AGING INDIVIDUALS WHO ARE DEVELOPMENTALLY DISABLED AND THEIR CAREGIVERS NEEDS A CURRICULUM

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Introduction

- Currently, there are 9.4 million adults with DD living at home with difficulties in ADLs in the United States (Brault, 2012).
- Caregivers who take care of individuals moderately to profoundly affected with developmental disabilities (DD), deal with behaviors that can be unexpected, out of the norm, and at times violent. Managing these behaviors can be a demanding task for caregivers as it can be mentally and physically draining (Gray et al., 2011).
- More than 80% of caregivers report that they are suffering from physical fatigue, emotional stress, and emotional distress or guilt due to the daily task of caring for those who are developmentally disabled (The Arc, 2011).
- Parents who are primary caregivers for their child with a disability also have concerns about who will care for their child when they can no longer provide care (Burke, Taylor, Urbano, & Hodapp, 2012).
- Unfortunately, many families do not plan for that future when they will no longer be in a position to care for their disabled child, leaving the disabled person’s siblings or next of kin to be potential future caregivers (Burke et al., 2012; Mccallion, 2006).
Social Work Relevance

- This curriculum is important to social work because it will address the biopsychosocial issues that caregivers face on a daily basis when dealing with individuals with DD.

- Caregivers are left with problems that they may be unable to solve alone. As such, there is an ever-growing need for thorough discussions about the concerns for aging caregivers and their eventual inability to take care of their disabled family member.

- When resources and information become more readily available to the caregiver population, better care plans can be implemented for individuals with DD, and their caregivers can have more direct access to the support they need to maintain their mental well-being.

- Social work professionals need to start with understanding the roles family caregivers play and the challenges they face, in order to help those caregivers find greater strength and control in their caregiving.
Cross-Cultural Relevance

- As adults with DD begin to live longer and outlive their parents, the concern about who will care for these individuals becomes increasingly relevant (Janicki, 2010).

- Currently, services offered to developmentally disabled individuals are not equally distributed, which causes a concern for areas with lesser resources (Bershadsky et al., 2012).

- Bershadsky et al., (2014) found that many minority families are unaware of the support services that are available to them.

- The World Health Organization has recognized the needs of aging adults with DD and identified the challenges they face in terms of service delivery and support (Janicki, 2010).

- Research also shows that minority families receive and use fewer services as a result of their limited knowledge about available resources (Choi & Wynne, 2000).
Curriculum Purpose

This project will specifically focus on the feelings and emotions that are associated with stressful caregiving demands. Caregivers and future caregivers will be able to understand the benefits of planning for the future, understand legal issues, and gain resources to serve an individual who is developmentally disabled while maintaining their own well-being.

Objectives

1. Identify psychological and social issues impacting present and future caregivers in relation to co-residing with a developmentally disabled individual.
2. Help alleviate present and future family caregiver stress by providing and identifying support resources.
3. Connect caregivers with informal and formal support networks that promote advocacy and foster stronger relationships between caregivers and relevant agencies and professionals.
4. Begin initial discussion with caregivers regarding future planning of caring for individuals with DD.
5. Help caregivers build self-awareness and develop advocacy skills to obtain resources in their community.
Curriculum Goals

● This curriculum is specifically intended to build the knowledge and skills of caregivers to overcome multiple common barriers that individuals with DD face on a daily basis.

● Caregivers can gain insight through this curriculum into the dynamics of their life and, as a result, better plan for future caretaking arrangements of their developmentally disabled family.

● Additionally, by sharing their concerns with one another, curriculum participants will serve as each other’s support and resource, and together tackle issues and challenges with being a caregiver for someone who is unable to care for himself or herself.

● Aims to empower individuals with DD and their caregivers to attain independence and achieve their goals.
Curriculum Design

Curriculum consist of three modules that are each three hours long.

**Module One:** "Managing our lives.” *Starting our roadmap.*
Focuses on caregiver stress and concerns that can arise as a result of being a caregiver for an individual who is DD. Topics discussed in this module include behavioral issues of the DD individuals and the caregivers, discussion of future planning, beginning steps to implementing a plan for the future, and dividing roles within a family.

**Module Two:** "Is conservatorship right for you?” *Steps to conservatorship.*
Touches on legal issues that are associated with being a caregiver of an individual who is DD. Participants will be educated on general information they will need to know about conservatorship. Participants will have opportunities throughout the module to discuss their concerns with peers about the legal processes.

**Module Three:** “Let’s get resourceful.” *Utilizing services to meet your needs.*
The third module is when caregivers will be educated on national and local community resources. There will also be opportunities for participants to share their knowledge and provide feedback about available resources in the community. Caregivers will be asked to brainstorm what resources are most important to them, and to discuss what resources are lacking in their community.
Curriculum Implementation

Facilitators will be provided with the following materials:

**Facilitator’s guide** - To address the needs and questions that facilitators may have, and helps them understand the organization of the curriculum. The guide will consist of the following:

- **Agenda** - Outlines the activities involved in that module.
- **Facilitator’s Tips** - Tips are helpful tools for effective facilitation of a session.
- **Materials Checklist** - Includes items needed to implement the activities.
- **PowerPoint Slides** - The slides will provide helpful information for each of the modules.
- **Guided Script** - This semi-scripted guide gives facilitators suggestions and/or direction on what to say during sessions.

**Participant Packets** - Each packet will provide visual aids that correspond to the curriculum material.

**Recruitment Strategies** - Flyers will be distributed to vendors, such as respite agencies and behavioral analysis agencies, who also work directly with families. These recruitment publications should be in large print and easy to read.
Future Recommendations

● It is recommended that all family members are included in curricula that address the care of individuals with DD. Suggestions for the development of new and improved curricula are to include individuals who are developmentally disabled to be part of the workshops.

● It is also recommended that the allotted time of the curriculum be extended to allow participants to gain in-depth knowledge on the various topics.

● Lastly, it is recommended that the curriculum seeks to develop cultural awareness of specific cultural differences that may be in a universal and diverse group and impact the group dynamics.

● Overall advocacy movement in the care of all individuals with DD is needed, and the advocacy should start with ensuring that caregivers receive proper support services.


