

A RESOURCE  
FROM  
NACG  
MEMBERS



# SUPPORTING CHILDREN OF ALL ABILITIES WHO ARE GRIEVING TOOLKIT





# Best Practices

Utilize the R.I.C.E. (Respect, Inform, Connect, Empower) Model created by Jennifer Wiles.

# R.I.C.E. MODEL

## Respect

Each participant feels heard, seen, and witnessed. We strive to preserve the dignity of each person we serve.

## Inform

Each participant learns that there is no timeline for grief, that there are many emotions surrounding grief, and that each person grieves in their own way.

## Connect

Each participant learns that they are not alone in their grief

## Empower

Each participant learns to use their unique strengths to help with their grieving process. Their strengths are recognized and validated.

**Philosophy:** Be sure your center's mission includes serving children/teens of all abilities and uses a strengths-based approach to supporting participants and programs. When possible, try to choose pictures, books and media that represent a diverse range of children/teens.

**Communication:** When possible, keep the following in mind:

- Create group rules to allow a safe space to share. This would include confidentiality and giving the group member the option to pass.
- Use clear, concrete, honest language.
- Speak directly to the child/teen.
- Incorporate multiple methods of communicating information. (Braille, Boardmaker, PECS, different languages, feelings, pictures, expectations.)

- Use age-appropriate language and adjust language/instructions/activities based on participant's age and other needs.
- Collaborate to meet the child/teen where they are. Respect the child/teen and allow them to set their own pace for grieving.
- Support volunteers by providing training and opportunities to process their experiences.
- View the family as partners in your bereavement work. Set the mission to work together to support the child. Build a bridge with the family.
- Listen to children/teens! Listen to their stories, listen to what they tell you what they need and will help them be successful in your program.

### **Assessment**

- Focus on participant's strengths, interests, and needs to facilitate their success within the program.
- Make sure all voices are heard in the assessment process, especially that of the child/teen.
- With the family's permission, it is often helpful to communicate with other professionals who are involved in the child's life, such as therapists and educators.

### **Activities**

- Adapt and plan activities that are strength-based.
- Give all participants the same chances and choices to fully participate at their own comfort level.

### **Program Space**

- Space should be accessible, comfortable, and safe for all participants.





# Frequently Asked Questions

### **1. How do I refer to a child with a disability?**

- The easiest way to refer to any child is by their name. Then if needed you can follow with more information. Here are some examples:
  - “This is Ian. He uses a wheelchair”.
  - “This is Jordan. They have autism.”
  - “This is Marisol. She uses this board/computer/sign language/her assistant to communicate.”
- Use Person-First Language. This means we acknowledge the child as a person and not their condition. For example, we would say, ‘child with a disability’ rather than a ‘disabled child’. Try to avoid using language that implies a negative connotation (e.g. “suffering from”, “afflicted with” or “defect”). According to the ADA, terms like “differently-abled”, “challenged”, “handi-capable”, or “special” can be condescending or confusing.
- And, of course, you can ask the child or their parent their preferred language!

### **2. How do you help a parent/caregiver tell their child with a disability that someone has died?**

Keep in mind all the things that we know as bereavement professionals! Use concrete language, reassure the child that they are safe and supported, give the child adequate time to process, help prepare for any death ritual and keep routines as consistent as possible. Remember R.I.C.E.: Respect, Inform, Connect and Empower (Wiles, 2020).

Here are a few tips for talking to children with disabilities about death:

- Promote trust by being honest, clear and timely with all communication. Encourage a trusted person to communicate the news to them.
- Keep information in small manageable pieces. Be prepared to repeat everything that you have said several times!
- Use supportive devices or social stories, if appropriate, to support your initial explanations to promote the child’s understanding.
- Explain that the child may feel an array of emotions when a person dies. Validate that all feelings are OK and help them name them.
- Explain what emotions a child may expect to observe in the people around them when a person dies.
- Always end with reassurance that they are loved, supported and safe.

### **3. What if I say the wrong thing or use the wrong term when communicating with a child with a disability or their family?**

We all make mistakes! Simply apologize and clarify what terms or language they would prefer. Responding with compassion for yourself and for the family will allow this to be a learning opportunity for all.

### **4. How can I make sure our space is welcoming and accessible to all?**

- Evaluate your environment. Check for physical access, clear signage, good lighting and clear spaces for movement. Be aware of sensory overload: manage sounds and lighting and avoid loud noises and bright, flashing/flickering lights. Keep wall

displays neat and organized. Also, manages smells such as scented candles, air freshener and perfumes.

- Create a “comfort corner” where kids can take a break and regulate their bodies and minds. Make it cozy and comforting. Have fidget toys or short books available. If possible, a volunteer can sit with the child and practice mindful breathing or centering exercises. By making this effort, you give the message that your space is welcoming and inclusive to all.

### **5. How can I make sure that our group activities are accessible to all participants?**

Respect all participants by planning strength-based activities that value the process over the finished product and that are flexible with materials and skills needed. Make sure all participants are considered when planning activities. Inform families of activities before the group, sending clear directions in simple steps and providing materials if possible. Connect participants of all abilities by offering multiple materials (clipboards, wider crayons, etc.) to all. Empower by breaking instructions into small, manageable steps and offer short breaks between activities.

### **6. How do I deal with challenging behaviors?**

Think about being proactive when dealing with challenging behaviors. Children of all abilities thrive in settings where they know what to expect. Setting clear group expectations and following a consistent routine in your groups will allow children to come in knowing what is expected of them and their peers. Think about developing the following: opening and closing rituals that create a container for your time together, exercises that focus on regulation that can be used to transition from one activity to the next, and a “comfort corner” in your space (see question 4). Develop group norms/rules/expectations together. Including an acceptance of everyone’s differences. Focus on naming everyone’s strengths. Explore and celebrate both differences and similarities and connections within the group as it is forming. These proactive approaches will help to ensure that children feel accepted, validated and supported.

### **7. How can I support our program volunteers in this work?**

- Remind volunteers they do know how to work and connect with children who are grieving, and that they can draw from the same skill set to meet each child where they are. A brief training or information session about working with children with disabilities is important. Think about partnering with local organizations that may have experience and resources to share. Everyone benefits from collaboration on this topic!
- Include volunteers in your proactive approach with schedules and group plans. Reassure volunteers that they can ask for support or ask questions at any time!

### **8. I’m not sure if I’m qualified to work with this population. What should I do?**

You’ve got this! Grieving children of all abilities need the same things: to be seen, heard, included, supported, and loved. The skills that you already bring to your grief work, open heartedness, flexibility, and inclusivity, qualify you to work with children of all abilities!

If you feel you need more education into disability topics, there are great resources out there! Please see our resources section for more information.



# Resource List



## Resource List

The inclusion of any organization or resource in this Resource List does not imply or constitute an endorsement or recommendation, nor does exclusion imply disapproval.

### For Children:

- *"I Have a Question About Death: Clear Answers for All Kids, Including Children with Autism Spectrum Disorder or Other Special Needs"*, by Arlen Grad Gaines and Meredith Englander Polsky. This book asks questions that a child might have about death. It uses straightforward text and clear illustrations to explain what death means specifically to children with autism spectrum disorder and other special needs. [Link to purchase here.](#)
- *"Finding Your Own Way to Grieve – A Creative Activity Workbook for Kids and Teens on the Autism Spectrum,"* by Karla Helbert. This book explains death in concrete terms, explores feelings that the child may encounter as a part of bereavement, and offers creative and expressive activities. [Link to purchase here.](#)
- *"Grief is a Mess,"* by Jackie Schuld. This book explores how grief is different for everyone and can change without warning. Illustrations to remind the reader to be kind to others and patient with themselves as they find their way through grief. [Link to purchase here.](#) [You can also watch a video here.](#)

### For Families:

- *"Understanding Death and Loss and What They Teach Us About Life: An Interactive Guide for Individuals with Autism or Asperger's and their Loved Ones,"* by Catherine Faherty. This book offers detailed, concrete explanations of illness, dying, life after death, losing a pet, and numerous other issues. Descriptions are written with caregivers in mind, and provides checklists and discussion tips to address many issues around death and loss. [Link to purchase here.](#)
- *"How People with Autism Grieve and How to Help,"* by Deborah Lipsky. The book is a first-hand account of how people with autism deal with the loss of someone in their life. Through the description of personal experience, and case studies, the book explores how people with autism feel and express the loss of a loved one, how they process and come to terms with their feelings of grief, and offers practical and detailed advice to parents and carers on a range of sensitive issues. [Link to purchase here.](#)
- *"Supporting People with Disabilities Coping with Grief and Loss: An easy-to-read booklet,"* by The Down Syndrome Association. This booklet can be used to explain the grief process to people with disabilities and those who support them. It also provides strategies to help people with disabilities move through grief and loss. [Linked here.](#)
- Grief and Development Disabilities. "Grief Out Loud," Podcast; Episode 20. The Dougy Center. [Linked here.](#)
- Friendship Circel is a resource for people with special needs and their families. The article [linked here](#) is specific to talking about death.

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### **For Families continued:**

- "How to Comfort a Grieving Child with Special Needs," Dallas Magazine. Article with helpful tips and suggestions for families and caregivers. [Linked here.](#)

### **For Professionals:**

- Additudemag. A comprehensive resource for families, professionals, and community members to learn about supporting someone with ADHD. It includes articles on parenting, a place where professionals can find many webinars and presentations, and a virtual version of their bi-monthly magazine. [Linked here.](#)
- National Down Syndrome Society. [Linked here.](#)
- Special Books by Special Kids: A platform for people with disabilities to share their stories and for people of all abilities to learn more about becoming advocates for inclusion and diversity. The website showcases videos to help children and teens with disabilities learn valuable skills in technology and communication. [Linked here.](#)
- Mrs. D's Corner – Books on Disabilities and Differences for Kids: A list of 60 books for children to help them learn about disabilities and inclusion. Each book includes a small excerpt on the website. [Linked here.](#)
- "Autism and Loss," by Rachel Forrester-Jones and Sarah Broadhurst. This book includes practical tools and resources for professionals working with people with autism who are coping with any kind of loss. [Linked here.](#)

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This toolkit was created by members of the NACG to support professionals who are working with children of all abilities who are grieving. The NACG has a range of free resources available on our website to support professionals and caregivers. You can access them at [www.childrengrieve.org/resources](http://www.childrengrieve.org/resources).

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*The workgroup was led by Jennifer Wiles, MA, LMHC, BC-DMT, HEARTplay Program, MA*

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A note on the use of the term "all abilities". We chose to use the term "all abilities" in this toolkit to promote a welcoming and inclusive message to all our participants and their families. This also reflects the current thinking that it is helpful to use person-first language, in other words, that we acknowledge the person first, and not their condition. So, we would say, "a child with a disability" rather than "a disabled child". In using the term "all abilities" we acknowledge our common humanity and that we are all people first! Please see our FAQ section for more information on use of language when working with people of all abilities with grief.