The Ellie Fund
Theory of Change Executive Summary, December 11, 2018

Introduction

The Ellie Fund's mission is to provide essential support services for breast cancer patients to ease the stresses of everyday life, allowing the focus to be on family, recovery, and healing. Founded in 1993 after a family fundraiser, the Ellie Fund today provides the following essential assistance free of charge to 775 breast cancer patients and their families residing in and/or receiving treatment in Massachusetts: Transportation to medical appointments, light housekeeping, nutritional and grocery assistance, childcare reimbursement, nutritious prepared/delivered meals and integrative therapy services.

The Ellie Fund is engaging in a Theory of Change process to build on its successful service delivery over 25 years and to catalyze its next chapter of growth and effectiveness. The goal of the Theory of Change session is for The Ellie Fund team to make the following organizational commitments and decisions: Clear mission, agency goals, target population, and outcomes sequence. With the resulting overarching clarity, the team will be ready to clarify each program's strategy through a logic model and to determine what key data it can measure to inform improvement. The Ellie Fund's staff and leadership teams can then use that learning to strengthen its programming, operations, and patient experience, and to prepare well for its next chapter of growth. This Executive Summary documents the Ellie Fund's Theory of Change decisions; accompanying notes document the discussion informing them.

Attendance

Marcia Boyle, Board Chair
Gail Fine, Board Member
Heather Shanahan, Board Member
Scott Dorsey, Board Member
Jeff Popkin, Board Member/Founder
Tom Jacob, Board Member
Meredith Bryan, Executive Director
Anne Meisner, Patient Services Manager
Hillary Harrelson, Development Director
Kaitlyn Ferrini, Events and Public Relations Manager
Carole Burpee, Finance and HR Manager
Kristen Sajak, Program and Fundraising Assistant
Julie King, Researcher

Target population:

Breast cancer patients in treatment -- radiation, chemotherapy, surgery, and/or reconstruction – who are men and women of all ages and all socioeconomic levels, who live in MA or are treated in MA.

Strengths/Assets of Target population:

- They have access to quality health care, a breast cancer specialist, and an advocate who is someone we trust
- They are committed to the treatment process
- They are willing to receive some services

In addition, patients may have any of the strengths or challenges below related to their diagnosis; these may shift over time:

Assets:	Challenges:
Grateful	Resentful
Support network of family/friends	Isolated
Available financial resources	Poverty, unemployed
Committed to care for family	Disconnected from family caregiving role
Motivated to fight	Passive
Treatment is nearby	Treatment is far away
Hopeful	Depressed, defeated
Informed about illness, treatment, side effects	Uninformed about illness, treatment, side effects

What is the problem that the Ellie Fund exists to address? After breast cancer diagnosis, patients suddenly feel:

- Emotional stress, resulting from diagnosis
- Confusion about how to navigate daily life and family care; not knowing what support they will need to get through each day.
- Anxiety
- Financial strain, increased expenses
- Overwhelmed: How do I do everything I'm responsible for and add the full-time job of being a cancer patient?

Why do we believe this problem exists?

- Sudden diagnosis results in an emotional crisis for patients.
- Each patient experiences uncertainty about their own prognosis and cure.
- Diagnosis represents interruption to patients' lives, strains their time and resource management.
- Patients experience underinsurance, even if they are fully insured: Co-pays, deductibles, barriers to care (transportation). The full cost of treatment is never covered by insurance.

Additional challenges of target population :

- Need support group of people who have been there and understand their experience
- Fear of cancer, of the unknown, of treatment and its side effects, of dying
- Side effects and pain management
- Loss of mobility and energy for daily life and responsibilities (more or less)
- Worry about becoming a burden to others (maybe)
- Difficulty asking for needed help (maybe)

Quality service definition:

- Reliable
- Individualized
- Flexible (patient allocates how they want services)
- Meet priority patient basic needs related to treatment/diagnosis stress, for example family meals and access to medical care (transportation)
- Not judgmental
- Consistent (don't pull back)
- Evolving over time (evaluate service mix and length periodically)

The Ellie Fund mission statement is strong:

- Does describe what the Ellie Fund exists to accomplish, what success looks like
- Is concise, clear, compelling, and concrete
- Clearly states target population and end goal

Organizational Goals (to align with existing operational plan):

1. Create measurement plan, based on agreements above
2. Strengthen staff and financial capacity needed to implement measurement plan and learn from data for improvement
3. Learn from our data and adjust program logic model accordingly:
    a. Which patients reach quality measures and end goals above? Based on these results, evaluate how long patients need support (length of grant), what services patients need,

when patients should reapply. Extend service time as needed, before marketing for additional patients. Assess practice of not turning away patients.

b. Strengthen referral partnership resources needed to reach end goals: What factors influence social worker decision to refer to the Ellie Fund? What factors influence the numbers of referrals to the Ellie Fund? What is role of social workers in referrals?

Questions for further research, decision, capacity building:

Target population:

- Research status of BRCA gene carriers and surgery patients, decide if they are target or service population.
- Board: Ask colleagues: Are we comfortable keeping policy of no income ceiling?

Measurement capacity:

- We don't know how extensive our (realistic) measurement process will need to be. We will need help to collect and analyze data and incorporate these tasks into our daily work.
- Automate application form; social workers (and counterparts) will need training and process adjustment; data will need review for accuracy.

Program strategy:

- Clarify existing research and findings relevant to breast cancer patients support needs during and after treatment, including implications for The Ellie Fund's services.
- ***For how long is grant needed for each patient?*** Answer this question by focus groups and research, then fundraise to meet that goal over time, even if it's longer than The Ellie Fund's current grant. Ask Emerson (radiologist): How do patient needs change over time? Seek her insights into optimal length and flexibility of grant. How many times are we unable to meet a need (limited by 12 dinner meals)? What services did we grant that were not utilized?
- What services were not utilized within current time period? Why not?
- How long should services continue per patient (for example food cards)? Survey patients who have completed treatment, either online or phone, offer an incentive. Assess practice of not turning away patients.

Partnership with social worker/patient advocate/patient navigator:

- Encourage patients who need extended services to reapply to the Ellie Fund
- Encourage patients to request referral elsewhere for longer-term services
- Develop network of referral partners who can help with pre-existing financial concerns (employment, financial management, etc.)
- Explore referrals for up to two years of services for metastatic patients
- Do hospitals provide cancer patient support group service? If not, do we want to provide this service, possibly online?
- Research status at each partner of providing list of relevant resources for cancer patients. For those not currently providing, work with social worker, patient advocate, or patient navigator to provide.

Resource development planning:

- Raise resources to meet quality goals at current service levels (before increasing numbers of patients served/year).
- What capacity would we need to reach and serve more of our target population? MA has 6,490 new breast cancer patients per year; the Ellie Fund currently serves 775 patients annually. (To clarify, we need more data: new patients served/year, total patients served/year.) Answer this question last, after you have defined and delivered on success for existing level of patients.