

# 1. How has your experience with caregiving impacted your life and/or work?

Appleton/Session 1 (Focus on Special Needs Caregivers) - Caregiver Responses

Topic	Comments
personal rewards	It has reorganized my priorities.
policy	Law requiring bubble-wrapped meds can cost \$75 for the weekend [respite related?].
respite	<ol style="list-style-type: none"> <li>1. Respite care is difficult.</li> <li>2. Availability when you need it.</li> </ol>
services	<ol style="list-style-type: none"> <li>1. Difficult managing finances, IRIS, IRS, etc., for care receiver.</li> <li>2. Programs are complicated, rules aren't well explained &amp; things often seem to change.</li> </ol>
social life	<ol style="list-style-type: none"> <li>1. No social life without my daughter.</li> <li>2. Difficult to maintain friendships.</li> <li>3. Made new friends who have special needs children.</li> <li>4. People don't necessarily understand what our life is like and don't always take time to learn.</li> <li>5. It is easier for [other people] to ignore that aspect or move on.</li> </ol>
support	<ol style="list-style-type: none"> <li>1. Important to have help providing care so I can, at times, focus on work.</li> <li>2. How do you trust a caregiver in your home without an established relationship?</li> </ol>
time	<ol style="list-style-type: none"> <li>1. Limited my available hours.</li> <li>2. Busier now than when I was working (son out of school).</li> <li>3. No time for me to socialize, sleep, read, take care of myself.</li> <li>4. My schedule revolves around my son - doctor appointments, special Olympics, other groups, laundry, meds, managing behavior.</li> </ol>
work	<ol style="list-style-type: none"> <li>1. Working fewer hours at lower pay rate.</li> <li>2. Forced to "retire" because I could not find acceptable respite care for 1-day retail.</li> <li>3. I retired with respite from a part-time job I held for 43 years.</li> <li>4. Have had to work part-time.</li> <li>5. Sometimes performance impacted by my child care needs.</li> <li>6. Employer changed handbook to accommodate care of sibling with disability.</li> <li>7. Flexibility in times and locations (when/where) I work is critical.</li> <li>8. Work sometimes has to wait until late.</li> <li>9. I left a significantly financially rewarding career to care for my son.</li> <li>10. How did I do this while working.</li> <li>11. Need an outstanding employer who is ok with my son sometimes coming with me.</li> <li>12. Early retirement allowed me to stay home and care for my son when he graduated from high school.</li> </ol>

## 2. What would you like to see in the area of caregiving?

Appleton/Session 1 (Focus on Special Needs Caregivers) - Caregiver Responses

Topic	Comments
caregiver wages	<ol style="list-style-type: none"> <li>1. Low wage makes hiring good caregivers difficult.</li> <li>2. We need to reward the career of caregivers to keep good ones and encourage new ones.</li> </ol>
policy	<ol style="list-style-type: none"> <li>1. Family caregivers paid for "errand" or "appointment" time.</li> <li>2. One policy for entire state vs county availability. The paperwork for caregiver care pay is excessive and time consuming.</li> <li>3. Bubble-packed prescription drugs when using a care facility for respite or short term stays is prohibitively expensive – can cost \$75/day for a weekend.</li> </ol>
respite	Help getting respite care beyond just giving us a list of names.
services	<ol style="list-style-type: none"> <li>1. Need more opportunities for activities in the community for people [with special needs] to engage in that meet needs and interests.</li> <li>2. We have difficulty finding things for our son to do when in community with a caregiver.</li> <li>3. More adult dare care, e.g., St Paul's Club Gabriel.</li> <li>4. One-stop site for supports.</li> <li>5. My son appreciates being with family &amp; close friends, he is pleasant and flexible about activities. We hope he will have opportunities, we can't care for him to engage meaningfully with people &amp; activities.</li> </ol>
support	<ol style="list-style-type: none"> <li>1. More support learning to screen options &amp; ensure care-receiver's safety.</li> <li>2. Need more well-trained caregivers for day services &amp; short-term care.</li> <li>3. More peer support opportunities.</li> </ol>
transportation	<ol style="list-style-type: none"> <li>1. Changes needed: easier transportation and times to fit my schedule vs. School bus schedule.</li> <li>2. Transportation for rural areas is rare and expensive - school bus is \$25 one way.</li> </ol>

## 3. Describe, in a few words, the experience of being a caregiver.

Session 1 (Focus on Special Needs Caregivers) - Caregiver Responses

Topic	Comments
personal rewards	<ol style="list-style-type: none"> <li>1. Simultaneously <b>rewarding, challenging &amp; worrisome</b> (when thinking about the future).</li> <li>2. an <b>adventure</b> I wouldn't trade for anything.</li> </ol>

## 1. How has your experience with caregiving impacted your life and/or work?

Appleton/Session 2 - Caregiver Responses (Seniors)

Topic	Comments
personal challenges	<ol style="list-style-type: none"> <li>1. Anticipatory grief</li> <li>2. Sometimes my mom thinks I'm her savior &amp; sometimes she hates me.</li> </ol>
personal rewards	Children learned to care/respect for grandparents/seniors.
social	<ol style="list-style-type: none"> <li>1. Unable to do things I like to do.</li> <li>2. Missing friends &amp; special events.</li> <li>3. Very much. My mother has lived with my husband and me for the past 10 years.</li> </ol>
support	<ol style="list-style-type: none"> <li>1. Local family members never get a break.</li> <li>2. In caring for my mom, I am the parent.</li> <li>3. When my mom was in nursing home I had to advocate when staff were not doing their job, I did not like being the [?] parent</li> <li>4. Caregiver burnout</li> <li>5. Insufficient training</li> </ol>
time	<ol style="list-style-type: none"> <li>1. Many weekends traveling to provide care for one family member.</li> <li>2. Long hours</li> <li>3. Hard on marriage &amp; time together with spouse.</li> <li>4. Lost some quality time with children.</li> </ol>
work	<ol style="list-style-type: none"> <li>1. Had to slowly stop teaching music out of home.</li> <li>2. The need to take time off [work] &amp; sacrifice income.</li> </ol>

## 2. What would you like to see in the area of caregiving?

Appleton/Session 2 - Caregiver Responses (Seniors)

Topic	Comments
caregiver wages	More money for the terrific caregivers who help us.
policy	<ol style="list-style-type: none"> <li>1. Caregiver tax credit</li> <li>2 Yeah for RAISE!!</li> <li>3. Funding for "care management" for provide pay customers, someone who will oversee a care plan for people alone or children who are far</li> <li>4. Better, more cost friendly insurance &amp; funding.</li> <li>5. I wish there was a less complex, more consumer-friendly system of benefits.</li> </ol>
respite	<p>More options for respite care.</p> <ol style="list-style-type: none"> <li>1. More caregivers to help those of us engaged in full-time caregiving.</li> <li>2. Lots of options available to improve reliability &amp; shorten time frames to use [respite?].</li> </ol>
support	<ol style="list-style-type: none"> <li>1. More professional and family help members.</li> <li>2. 1:1 support for caregivers.</li> </ol>

### 3. Describe, in a few words, the experience of being a caregiver.

Appleton/Session 2 - Caregiver Responses (Seniors)

Topic	Comments
personal challenges	1. <b>Enriching</b> but <b>challenging</b> & <b>exhausting</b> .
personal challenges	2. <b>Heartbreaking</b> to see her fail.
personal challenges	3. <b>Sad</b> to see mom failing.
personal challenges	4. <b>Frustrating</b>
personal challenges	5. <b>Thankless</b> at times.
personal rewards	1. <b>Endearing</b> to help my mom.
personal rewards	2. Parent does express a lot of <b>love</b> and <b>gratitude</b> .
personal rewards	3. <b>Grateful</b> to be able to help.
personal rewards	4. In some ways, a great <b>blessing</b> .
siblings	<b>Sad</b> dynamics with siblings.
social	1. <b>Hard</b> on <b>social life</b> and <b>marriage</b> relationships
social?	2. Limited travel opportunities.
support	<b>Stress</b> as time goes on.