Lifelong Advocates for Marylanders with Developmental Disabilities

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What to Expect
When By Their Side Services Begin

By Their Side Lifelong Advocacy for Marylanders with intellectual/developmental disabilities is provided when their parents (or other sponsors) are no longer here, and serves as a resource for siblings or other primary family contacts and Trustees. Services are pre-funded and begin upon the passing or incapacity of the sponsor/s. Annual assessment visits, with follow up to concerns, continue for the lifetime of the member.

1. By Their Side learns of the sponsor's passing.

- Parents or other sponsors leave instructions with family members or their attorney to notify By Their Side of their death in order to activate Lifelong Advocacy services.
- By Their Side periodically updates contact information in the individual file. The U.S. Postal Service's Address Service provides forwarding information; calls are made to the sponsor or family designee if letters are undeliverable. *Please notify us if you relocate.*

2. A Personal Advocate is assigned and initiates services.

A. The Advocate reviews the individual's By Their Side file including
- Family Intake information specifying advocacy concerns to help guide their work.
- Other background information and reports provided by family.
- Letter of Intent outlining additional Advocacy Plan Services desired, if any.
(*Please note that it is important to make your wishes very clear about this.)*
- Authorization for Services/Release of Information.
- Contact information

B. The Advocate completes an initial home assessment with your son or daughter
Explains our role and that (sponsor) arranged for us to visit and assist

Updates Agreement for services (or with guardian)

Learns immediate preferences and needs, hopes for future, and any problems to resolve

Observes living situation and staff interaction
-Reviews medical file, Individual Plan, and progress on goals
-Discusses needs with staff including health and safety, financial, life enrichment
-Identifies follow up and documents visit in individual file

C. Contacts sibling or other designated family representative and/or Trustee
-Provides report of visit and follow up plans
-Relates any identified financial needs to Trustee
-Learns concerns and offers guidance or assistance; remains available to consult.
-Discusses *By Their Side Lifelong Advocacy* role and whether additional Advocacy Plan Services are desired based on Letter of Intent or initial assessment visit.

D. Contacts team: Resource Coordinator, Day and Residential Coordinators
- Explains By Their Side's role and forwards Agreement/Release of Information
- Requests current Individual Plan and invitation to future IP meetings
- Discusses progress, needs, and identified concerns noted at visit or by family

E. Follows up with responsible party to resolve the identified concerns
- Involves Resource Coordinator as needed

3. Thereafter, the Personal Advocate completes an annual assessment with follow up.

A. Attends the Annual Planning meeting
- Prepares for meeting through review of past year Individual Plan and advocacy issues.
- Contacts family representative, if out-of-state, to learn concerns
- During the meeting, assists the team to identify and address health and safety needs as well as preferences and other life enrichment opportunities
- If there is a Trust, helps the team consider appropriate use of financial resources.
- Serves as a liaison with Trustee if desired by family.
- Provides meeting report to family representative and/or Trustee
- *A home or day program visit may be substituted for the planning meeting at the request of family or if the Advocate is unable to attend the meeting.*

B. Follows up to address concerns.

C. Serves as a resource to sibling/family representative and/or Trustee
-Some siblings use email or calls for input into a question or strategy.
-For out-of-state siblings or professional Trustees, the Personal Advocate's reports are a primary source of information about individual well-being and financial needs.

4. The Personal Advocate is available to provide additional advocacy support through Advocacy Plan Services.

- Annual Advocacy Plans allow the sibling or trustee to specify the number of Advocate visits and monitoring contacts each year in addition to attending the annual planning meeting. The Advocate's reports keep them informed, and follow up on concerns is provided.
- Funded at an hourly rate, Annual Advocacy Plans are renewable and modifiable on an annual basis, with discounts available.
- Intensive short-term advocacy assistance is available to address a specific concern, for example attending a team meeting with family, working to resolve a particular concern or change a provider if needed, or providing additional visits over a specified period.