

Developmental Disabilities Advisory Committee

CenterPoint Human Services

By the sides of the long and winding road that has led to current service practices for people with disabilities there are monuments to changes in perception, thinking, and respectful acceptance. The changes have been hard-won; credit for them is due to parents and professionals who have shared a vision of equality and possibilities for children, adults, and their families.

The monuments take the form of public laws and ideals put into practice. For more than a quarter-century, DD Advisory Committee has played a role in this journey. As we look at today's landscape, we must acknowledge our nation's major achievements in regard to people with developmental disabilities and know that behind each has been stalwart and effective advocacy by consumers, parents, and professionals:

- 1963: The Mental Retardation Facilities & Community Health Facilities Construction Act
- 1970: PL 91-517 – Amendment and refinement of this act
- 1975: PL 94-103 – Developmental Disabilities Assistance & Bill of Rights Act
PL 94-142 - Education of All Handicapped Children Act, requiring an Individual Education Plan (IEP) for each child of school age. This law was extended and refined in 1998 – see below.
- 1978: PL 95-602 – Further legislation refining rights and expectations
- 1981: PL 97-35 - Omnibus Reconciliation Act
- 1984: PL 98-527 – Refinement of the language
- 1987: PL 100-146 – Addition of acknowledgement of central role of families & communities; assertion of consumer & family participation in treatment planning
- 1990: PL 101-496 – Community integration & inclusion, and family supports added; Americans with Disabilities Act signed into law
- 1994: PL 103-230 – Describing the purpose of Councils
- 1996: PL 104-183 – Reauthorization of the prior law
- 1998: PL 99-457 – Extension of the Education of All Handicapped Children Act to apply to infants, toddlers, and preschoolers – this law has been refined and reauthorized through the years and is now known as IDEA. It requires treatment planning based on an Individualized Family Service Plan (IFSP) which includes the participation of family members (and those whom they choose), and all professionals who provide services to a child.
- 2000 +: These laws have been reauthorized and refined, including the additions of quality expectations.

In addition to legislative milestones, DD advocates have introduced paradigms for change such as Social Role Valorization and Self-Determination, altering forever the public's experience of children and adults who have disabilities. With renewed vision for the potential of their sons and daughters, families face a much brighter and more hopeful future today.

This is the history of progress toward a system of care for people with DD. Long before "System of Care" came into being as a concept, DD Advisory supported the tenets of collaboration, person-centered and family-centered care, with emphasis on people's strengths, rather than their deficits. Then, as now, we embraced the ideal of quality-driven supports, by working and strategizing with our community partners.

During the past quarter-century, we have seen many changes in the service structure. Many of those changes have been very good – giving a stronger and more respected voice to adults and to families of children who depend upon the service system. Public laws have demonstrated an increasing recognition of the urgency to begin services as early as infancy for children who are at risk for developmental delays and may need services and supports throughout their lifetime. (Research has documented the effectiveness of Early Childhood Intervention in significantly improving lifetime outcomes for children, thus saving tax dollars.) IDEA mandates family-centered treatment planning. The Person-Centered planning process for older children and adults is designed to include teams of family members, providers, and others of the person's choosing. For both children and adults, team meetings must be held on a required schedule, but consumers and families of children may request a meeting at any time.

People with developmental disabilities are experiencing choice and independence never envisioned five decades ago. Building on strengths, recognizing people's interests, and dealing respectfully with all recipients of services elevates the service system, and makes for a better community for all of us.

We've been traveling this long and winding road, and it stretches before us still. There is more work to be done as we move toward a system even more equitable and quality-driven, and as we continue to deal with service gaps and improvements. However, as we look over our shoulders at how far we have come, we must pause to celebrate. Then it's time to get back on the road.

DD Advisory meetings are held at 5:30 p.m. on the first Thursday evening of each month, other than July and December. All are welcome. To be notified, call Laura Gorycki at 336-714-9136, or email lgorycki@cphs.org.