SEEKING RESIDENTIAL SUPPORTS FOR THOSE WITH TUBEROUS SCLEROSIS

Tuberous sclerosis (TS) develops differently in each child. The information below is for caregivers of those individuals with developmental disabilities and/or mental retardation who will need supports provided through programs funded by state/federal service systems.

For those seeking residential supports for their dependent with TS, it is important to devote time and effort reviewing the available options. It is also wise to ask as many questions as possible to fully understand the program and the staff to whom a dependent will be entrusted.

Before placement is agreed upon, meet with the team that will be caring for the dependent and inform them of expectations and the individual's needs. Provide a copy of the dependent's treatment plan from each involved professional. When the services that will be provided have been agreed upon, GET IT IN WRITING WITH SIGNATURES. Keep notes of every conversation with the staff, including the staff person's name, the date and the problem that was discussed. The ideal scenario is to be able to choose a provider and have the ability to design the program. In most cases, though, this does not occur. When choice is not an option, it is still vital to understand what to advocate for in the future.

An excellent place to start this investigation is at www.TheArcLink.org, a national service provided by The Arc (formerly the Association for Retarded Citizens). The site lists all state-approved residential providers, service coordinators and entry points for each state (all 50 states will be included by 2002). Parents can access basic information about each provider, plus consumer satisfaction information about many of them.

While each state has access to the same federal funding for supports (families are seldom asked to contribute financially), the states vary widely in terms of philosophy of service and how much they supplement with their own funds. There is frequently a large disparity between providers, even within a given state or community. Parents should be sensitive to the variety of residential support alternatives that are available. In many states the options follow along a continuum from nominal residential supports found in semi-independent supportive apartments and foster (family) care, to group homes and small/large heavily regulated, Medicaid funded community homes (ICF/MR's). The list also includes state developmental centers, though most states are trying to close or drastically reduce their size.

The ideal situation is when the provider will design residential supports around a dependent's unique needs. This may exist in those states that actively participate in the Medicaid waiver (flexibility given states to use Medicaid funds with less federal oversight). Where this is not possible, parents or the consumer may opt to take the next available opening in an existing residential model that closely matches the level of residential supports needed.
Where choice is available, parents should be sensitive to:

1.) Philosophy: Many providers take pride in being "people centered", by empowering the individuals they serve and maximizing choices in the details of their daily lives, where appropriate. Still others are more "traditional," or their services are more one-size-fits-all.

2.) Size: Smaller is usually better, but keep in mind that just because a home only serves a few individuals doesn't automatically mean that the individuals are empowered or given appropriate choices or input on how their life is structured.

3.) Residents: Notice the functioning levels of the other residents. A large number of lower functioning residents can compromise the quality of care provided by overburdened staff.

4.) Staffing: Compare the ratio of staff to residents when evaluating providers. Ask for information about the longevity of the staff. Do they have a difficult time filling vacancies? What are the compensation and fringe benefits levels? Are they unionized?

5.) Location: Is the home in the community or is it remote? Does the home have a vehicle and/or easy access to public transportation? Is it close to the type of community activities your son/daughter would enjoy?

6.) Human rights/abuse records for agency: The local chapter of The Arc or other advocacy groups can frequently share whether an agency has a problem. The regional state regulatory agency may also be a source, although sometimes not as candid.

7.) Financial solvency: Some programs are funded and managed better than others. Compare providers as to their financial stability. Do they have reserves, a foundation, etc.?

8.) Day programs: Frequently when you select a residential provider you are also picking the day supports. Make sure you are comfortable with the program site your son/daughter will be going for day supports. Visit and compare the alternatives. Are the supports inclusive and offered in the community? What choices do you have to mix and match?

If there is a waiting list and a family's need is immediate, they should speak with the provider, the state official assigned to their region, or local advocates regarding the process for a "Priority Placement". If their need is not immediate, they should still get placed on the list and defer until they are ready, if a placement is offered.

**HOW TO FIND LOCAL AREA SUPPORTS**

It is always best to start thinking about residential supports well in advance, years if possible. Here is a list of possible local contacts that can be used for obtaining residency options (placed in order of preference):

1) Local parent advocacy associations, such as a chapter of The Arc, United Cerebral Palsy Association, etc. They usually will be more candid than government regulators.

2) State association office. If the advocate is also the provider, be sure to get an independent reference of the quality of their services.

3) The county, regional or state developmental disability department that regulates and funds the providers.

4) The local school system or social service office may assist in finding the correct contact.

5) Also, each state has a Developmental Disability Service Council that may be a referral source.

6) National organizations can frequently be of service in pinpointing local providers or advocates by directing fami-
lies to the correct people to call in each state, whether it is the state government authority or advocate. Below is a partial list:

THE ARC OF THE UNITED STATES  
Contact: Research and Program Services  
Phone: (800) 433-5255  
Web site: www.thearc.org  
E-mail: info@thearc.org

NATIONAL ASSOCIATION OF STATE DIRECTORS OF DEVELOPMENTAL DISABILITIES DIRECTORS  
Phone: (703) 683-1234

NATIONAL ASSOCIATION OF DEVELOPMENTAL DISABILITY COUNCILS  
Phone: (202) 347-1234  
Web site: www.naddc.org

AMERICAN NETWORK OF COMMUNITY OPTIONS AND RESOURCES (ANCOR)  
Phone: (703) 642-6614  
Web site: www.ancor.org  
E-mail: ancor@radix.net

ADDITIONAL WEB SITES

www.jik.com/ilcs.html - This site contains a listing of independent living center links.

www.rehabnet.com - This site contains a listing of residential, supported and independent living and long-term care programs.

www.independentliving.org - This is the site of the Institute on Independent Living.

Written by Frank Capone, CEO of Liberty, a multi-faceted human service agency and a chapter of the New York State ARC.

*Tuberous Sclerosis Alliance Fact Sheets are intended to provide basic information about TS. They are not intended to, nor do they, constitute medical or other advice. Readers are warned not to take any action with regard to medical treatment without first consulting a physician. The TS Alliance does not promote or recommend any treatment, therapy, institution or health care plan.*