FFE Final Report: HDI Consumer Advocacy Toolkit (CAT)

February 2019

1. Staff:

Staff for the project included Caroline Gooden, PI; Jennifer Ulbricht, CAC member; Lyndsey Coleman and Hoda Shalash, STEPS employees.

2. Response to need:

There is a need for resource materials to promote self-advocacy among families and consumers of services for persons with disabilities. The Consumer Advocacy Toolkit was envisioned by Jennifer Ulbricht, CAC member, to provide a resource where diverse users could develop advocacy skills and locate resources to support their family members and friends with disabilities in KY. While a variety of resources exist in the state of Kentucky through local, state, and national programs, families and professionals must be able to identify their needs and locate appropriate resources. The Toolkit facilitates the creation of these necessary skills, such as learning specific places to find assistance (for example, SSI contact persons) or learning skills for requesting specific services (for example, developing specific advocacy goals with the assistance of KY Protection and Advocacy). The Toolkit includes real-time short stories to motivate users for successful advocacy.

3. Process

The development of the Toolkit occurred in four phases.

- We researched current advocacy resources to determine gaps in advocacy resources in the field.
- We developed the first draft of the Consumer Advocacy Toolkit, including statewide resource information, self-advocacy recommendations, motivational materials, and selfassessment materials to help guide users to effective advocacy. The Toolkit was geared to a diverse audience of users, with no more than a 6th grade reading level and adherence to principles of universal design.
- We piloted the Toolkit to seek suggestions for improvements, through online surveys, email responses, and feedback from CAC members.
- Based on the feedback received, we refined the Toolkit to increase accessibility, ease of use, and more comprehensive resources.

4. Final product

Unique features of the Toolkit include question-and-answer sections where users fill in the blanks to define their experience and needs by writing or typing. There are 5 sections, including:

- 1) defining self-advocacy;
- 2) identifying individual strengths, needs, and persons to help meet advocacy goals;
- 3) user goal-setting for advocacy;
- 4) advocacy activities; and
- 5) key resources, both state and national.

In addition, there are motivational text boxes to illustrate positive outcomes of self-advocacy. References are included for users who want to dig deeper. Resources are also provided to identify agencies who can help with needs such as school, SSI, and Medicaid waivers. The Toolkit is not specific to age, gender, diagnosis, or profession. It acts as a

foundation for advocacy, by teaching new skills, allowing the user to learn about themselves, and providing real life examples of successful advocacy.

5. Supporting HDI's mission

The Toolkit expands HDI's service provision to stakeholders across the Commonwealth through a user-friendly self-advocacy resource that builds leadership and advocacy skills. The HDI Resource manual is one of many resources listed; users are encouraged to seek additional information as needed.

6. Outcomes and Sustainability

Anticipated outcomes for users of the Toolkit include 1) a user-friendly Toolkit designed to increase advocacy skills for persons with disabilities across the Commonwealth; 2) increased efficacy for advocacy; 3) increased problem-solving abilities; and 4) increased motivation to advocate effectively. We measured these outcomes through a 5-question survey administered pre-Toolkit use, which will also be administered post-use when the Toolkit is published on the HDI website. All pre-Toolkit use responses were used to refine the Toolkit.

The Toolkit will generate new knowledge by informing and supporting users with effective advocacy skills. The Toolkit will be maintained on the HDI website; hard copies will be available upon request and by dissemination to community locations. The CAC may also maintain the Toolkit as part of its ongoing advisory capacity to HDI, as they are invested in its use.