

**Outstanding Leadership in Disability Law Virtual Symposium
Wednesday, July 14, 2021**

Panel 3: From Institutions to Community: The Power of the Protection & Advocacy (P&A) and Self-Advocate Partnerships

Time: 3:45-4:45 pm ET

Moderator

- **Tia Nelis**, Self-Advocate Engagement Coordinator, TASH

Presenters

- **Curt Decker, J.D.**, Executive Director, National Disability Rights Network
- **Jack W. Derryberry, Esq.**, Legal Director, Disability Rights Tennessee
- **Chester Finn**, Self-Advocate and Speaker

Synopsis, Learning Objectives, and Citations

Synopsis

Initially focused on safeguarding the well-being of individuals living in institutions, the Protection & Advocacy network (P&A) has broadened authority to provide legal representation and advocacy services to all people with disabilities to help ensure full access to inclusive education, entitlements, healthcare, housing, voting, and competitive/integrated employment (just to name a few) and has been at the forefront of the deinstitutionalization movement. Panelists will discuss how the P&A partners with self-advocates to raise public awareness of legal and social issues affecting individuals with disabilities and how these partnerships have resulted in closures of institutions and the expansion of opportunity, inclusion, and self-determination for people with disabilities.

In the early 1970s, investigative reporter Geraldo Rivera exposed horrific abuse of people with disabilities who resided at Willowbrook State School, a New York state institution on Staten Island. Public outrage about conditions at Willowbrook and other institutions prompted Congress to act in 1975 to enact the *Developmental Disabilities Assistance and Bill of Rights Act* (DD Act) which led to the creation of a nationwide system of state-level, Protection & Advocacy (P&A) organizations. Under the DD Act, the governor of each state must designate an agency to be the P&A that is independent of any service provider. Most P&As are private non-profit organizations that pursue legal, administrative, and other appropriate remedies under all applicable federal and state laws to protect and advocate for the rights of individuals with developmental disabilities.

The P&As initial focus was to safeguard the well-being of individuals living in institutions and P&As continue to monitor, investigate and attempt to remedy adverse conditions in large and small, public and private, facilities that care for people with disabilities and has since broadened to one that secures the rights of persons with all types of disabilities wherever they reside. Under the DD Act, statutes were expanded to give the P&As additional authority to ensure full access to inclusive educational programs, financial entitlements, healthcare, accessible housing, transportation, voting rights, and productive employment opportunities, as well as investigation and prevention of abuse and neglect.

P&As have a long history of partnering with self-advocates to raise awareness and bring about system change beginning nearly fifty years ago when Bernard Carabello joined forces with Geraldo Rivera to share his experiences at Willowbrook State School in New York. Four decades ago in Pennsylvania, Roland Johnson, as the president of Speaking for Ourselves of Pennsylvania, was an ardent advocate for the closure of state run institutions for individuals with ID/D documented after growing up at Pennhurst State School and Hospital. Then in 1991, members of People First of Tennessee moved from raising their individual voices against institutionalization to become the first organization by individuals with ID/D to file class action litigation in *People First v. Arlington Developmental Center* and *People First of Tennessee v. Clover Bottom Developmental Center*.

Learning Objectives

Participants will acquire knowledge and improve their skills in representing and advocating for individuals with disabilities in the following areas:

- Understanding how P&As partner with self-advocates in raising awareness for systemic change including litigation as necessary for full inclusion and to end segregation of people with disabilities.
- Understanding the role and authority of the P&A System in investigating actions of violations of ADA and other federal laws requiring integration and affirmative steps to eliminate barriers to full inclusion of people with disabilities.
- Understanding the ADA and *Olmstead* in challenging segregation and fulfilling the promise of full inclusion.

Citations & Resources

- 42 USC Ch. 144: DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS
- Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act of 2000) (42 U.S.C. 15001 et seq.)
- *NYSARC v. Rockefeller*, 706 F.2d 956 (2d Cir. 1983)
- *People First of Tennessee v. Arlington Developmental Center*, 2:92-cv-02213-JPM (W.D. Tenn.)
- *People First of Tennessee v. Clover Bottom Developmental Center*, 3:95-cv-01227 (M.D. Tenn.)
- *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 119 S.Ct. 2176, 144 L.Ed.2d 540 (1999)
- *Lane v. Brown*, 166 F.Supp.3d 1180 (2016)
- *Willowbrook: The Last Great Disgrace-Geraldo Rivera 1972 Exposé* (full short documentary). A shocking exposé of the deplorable conditions and abuses from the Willowbrook State School for children with intellectual disabilities.
<https://www.youtube.com/watch?v=bpVEjzO6Dd0>