



Pathways for Respite Care: Faith Communities and Families Impacted by Disability



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One mom's story

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Definition of a Caregiver

- "anyone who provides physical, emotional, spiritual, financial, or logistical support to a loved one with a chronic, disabling or life-threatening condition"



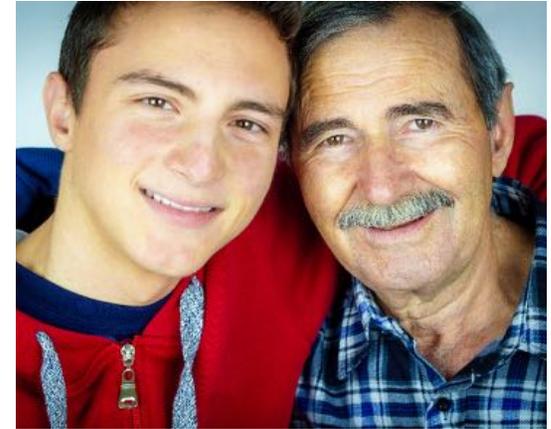


Caregiving is Critical

- Without “informal” caregivers the cost of care would be overwhelming
- Patients are living with diagnoses for longer
- Caregivers often are juggling work and family
- Long distance caregiving is common

Caregivers in Colorado

- Nearly 4 in 10 Americans are Caring for Someone with Significant Health Challenges
- 843,000+ Family Caregivers in CO
- Caregivers need support!



Respite Care in Colorado

- How to access respite:
 - Medicaid waivers
 - Area Agencies on Aging
 - Community-Centered Boards
 - Community organizations (Colorado Respite Coalition)
 - Private pay
- Respite looks different for every family.

Challenges in Finding Respite Care

- Respite is costly for families
- There is a provider shortage in Colorado and nationwide
- Families do not feel comfortable leaving their loved one
- Families do not have support systems (relatives, friends, community)



How Can Faith Communities Help?

- Most congregations have many individuals with health care challenges, disabilities or facing the difficulties of aging
- Many families lose the support system of their faith communities when they become caregivers
- Faith communities can provide support for caregivers in a variety of ways – it can be simple!
- 2017-2019 – Colorado Respite Coalition will be working with faith communities to provide resources to help caregivers



One mom's solution: Night Lights, INC



What is Night Lights?



- a free respite care organization for families with children with special needs and their siblings.
- children ages 1 month – 12 years .
- one-on-one care from trained, background-checked volunteers.
- one Friday each month from 6:30-10:00pm.
- arts and crafts, music, free play, dog or cat therapy, a snack and movies.
- Registered Nurse at each Night Lights evening.

What is Night Lights?



- Each site is overseen by a Leadership Team specific to that site.
 - Responsibilities of a Leadership Team
 - Plan the Night Lights evenings
 - Train volunteers and do reference checks and background checks
 - Interview families/review paperwork (paperwork must be updated yearly)
 - Pair each child with their volunteer and oversee the evening
 - Current CPR/First Aid and CPI (Crisis Prevention)
 - Set up/Clean up
 - Work with the church to reserve space for Night Lights
 - Fundraising for their site

Night Lights Vision, Mission, Core Values



- Vision – Night Lights vision is to express God’s love and value for children with special needs across the globe.
- Mission – Night Lights provides respite care programs that create safe and accepting environments for children with special needs and their siblings.
- Core Values – Acceptance, Respect, Compassion for others, Integrity, Awareness
- ****Night Lights is a Christian-based organization. Families and volunteers of all background are welcome to participate in Night Lights, and are valued.**

What does a Night Lights evening look like?



- Leadership Team arrives early to set up activities
- Volunteers and Nurse arrive at 5:30pm for dinner and announcements (dinner is donated by local restaurants)
- Families check in at 6:30pm
- The evening is child-lead, but adult supervised. Volunteers are encouraged to engage and participate with the kids.
- Movie at 8:30pm
- Pick-up at 10:00pm

Why partner with faith – based communities?



- Night Lights is a Christian based organization
 - we started as a ministry of a local church in the Denver Metro area.
- 501c3 non-profit status
- Benefits of partnering with churches
 - Facilities that are appropriate for children (in-kind donation)
 - Most churches have a high value for service,
 - so it’s an accessible avenue for volunteers
 - There is a community outreach focus
 - NL falls in line with mission/vision of church

What about our faith statement?



- Our faith is part of Night Lights’ history and it’s our foundation of how we operate while representing Night Lights.
- We welcome and value anyone who wants to participate in Night Lights, regardless of their faith, background, etc.
- Staff and volunteers are not allowed to discuss faith beliefs, religion or any other sensitive topic with each other or children.
- Our responsibility is to respect and care for those in the disability community, and not try to change their beliefs.

Statistics



- **17.6% of all children in Colorado age 1 – 14 have a special health care need.**
 - That's an estimate of 162,000 children.*
- **Respite is typically the most frequently requested and least available family support service.***
- **Respite saves tax dollars by helping to prevent abuse or neglect, and provides the physical and emotional recuperation time parents need to be able to sustain their families.***
 - * Colorado Dept. of Health and Public Safety

Disabilities and Family Life



- “...it is not the child’s disability that handicaps and disintegrates families; it is the way they react to it and to each other” (Dickman & Gordon, 1985, p. 109). *Becoming a Resilient Family: Child Disability and the Family System* By C. Amber Havens National Center on Accessibility

Impact on Siblings



- Often times siblings become secondary caregivers.
- Night Lights offers respite to the siblings as well.
 - They get their own volunteers and freedom from their responsibilities.
- Parents often experience guilt, shame, and fear with their “typically developing” children due to the amount of time, energy, and effort it takes to care for the child with special needs.

Cost of Implementation



- Night Lights does not require churches to contribute any monetary funding,
 - however, it is very helpful to have the facility given at no-cost (in-kind donation).
- Sites are expected to be financially self-sufficient and are given a variety of ways to fundraise.
 - Accountability with ED, Program Director, Board
- Night Lights provides a substantial liability policy for each site.
- Each site receives a start-up stipend from NL corporate

Role of Churches



- Support the Night Lights mission and vision
- Provide the facility as an in-kind donation
 - Safe/accessible place for children with disabilities
 - Small storage space for supplies
- Provide access to volunteers (up front announcements, newsletters, show videos, church bulletin, ministry fair)
- Maintain the facility



Goals for Night Lights



- Expand Night Lights across the country
- Continue partnerships with churches and provide a place of respect, acceptance and compassion for the special needs population within faith-based communities.

Needs and Gaps

- JFK Partners LEND: Spiritual Care
- Iliff School of Theology
- Questionnaire
 - Organizational structure
 - Current respite ministries
 - Desire to include respite
 - Barriers and needs to implement respite
 - To inform outreach and training efforts



Findings

- 9 states
- 42 respondents
- Types of organizations
 - Protestant congregations (both conservative and liberal)
 - Programmatic ministry (youth camp)
 - University
 - Non-profits
 - Non-denominational Christian congregations
 - Variety of mission statements (most were inclusive)



Findings

- 100% have members with disabilities
- Most are small organizations (<100 weekly attendees)
- 82% fiscally solvent
- 60% have no respite services/ministries



Findings

- Support disabilities in other ways (42% said no)
- Those that do
 - Lay ministries
 - Include in worship
 - Adapted service
 - Camp/retreats
 - Specially designed clubs



Findings

- Barriers
 - \$\$ (87%)
 - Lack of training/volunteers (71%)
 - Physical space (43%)
 - Not in mission statement (43%)
 - Time (29%)



Conclusions

- Most groups want to support disabilities
 - But don't have systematic programs
 - Try to accommodate in other ways
- A variety of barriers
 - Mostly logistical
- Lack of awareness
- Not due to lack of fit with mission
- Opportunities to partner



Community of Listeners

- Questions?
- What have you faced?
- Any solutions you have discovered?