Developing and Using a Caregiver Simulation to Create Empathy Among the Non-Caregiving Community
Objectives

• Discover the steps involved in organizing and implementing a simulation.

• Learn how to choose your audience/location for your event and recruit volunteers.

• Hear feedback from simulation participants.
In 2016, the “Sharing the Care” group in Huntsville, AL created and implemented a Caregiver Simulation in order to show empathy for a “Day in the Life” of a caregiver across the lifespan.

By using community resources that serve the lifespan, this simulation offers insight to the day-to-day struggles facing caregivers.
Why a simulation?

- Members of the non-caregiver community may not understand the day-to-day challenges of being a caregiver
- Establishes empathy
- Educates about the value of respite care
- Creates a real-life scenario that is stressful
- Help healthcare professionals to learn more about resources in the community
Why a simulation?

“I’m always looking for opportunities for real-life experiences for my students to experience a more real version of what being a part of someone’s life with a disability is like. So, this was one additional way to expose them to that life.”

-Faculty member; College of Education
University of Alabama at Huntsville
How to start....

• Who? Who’s my audience?

• What? What’s my goal?

• When? When is a good time?

• Where? Where is my location?
Choose your audience/location

College or University

- Social Work
- Nursing
- Physical Therapy
- Special Education
Choose your audience/location

Community Members

- Church
- Community Center
- State Agencies
- First Responders
Choose your audience/location

**Healthcare Professionals**

- Nurses
- Social Workers
- Hospital Case Managers
- Home Health
- Hospice
Time is important!

- Time of the year
  - Think about the school semesters
  - Consider holidays/sporting events

- Day of the week
  - Consider your volunteers
  - Monday and Friday are usually too busy

- Time of day
  - 9a-11a works well for students
  - Afternoon may be better for professionals
Setting a goal

• Think about your scenarios
• Our goal was 30-40 participants in order to fill all of the “roles”
• Get RSVPs if possible
• You’ll need to set a limit too (you’ll only have nametags and props for a certain number of people). We had to turn people away.
• When scheduling the event, discuss your participation goals with the school or church to set the expectations
Recruiting Volunteers

- State agencies
- Home Health
- Hospice (often have volunteer roster)
- DME
- Adult Day Care
- Hospital volunteers
- Church ladies group

We put together a goodie bag with everyone’s brochure, so this is often a great motivation to get volunteer support.
Family Scenarios

The heart of the simulation are the family scenarios. We used 5 different scenarios for our simulation.

Each participant will have an active role in a family scenario, either as a caregiver or care recipient.

These family scenarios come with a background, props, daily tasks and even an impending dilemma.
Family Scenarios

As participants arrive, they receive their nametag.
Family Scenario Example

Owen, Rose and Jim Reed

Caregiver: Rose, aged 87, has been a homemaker all her life and thinks that she should be able to take care of her husband Owen and her live-in son Jim.

Care Recipient: Owen, aged 88, is unsteady on his feet and has macular degeneration, a progressive disease that has left him almost blind. He depends a lot on his wife, Rose.

Son: Jim, age 52, a veteran, who is deaf and lives in the home with his parents.
Family Scenario Example

- **Emotional** - Rose feels guilty about needing help with Owen. In her day, women took care of their families and did everything for themselves.
- **Physical** – Owen is failing in general and depends upon Rose for most of his activities of daily living.
- **Social** – Since their son lives with them, many friends are unsure how to they can assist therefore they avoid visiting.
- **Financial** – They are of very modest means, but can cover current expenses. They hate the idea of spending money on extra help in the home. Monthly income is $2,000.00 and they pay the mortgage which is $775.00 and the utilities which are $200.00.
Family Scenario Example

**Roles:** Caregiver Rose, Care recipient Owen, Care recipient Jim,

**Props:** Cane (fall risk), ear plugs (hard of hearing), sunglasses (low vision)

**Prop Instructions:** Please use the cane throughout the simulation if your character is a fall risk. If you are deaf or hard of hearing place ear plugs in your ears the duration of the simulation. Also, if you have low/no vision place sunglasses on to simulate this trait.

**Dilemma(s):** Get help with activities of daily living for Owen.

**Possible Interventions:** Home Care Agency, Church, Area Agency on Aging, AIDB, Alabama Respite
Family Scenario Example

Grant and Kristin Johnson

Caregiver: Grant, age 42, a veteran, lost his wife to cancer and is a single father to a nine year old. He works at a bank and is struggling to make ends meet.

Care Recipient: Kristin, age 9, has Cerebral Palsy and uses a power wheelchair.

Mother-In-Law: Grant’s late wife’s mother, Linda lives in the same town as Grant and Kristin. Her advanced age allows her to help with Kristin in a limited manner.
Family Scenario Example

- Emotional – Grant mourns the loss of his wife and the family life he had hoped for. He suffers from depression and takes daily medication for it.
- Physical – Kristin uses a power wheelchair and needs help with most ADL’s.
- Social – If Kristin is removed from the classroom she will be isolated and only have her father as a social companion.
- Financial – This family lives on only the father’s income, bringing in $2000.00 a month and they pay the mortgage which is $1000.00 and also $300 in utilities.
Family Scenario Example

Roles: Grant, Kristin

Dilemma(s): Kristin received a prescription for a new wheelchair but the copay is $1000 and Grant cannot currently afford it. If they do not find an agency to help cover costs, Kristin will have to be home schooled by a tutor and Grant will have to quit his job to be with her during the day.

Props: Wheelchair

Prop Instructions: If you are Kristin please make sure to use wheelchair entire time throughout simulation.

Possible Services: Church, Alabama Respite, Home Health Agency, Social Services, UCP

Note* Grant and Kristin attend work and school. This is represented by Grant checking in at the employment table after taking Kristin to school at the church. Each will stay for five minutes. This only happens one time during the entire simulation.
Family Scenario Example

All of the supplies needed for each family scenario are placed in plastic bins and clearly labeled.
Family Scenario Example

Family groups join together to read their back story and gather their props.
Logistics

• The simulation is divided into three 15 minute segments.
• We use a whistle to signify the start and end of each segment.
• There is a “waiting” area set up on one end of the room that is the “home” for the participants at the end of each segment.
Logistics

• The room is set up with several tables (similar to a health fair) with signs identifying each agency, task or resource.
• The family groups move about the room to complete a series of tasks.
Completing Tasks

• The primary focus during the simulation is for each “family” to complete a series of daily tasks along with their “dilemma” that was assigned in their story.
• In order to accomplish these goals, they will visit various community resources. Task cards are given to each group and the card is initialed when they complete each task.
Task Card

Tasks to be completed by participants in addition to dilemma

CG=Caregiver  CR=Care Recipient

1. CG and CR both get 3 meals each day. (This is represented by going to the grocery store and paying for food)
2. CG and CR both get meds. (Represented by visiting the pharmacy and paying $50.00)
3. CG and CR both get 8 hours of sleep. (Represented by going home at the end of each cycle.)
4. CG and CR both get weekly exercise. (Represented by going to the YMCA and walking in place for a minute-if unable to walk must sit in wheelchair and do arm rotations).
5. CG maintains schedule of doctor appointments for self and CR. (Represented by sitting in the doctor’s office for 2 minutes (one minute for CR and one for CG).

6. CG pays bills. (Represented by going to the bill center and signing in/paying for utilities and rent/mortgage)

7. CG receives one hour of respite. (Represented by 2 minutes of downtime at AL Respite)

8. CG manages finances. (Represented by accessing additional funds at the bank)
<table>
<thead>
<tr>
<th>Task Card</th>
<th>Department of Human Resources</th>
<th>Area Agency on Aging</th>
<th>Alzheimer’s Association</th>
<th>Hospital/Doctor</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><img src="image1" alt="DHR" /></td>
<td><img src="image2" alt="TARCOG" /></td>
<td><img src="image3" alt="Alzheimer's Association" /></td>
<td><img src="image4" alt="Hospital" /></td>
</tr>
<tr>
<td>Pharmacy</td>
<td><img src="image5" alt="Pharmacy" /></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grocery Store</td>
<td><img src="image6" alt="Grocery Store" /></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bill Center</td>
<td><img src="image7" alt="Bill Center" /></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bank</td>
<td><img src="image8" alt="Bank" /></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employment</td>
<td><img src="image9" alt="Employment" /></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>YMCA</td>
<td><img src="image10" alt="YMCA" /></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Veteran’s Administration</td>
<td><img src="image11" alt="Veteran's Administration" /></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alabama Institute for the Deaf and Blind</td>
<td><img src="image12" alt="AIDB" /></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>United Cerebral Palsy/Alabama Respite</td>
<td><img src="image13" alt="Respite" /></td>
<td><img src="image14" alt="Church" /></td>
<td><img src="image15" alt="Homecare" /></td>
<td><img src="image16" alt="Hospice" /></td>
</tr>
</tbody>
</table>

*Note: The images represent various organizations and services.*
Transportation Tickets

• All family groups will start the simulation with a certain number of “transportation tickets”.
• These tickets symbolize transportation expenses (gas, bus, train, etc.)
• Each family group must present a transportation ticket for every table they visit.
• Once they run out, they must purchase more. (you should pre-determine which agencies will sell tickets and notify participants)
Wild Cards

- During the simulation participants will receive wild cards that signify some sort of change to their day.
- Wild cards may be negative or positive.

Owen takes a fall and breaks his leg in 2 places, report to the emergency room and ask for a wheelchair.

Grant’s only mode of transportation has died, leaving him no way to go. You must purchase more tickets at AAA or DHR to continue your day.
Vouchers

• Many of the area agencies have vouchers to families that qualify.
• There are vouchers for the Pharmacy, Home Care, Groceries and Day Care.
• We do not tell participants about these vouchers!
• It’s up the family groups to “find” these surprise vouchers by going to the resource tables. Some families spend their money on bills and daily tasks only to discover they could have received a voucher.
Debt Stickers

• Each family is given a budget and each family is different.
  • Owen and Rose Reed will have $1500 in their envelope and $1500 held at the bank
  • Grant and Kristin will have $1000 in their envelope and $1000 held at the bank.

• If a family spends all of their money, they can choose to visit the Pay Day loan table and go in Debt. - THEY RECEIVE A DEBT STICKER THEY MUST WEAR.
DHR Stickers

- A family may be turned into DHR for leaving their care recipient unattended, not giving them food or meds, or as a WILD CARD.
- Families will receive a DHR sticker and have to stop what they are doing and proceed to the DHR table to deal with their offense.
Props

The props are important to making the simulation feel more REAL.

Partner with a local Durable Medical Equipment (DME) company to provide these props if possible.
Props

Depending on the number of participants, you may need 4-8 of each piece of medical equipment.
Props

Some props may be purchased/donated.
Props

Remaining props can be created and printed.

- Name Tags
- Signs
- Wild Card, DHR, Debt Stickers
- Money
- Insurance cards
- VA paperwork
- Voucher cards
- Transportation Tickets

![Image of a Medicare card]

![Image of a voucher card]

Voucher
Pharmacy $
Pre-Simulation Interviews

Can you tell me about Respite/Respite Care?

“I know 0%”

“An organization maybe?”

“I have heard that word but I can’t remember what it means”

“I have no idea”

“Never heard of it”

“It sounds familiar”

“I probably should know, considering my major”
Pre-Simulation Interviews

Have you ever been a caregiver?

“No”

“No, but my mom was”

“No, never have”

“Yes, I worked as a mentor for autistic children”

“Yes, I have been a caregiver for some of my family”

“Yes, my grandfather”
Pre/Post Testing

• Collecting data is always important.
• Participants complete a pre and post test.
• Questions (rate on scale from 1-5)
  • How important is Respite?
  • How much support do you think the government provides to family caregivers?
  • How easy is it for caregivers to access resources?
  • How stressful is a normal day for a family caregiver?

• What are some of the challenges you think family caregivers face each day?
Pre/Post Testing

- How much does a skilled caretaker earn per hour while providing care for someone with a physical, cognitive or medical condition? *Circle one*
  - $5-$10
  - $11-$15
  - $16-$20
  - $21-$25
  - $26-$30
  - $31-$35
  - $36-$40

- Which of the following do you feel are equipped and willing to care for a person with physical, cognitive or medical conditions? *Circle all that apply*
  - Paid nanny
  - Babysitter
  - Local day camps
  - Fitness center child watch
  - Fee based after school care
  - After school clubs
Pre/Post Test Results

The areas that seemed to have the biggest impact:

- Importance of respite
- Stress on the caregiver
- Resources available
- Reality of the cost
Pre/Post Test Results

• Pre Test Answer

What are some of the challenges you think family caregivers face every day?

having to balance other everyday responsibilities

• Post Test Answer

What are some of the challenges you think family caregivers face every day?

emergency mishaps their own disabilities
Simulation Evaluations

Caregiver Simulation Evaluation

1. How do you feel the caregiver simulation process (instructions) could have been explained better?  
   It would have been better if we received the instructions on paper or ahead of time.

2. What did you enjoy the most about the caregiver simulation?  
   I really liked how interactive it was. I learned about what other agencies do.

3. What did you enjoy the least about the caregiver simulation?  
   The time limit was hard to work with to get all the tasks done.

Please provide additional feedback (ideas) to help us better prepare for our next simulation to ensure success.  
To engage participants more the agencies can be more spread out with information on them such as posters or brochures.
Can you tell me about Respite/Respite Care?

“People who need a break, that need rejuvenated, to take care of their loved ones again, so they get a break, come back and have a fresh start”

“Relief for the family member; provides them an opportunity to maybe do a chore”

“Help for the caregivers to give them a break to get tasks done”