on a specific topic please [E-MAIL ORT](#).

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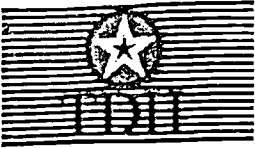
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Methods of Communication

Family-Centered Care

Family-centered care is based on an approach to service delivery that emphasizes the importance of the family as the constant and primary influence in the child's life. With this approach, professionals work with the family as a whole, taking into consideration what is happening within the whole family and the implications for the child with a disability. To work with one family member separate from the other family members is like trying to put together a puzzle without all the pieces. The child's behavior, characteristics, and resources influence other family



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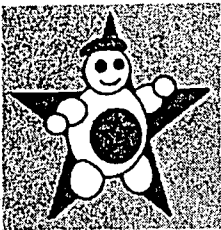
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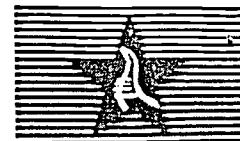
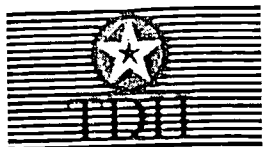
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Interacting with Children with Disabilities and their Families

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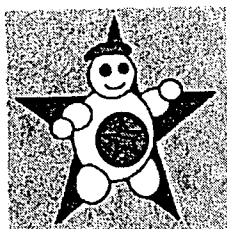
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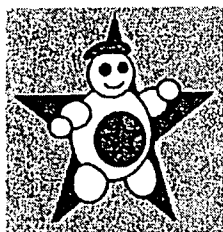
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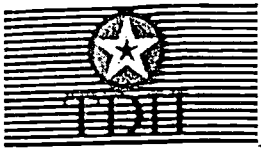
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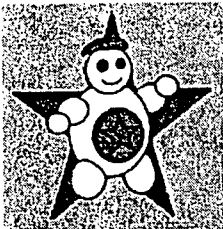
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INTRODUCTION TO HEALTH CARE PROVIDERS

This section is designed for health care providers. In focus groups held around the state, health providers have shared that connecting families to needed services is one way of preventing further disability in children with special needs. To connect families to needed services, health providers must be able to identify the need and the service. We have focused on family-centered planning as the method of identifying needs. This section includes resources for interviewing families, prioritizing needs, documenting assessments, and educating families for positive outcomes. There is also a section targeting young adults transitioning from pediatric to adult care and from school to college or work.

This area of the website will continue to grow and develop as you help us determine the topics that are needed. To suggest a specific topic or website or to send a comment, select the EMAIL ORT icon.

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METHODS OF COMMUNICATION

Interacting With People With Disabilities

People with disabilities are people first. Using positive language empowers them. When communicating with or about a person with a disability it is important to put the person first. People First Language describes the person and their abilities first, then describes their disability. Following are some helpful resources about relating and communicating with and about people with disabilities.

for further information on interacting with people with disabilities link to:

[Archives of Pediatric and Adolescent Medicine Families' Recommendations for Improving Services for Children with Chronic Conditions \(May, 1998\)](#). Garwick AW, Kohrman C, Wolman C, Blum RW.

[Choosing Words with Dignity, Person First Language](#) A document maintained by the University of South Florida.

[Communicating With and About People with Disabilities](#) A document maintained by



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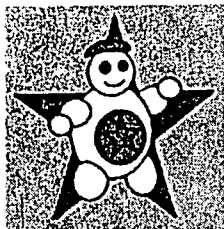
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INTRODUCTION TO THE EMPLOYERS PAGE

People with disabilities are an untapped resource of knowledge, skills, and abilities. Gaining knowledge and information about their jobs and benefits is important to people with a disability and people who work with them. Information can be vital to an employer in developing a good working relationship with an employee who has a disability.

We plan on putting information in this area that can assist an employer become more familiar with interacting with a person with a disability and the laws protecting persons with disabilities in the work environment. This area of the website will continue to grow and develop. As we determine the topics that are needed, we will research them and add the information to our website. If you would like us to add information on a specific topic select the E-MAIL ORT icon.

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METHODS OF COMMUNICATION

In talking to people with disabilities, families of children with disabilities, and health care providers, communication was identified as one of the main areas that, if improved, could lead to an improved quality of life for people with disabilities. The On the Right Track project has chosen to focus on communication to enhance health. We hope to address the questions and needs of employers who hire individuals with disabilities.

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Interacting with People with Disabilities

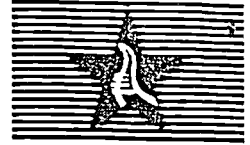
Remember, people with disabilities are people first. Using positive language empowers people. When communicating with or about a person with a disability it is important to put the person first. People First Language describes what a person HAS not what a person IS. The following resources are helpful tools on how to relate and communicate with and about people with disabilities.

for further information on interacting with people with disabilities link to:

[Communicating With and About People with Disabilities](#) A document maintained by the President's Committee on Employment of People with Disabilities.

[The National Business & Disability Council](#) A corporate resource on all issues related to the successful employment and integration of individuals with disabilities into America's workforce. Services assist the business community's ability to provide full access to their places of business and employment, as well as to their products and services.

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ABOUT ON THE RIGHT TRACK

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This page serves as an introduction to the On the Right Track program activities at the Texas Department of Health.

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Contact Information

On the Right Track

Texas Department of Health

1100 W. 49th St., Austin, TX 78756

(512) 458-7111 ext. 3131

Fax: (512) 458-7238

E-mail: ORT@tdh.state.tx.us

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Grant Staff

Linda Jones, MSPH, Program Coordinator

Lesa Walker, MD, MPH, Principle Investigator

Ida Miller, MSN, MPAff, Communication Coordinator

Jennifer Mallow, MSW, Project Specialist

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Grant Award

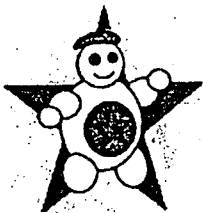
In July 1997, the Centers for Disease Control and Prevention's Office on Disabilities and Health awarded a four-year grant to the Texas Department of Health (TDH) for the On the Right Track project.

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Advisory Committee

On the Right Track is advised by a committee of people with disabilities, parents, advocates, and providers for children with special needs. The 22-member committee guides the project staff in their efforts to educate providers, educators, families, and individuals on the prevention of learning problems that may develop as a result of a disability.



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Secondary Learning problems

Secondary learning problems might result when:

1. a student is less involved in class activities because of a primary disability;
2. a person has problems reading, writing, or making decisions because of a primary disability; or
3. a person can't concentrate because of depression resulting from a primary disability.

For example, a child with cerebral palsy (primary disability) develops pneumonia (secondary condition) that keeps him or her out of the classroom. The child's learning is affected because of missed classes.

A teenager has paralysis from the neck down (primary disability) due to a recent accident. The teen has returned to school, but feels depressed (secondary condition) and isolated. The teen experiences learning problems due to the depression.



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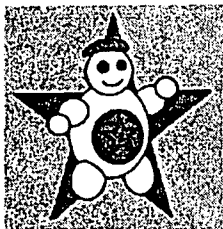
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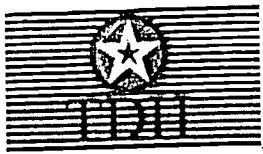
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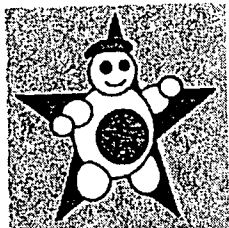
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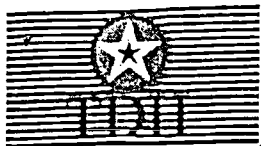
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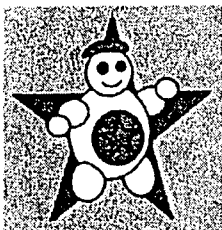
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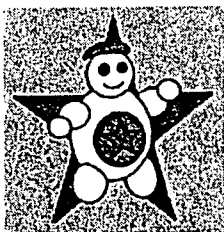
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INTRODUCTION TO HEALTH CARE PROVIDERS

This section is designed for health care providers. In focus groups held around the state, health providers have shared that connecting families to needed services is one way of preventing further disability in children with special needs. To connect families to needed services, health providers must be able to identify the need and the service. We have focused on family-centered planning as the method of identifying needs. This section includes resources for interviewing families, prioritizing needs, documenting assessments, and educating families for positive outcomes. There is also a section targeting young adults transitioning from pediatric to adult care and from school to college or work.

This area of the website will continue to grow and develop as you help us determine the topics that are needed. To suggest a specific topic or website or to send a comment, select the EMAIL ORT icon.

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- [Resources for Professionals Transitioning Young Adults with Disabilities](#)

METHODS OF COMMUNICATION

Interacting With People With Disabilities

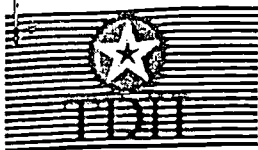
People with disabilities are people first. Using positive language empowers them. When communicating with or about a person with a disability it is important to put the person first. People First Language describes the person and their abilities first, then describes their disability. Following are some helpful resources about relating and communicating with and about people with disabilities.

for further information on interacting with people with disabilities link to:

[Archives of Pediatric and Adolescent Medicine Families' Recommendations for Improving Services for Children with Chronic Conditions \(May, 1998\).](#) Garwick AW, Kohrman C, Wolman C, Blum RW.

[Choosing Words with Dignity, Person First Language](#) A document maintained by the University of South Florida.

[Communicating With and About People with Disabilities](#) A document maintained by



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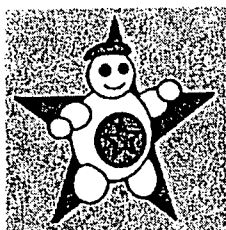
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INTRODUCTION TO THE EMPLOYERS PAGE

People with disabilities are an untapped resource of knowledge, skills, and abilities. Gaining knowledge and information about their jobs and benefits is important to people with a disability and people who work with them. Information can be vital to an employer in developing a good working relationship with an employee who has a disability.

We plan on putting information in this area that can assist an employer become more familiar with interacting with a person with a disability and the laws protecting persons with disabilities in the work environment. This area of the website will continue to grow and develop. As we determine the topics that are needed, we will research them and add the information to our website. If you would like us to add information on a specific topic select the E-MAIL ORT icon.

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METHODS OF COMMUNICATION

In talking to people with disabilities, families of children with disabilities, and health care providers, communication was identified as one of the main areas that, if improved, could lead to an improved quality of life for people with disabilities. The On the Right Track project has chosen to focus on communication to enhance health. We hope to address the questions and needs of employers who hire individuals with disabilities.

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Interacting with People with Disabilities

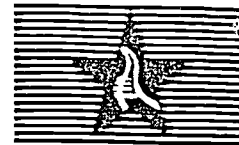
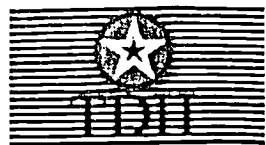
Remember, people with disabilities are people first. Using positive language empowers people. When communicating with or about a person with a disability it is important to put the person first. People First Language describes what a person HAS not what a person IS. The following resources are helpful tools on how to relate and communicate with and about people with disabilities.

for further information on interacting with people with disabilities link to:

[Communicating With and About People with Disabilities](#) A document maintained by the President's Committee on Employment of People with Disabilities.

[The National Business & Disability Council](#) A corporate resource on all issues related to the successful employment and integration of individuals with disabilities into America's workforce. Services assist the business community's ability to provide full access to their places of business and employment, as well as to their products and services.

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ABOUT ON THE RIGHT TRACK

[Adults with Disabilities](#)

This page serves as an introduction to the On the Right Track program activities at the Texas Department of Health.

[Families](#)

Contact Information

On the Right Track
 Texas Department of Health
 1100 W. 49th St., Austin, TX 78756
 (512) 458-7111 ext. 3131
 Fax: (512) 458-7238
 E-mail: ORT@tdh.state.tx.us

[Educators](#)

[Disability- Specific Resources](#)

[Texas Resources](#)

Grant Staff

Linda Jones, MSPH, Program Coordinator
 Lesa Walker, MD, MPH, Principle Investigator
 Ida Miller, MSN, MPAff, Communication Coordinator
 Jennifer Mallow, MSW, Project Specialist

[Healthcare Professionals](#)

Grant Award

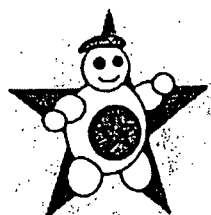
In July 1997, the Centers for Disease Control and Prevention's Office on Disabilities and Health awarded a four-year grant to the Texas Department of Health (TDH) for the On the Right Track project.

[Employers](#)

[About ORT](#)

Advisory Committee

On the Right Track is advised by a committee of people with disabilities, parents, advocates, and providers for children with special needs. The 22-member committee guides the project staff in their efforts to educate providers, educators, families, and individuals on the prevention of learning problems that may develop as a result of a disability.



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Secondary Learning problems

Secondary learning problems might result when:

1. a student is less involved in class activities because of a primary disability;
2. a person has problems reading, writing, or making decisions because of a primary disability; or
3. a person can't concentrate because of depression resulting from a primary disability.

For example, a child with cerebral palsy (primary disability) develops pneumonia (secondary condition) that keeps him or her out of the classroom. The child's learning is affected because of missed classes.

A teenager has paralysis from the neck down (primary disability) due to a recent accident. The teen has returned to school, but feels depressed (secondary condition) and isolated. The teen experiences learning problems due to the depression.



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Organization/Address: 3001 Lake Austin Blvd.,	Telephone: 512-471-7891	FAX: 512-471-0585
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