Partnering with a Local Non-profit Health Agency: A Needs Assessment for the Columbia Muscular Dystrophy Association Office

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Current Project Overview

- Leadership Project in conjunction with the CDC-funded grant “South Carolina Study of Rare conditions in Adolescents and Young Adults”
- Supervised by Dr. Suzanne McDermott
- Initial Aim: Connect with Columbia MDA and its families to recruit participants for Rare Conditions Study
- Current Aim: Identify unmet needs of young adults who are being served by the Columbia MDA
Background
What is Muscular Dystrophy?

“The muscular dystrophies (MD) are a group of more than 30 genetic diseases characterized by progressive weakness and degeneration of the skeletal muscles that control movement. Some forms of MD are seen in infancy or childhood [Duchenne MD], while others may not appear until middle age or later. The disorders differ in terms of the distribution and extent of muscle weakness (some forms of MD also affect cardiac muscle), age of onset, rate of progression, and pattern of inheritance.”

(National Institute of Neurological Disorders and Stroke, 2014)
Muscular Dystrophy Association

“Nonprofit health agency dedicated to finding treatments and cures for muscular dystrophy, amyotrophic lateral sclerosis (ALS), and other neuromuscular diseases which result in progressive muscle weakness.”

The agency 1) Links people to health care; 2) Provides support services; 3) Engages in advocacy; 4) Educates the community; and 5) Fundraises for neuromuscular research

Nationally, young adult transition has been a priority of the Muscular Dystrophy Association in the past few years

http://transitions.mda.org

(MDA, 2014)
Beginnings of a Community Partnership
MDA Columbia Support Group

- Meets Monthly
- Open to all adults
- Receptive, welcoming group
- All middle-aged adults and older - no young adults
Needs Assessment Survey
What are we seeking to learn?

- Client Demographics (age, sex, race, neuromuscular disease)
- Client’s home MDA Clinic (Greenville, SC; Charleston, SC; Augusta, GA; Charlotte NC)
- Level of involvement with local MDA office and participation in existing activities
- Reasons for non-participation in existing activities
- Other sources of support, information, or services
- Level of interest in specialized services, supports, or information for young adults
- Preferred method of information/resources
- Topics that are of interest to current young adult clients
Survey Questions

► How involved have you been with the Columbia MDA office?

► In the past 6 months, have you participated in any activities or services offered through the Columbia MDA office?

► If yes, please check all of the activities in which you have participated:
  ► Clinic
  ► Summer Camp
  ► Loan Closet
  ► Flu Shots
  ► Lock-ups
  ► Muscle Walk
  ► Educational Programs
  ► Support Group
  ► Other: ____________

► If no, why not? (Please select all that apply.)
  ► Current activities are of no interest to me.
  ► My needs are substantial and prevent me from participating.
  ► I do not have transportation to access current activities.
  ► I do not feel like I encounter people who are like me at current activities.
  ► Other: ____________
Survey Questions

- From what other sources do you receive support, information, or services: (check all that apply)
- On a scale of 1 to 5 with 1 being the least interest and 5 being the most interest, how interested are you in services, supports, or information specifically for young adults with neuromuscular diseases?
- Through what method(s) would you most prefer to receive information or resources from your local MDA office? Check all that apply.
Survey Questions

If available and offered by my local MDA office, I would be interested in resources, trainings, or programs related to the following topics: (check all that apply)

- Employment and Workplace concerns
- Financial Management
- Relationships & Intimacy
- Health & Wellness
- Emotional Well-being
- Physical Activity/Fitness
- Social activities
- Health care providers
- Disability Income
- Independent Living Options
- Transportation
- Legal Resources
- Political Advocacy
- Continuing education/Higher Education
- None of the above
- Other: __________________
Survey Dissemination & Data Collection Process

- Survey created in Google Documents
- Surveys were mailed with an invitation letter to participate
  - 92 total to people in GA and SC
  - 64 to people in SC (Rare Conditions Study flyer included)
- A link to online version of survey was included in letter
- Self-addressed, stamped envelopes included
- As surveys are returned to Columbia MDA, paper survey data will be input to Google Documents
Future Directions

- Data collection will continue through early April.
- Final results will be calculated
- Based on these results, the Columbia MDA office will be able to:
  - Assess why young adults may not be involved with current activities
  - Determine the level of interest among young adults in activities and programs specifically for their age group
  - Know the communication preferences of young adults being served by the agency
  - Plan future programs and trainings that will address the unmet service needs of young adults being served by the agency
- Needs Assessment Survey instrument will be shared with National MDA so other local MDA offices can use it as well
References
