

The Arc

Advocating and navigating on behalf of the disabled

It is no small task to navigate the labyrinth of programs that benefit the developmentally disabled. An impossibly complex patchwork of governmental agencies and programs support their needs, including housing, income, health, employment, transportation, recreation, and education. Fortunately, help is available through The Arc, a non-profit 501(c) (3) organization that assists families of the developmentally disabled for free (not counting the \$35 annual membership fee).

The Arc of Northwest Wayne County, in Redford, (313) 532-7915, and The Arc of Oakland County, in Troy, (248) 816-1900, are just two of the many branches of The Arc around the country that help families with special needs children. They are both affiliated with The Arc Michigan and The Arc of the United States and together form the largest “grassroots” (a term, coined by Senator Beveridge in the early 1900s, that means an organization “grown from the soil of people’s hard necessities”) volunteer advocacy organization of its type.

Originally, Arc was an acronym for Association of Retarded Children and later for Association of Retarded Citizens. Now the name is not an acronym at all; I am told that it’s just a name. But I can’t help seeing it as a symbol, like Noah’s Ark, of an organization that rescues pairs (in this case parents and their vulnerable children) from the perils of the world.

According to The Arc philosophy, the developmentally disabled should be fully included in society and to the greatest extent possible retain control of their own destiny. In keeping with this philosophy, their mission is to help the developmentally disabled find supported living arrangements, educational opportunities, employment, and financial assistance to allow them the greatest opportunity for growth and personal freedom. In their view, institutional living and legal guardianships are simply not acceptable.

According to Christine Lerchen, executive director of The Arc of Northwest Wayne County, The Arc is a “system navigation” and “advocacy” organization that connects members to available community services and resources. Funded by the United Way, Community Mental Health (a program of Medicaid), membership fees, and private donations, The Arc helps par-



Tessa and Eliza play at the Arc.

ents locate resources that will allow their children—no matter how impaired—to realize their greatest potential. According to Ms. Lerchen, “competence is presumed.”

Housing

The Arc attempts to replace traditional institutional living with more humane living arrangements within the

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community. They coordinate with Community Living Services (a program of Community Mental Health) and other organizations to allow the individual, with appropriate support, to live and work in the community. They can, for example, arrange for a non-challenged roommate to live with the special needs individual, and arrange for a separate

financial intermediary service to pay bills and handle other financial matters.

Guardianship

A full guardianship requires a showing that the ward is not competent to make his or her own personal decisions, and once granted ends their right to self-determination. Alternative arrangements such as conservatorships (appointment of someone to make financial decisions), limited guardianships, and powers of attorney allow for the greatest personal dignity and autonomy. Some branches of The Arc provide guardianship services and may also act as the representative payee for social security payments.

Powers of Attorney

Powers of attorney are viewed as a more humane alternative to court-appointed guardianships. Children with special needs often possess the legal capacity to create legally enforceable



Judy brings Austin to the Arc.

powers of attorney. In such cases, they can appoint an agent to make their financial decisions and a patient advocate to make their medical decisions.

Education

Children with disabilities are eligible for educational and vocational training up to age twenty-six. The Arc can help families find appropriate educational services either within mainstream

schools or in separate facilities. They advocate on behalf of families, providing extra clout when families are having difficulty being heard by busy school administrators.

Disability Income

Disabled children and adults who meet the social security definition of disability may qualify for SSI (supplemental security income), SSDI



Mark Accettura

(social security disability insurance), or social security income. These programs are also a gateway to Medicare and Medicaid coverage and are therefore essential benefits for families who qualify. The Arc can direct families to these and other programs that offer income and health assistance to families with developmentally challenged children.

Future Planning

Staffed by paid employees and volunteers who often have special needs children of their own, The Arc is sensitive to the transition that occurs when parents of special needs children either pass or are no longer able to care for their children. They offer a program known as “futures planning” to educate parents as to the tools that are available to protect their children after they are gone. One such tool is a “special needs trust.”

Special needs trusts are revocable trusts created to provide ongoing support for special needs children after a parent’s death. Special needs trusts are carefully drafted to direct that trust funds are only be used to supplement existing government benefits. In this way, the parents’ inheritance, while still available to meet their child’s needs, will not disqualify the child from future government benefits. A special needs trust should only be drafted by qualified estate planning and elder law attorneys. The Arc maintains a list of attorneys who can provide such services.

The good news is that you don’t have to go it alone. Help is available by calling an Arc chapter near you to become a member and begin sharing their vast body of knowledge acquired in the fifty plus years of helping families with special needs children. The current economic climate and the resulting stress that it will put on programs for people with special needs dictates that you