

## ADVOCACY EXAMPLES

Advocacy: to support; to promote the needs and interests of others.

By Their Side provides advocacy for people with intellectual and developmental disabilities in the form of assessment visits, monitoring, support in planning meetings, work to resolve identified concerns, and update reports to families or trustees. The wishes of each person and their family's insights guide their Advocate, as well as a strong understanding of the service system and the belief that with planning and support, each person can live a rewarding life of their choosing.

## Advocates help people pursue their interests.

David loved art, so his Advocate arranged weekly Trust funded sessions with a mentoring artist. His talent and passion for art grew, so his Advocate located a supportive Art Studio where he now works on art several days a week, participates in exhibits throughout Baltimore, and is helped to market his work. David's art was selected for review by a national art publication.

# Advocates carry forward parents' wisdom and knowledge.

John expresses pain through his behavior rather than verbally. Thanks to information provided by his parents decades earlier, his Advocate was aware that the replacement hip John received as a young man may one day need revision. Long after his parents were gone, this information expedited John's diagnosis and treatment. With additional hip surgery, John was living comfortably once again.

# Advocates respond when needs change.

When Chuck's Advocate learned of his hospital admission, she visited and found him intubated, alone, and anxious. Medical Assistance will not pay for hospitalization and residential staff on the same day. She posted a note for nursing shifts with Chuck's communication style, nickname, and TV preferences, and called his distant brother about a companion. A family member flew in the next day.

With advanced age, Ann developed irregular sleep patterns, cognitive decline, and she participated minimally in her day program. Her Advocate suggested retirement, and with her team's help, Ann's day program funds were transferred to residential support. Ann enjoys short, individualized outings to remain active and naps when she needs to.

# Advocates involve specialists when needed.

Ben had an anoxic brain injury as a teen. When By Their Side became involved several years later, his Advocate arranged a neuro-psychological evaluation that identified Ben's short term memory impairment for the first time. The evaluation answered many questions, and his team was better able to plan necessary support and safeguards.

#### Advocates address health and safety needs.

Despite attempts by Mark's Advocate to resolve the ongoing issue of overdue medical appointments with his residential service provider, the problem continued. Mark has complex health needs, so his guardian decided it was time for a change. His Advocate helped them interview other agencies, and new support staff. Mark still enjoys living in his Trust-owned home, likes his new staff, and his new agency provides good oversight.

When Susan and her Advocate met, she noticed Susan's slumped posture in her wheelchair and suggested a wheelchair positioning evaluation. Susan is more comfortable in her new wheelchair and is better able to make eye contact.

# Advocates support individual rights.

John's speech therapist recommended a speech device that cost \$5000 but his Managed Care Organization denied funding. When his Advocate appealed the decision to Maryland DHMH, funding was approved because although an adult, John's speech disability existed since childhood. His speech therapist has since used this precedence-setting decision to access funding for others.

Surprised to hear Susan's financial account was depleted, her Advocate asked to review her financial statements. Susan had been charged by her residential agency for a nursing visit following each of her recent hospitalizations. State Regulations require that a delegating nurse direct residential staff to implement physician orders, but this is funded by Susan's DDA budget. Her Advocate requested a refund.

# Advocates work closely with parents or siblings, near and far. They serve as local eyes and ears, sounding boards, and partners in advocacy.

Jack does not communicate verbally, but his sister Jean understands him well. They visit each week, except when Jean travels for work. Then she arranges for Jack's Advocate to visit. Jack likes his Advocate so her visits helps him cope, and his Advocate's update reports help Jean stay involved.

#### Advocates work with Trustees to facilitate use of Trust funds, when available.

Trustees can rely on By Their Side Advocates' experience and first hand assessments to identify needs and life enrichment opportunities. Examples range from replacing a squeaky mattress for a better night sleep to funding a companion while in the hospital, a new suit for church, or an assistive technology assessment to enhance independence. Requests are also made to fund preferred outings and vacations.

#### Advocates help families to address a short term need.

Jane's elderly mother knew her daughter would need full time supervision to be safe, but the State didn't understand, so she involved By Their Side. Their Advocate provided a report to the State detailing Jane's support needs and safety risks, with examples, and accompanied Jane and her mother to meet with a State representative. Jane's full time residential services began the same year.

# By Their Side works to solve problems, and helps parents prepare for the future.

Families call for assistance, resources, and attend By Their Side's educational seminars. By Their Side collaborates with others to develop resources that address shared concerns, like planning for the future of only child. For resources and upcoming events, visit <a href="www.bytheirside.org">www.bytheirside.org</a>

For information, contact

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