

# Autism & Grief Project

## Fact Sheet



### Disenfranchised Grief

Disenfranchised grief is grief that is not openly acknowledged, socially supported, or publicly mourned. First described by Dr. Kenneth Doka (1989), the term is used to describe a grief experience marginalized by society. When grief is disenfranchised, complications in the grieving process can occur. These complications can be magnified for a person with autism as well as for people with intellectual and developmental disabilities.

Adults with autism are often disenfranchised in their everyday lives. They often are not given social opportunities to engage with others or are otherwise marginalized, particularly if they find it challenging to interact with others in social situations, if they choose not to engage, or if they also have an intellectual disability.

#### **Some examples of losses that are frequently disenfranchised include:**

- the death of a beloved animal companion
- a non-death loss, such as loss of a job, special activity, object, a move, or a divorce
- the loss of a caregiver, both for autistic adults living with family and those living in congregate care settings
- the death of someone important in the griever's life, but the connection to that person was unknown to others (especially true when the individual lives away from family)
- the death of a celebrity or public figure, even when the connection to the person is not understood by others
- a death from advanced age or prolonged illness, because death is expected
- a death that is stigmatized by a culture or situation (for example, death by suicide)

#### **How an Autistic Adult's Grief is Disenfranchised**

There are many ways that family members, friends, and others disenfranchise an autistic adult's grief. Here are some:

- ignoring their emotional needs during a loved one's illness
- stigmatizing manner of death such as suicide or overdose
- keeping them from saying goodbye or visiting at the end of the loved one's life
- attempting to force, guilt, or cajole the individual into participating when the individual does not want to ("you have to be there;" "don't you love the person;" "you'll regret if you don't go see them")
- choosing not to communicate with them about a life-limiting illness or death

- not recognizing a relationship (such as after the death of an LGBTQ spouse or partner)
- expecting that they do not understand what is happening
- excluding them from funeral or memorial services
- assigning “difficult” behaviors to the individual rather than to the individual’s reaction to a loss.
- failure to recognize unexpected reactions, such as laughter, as grief

## **Responding to Disenfranchised Grief**

The ways professionals can enfranchise grief for an autistic adult should be individualized, but may include:

- Helping the individual find expressive language or other forms of communication to share their thoughts or feelings
- Encouraging acceptance of forms of communication an autistic person might use
- Advocating for opportunities for the individual to be included prior to (if known), or during and after the death. This could include:
  - caregiving and/or visiting a person who is sick
  - helping, as able, with the memorial or funeral planning
  - attendance at any ceremonies (or the opportunity to create their own), or private attendance if they are uncomfortable in larger groups
  - finding ways to honor the deceased
  - providing opportunities to share their memories of the person, such as art, writing, or other creative or spiritual activities
- Helping the autistic adult to visit the person’s grave, especially if the formal rituals have already happened, or the person with autism was not included or able to participate
- Advocating for the individual to not be forced to participate
- Validating the person’s experiences of both loss and the situational factors that are disenfranchising by:
  - Providing reassurance that many people will want to provide support, including relatives, friends, and clergy
  - Using the resources available (draw on colleagues, faith leaders, therapists, and other community supports) to acknowledge the grief of the individual with autism and all of their feelings and share what you have learned with other colleagues in your community so they will be better prepared to support and advocate for adults with autism
  - Including the grieving person with autism as much, and as often, as they would like to be in both the planning for and attendance in the events and rituals that may surround the loss or death
  - Being open to ideas that the autistic person may have about ritual, even if they are nontraditional.
  - Not medicalizing or being critical of their expression of grief

## Case Studies - Disenfranchised Grief

Arthur is a 48-year-old man who lives in a group home with two other men with similar needs. Arthur, Noah, and Benjamin have lived together for nearly 15 years. Their friendship has been a constant in their lives, despite staff changes and other life events. Last month, Benjamin was scheduled for routine surgery, but suffered serious complications and died in the hospital. Staff at the apartment notified Arthur and Noah of Benjamin's death, but never told them many details, including where and when the funeral was held. One day the men returned from grocery shopping to see Benjamin's room being cleaned out by a moving company, which greatly upset Arthur. He began shouting at the movers, telling them not to touch Benjamin's things, and then started crying uncontrollably. Arthur retreated to his own bedroom, where he cried himself to sleep.

### *Reflection Questions*

- Was Arthur's grief disenfranchised? Why or why not?
- If you were a staff member at Arthur and Noah's apartment, how might you approach this situation?
- What ritual needs might be helpful here?

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Sarah is 65 years old and lives in a community/ group home with three other women. Her older brother George, whom she used to live with, had dementia and recently died. No one communicated with Sarah about George's illness over fears it would be upsetting and cause her distress. She has since been told about George's death, but staff assumed she would quickly forget her brother and move on. Sarah understands that George is dead and is upset she wasn't able to spend time with him since moving to the home. When staff members of the home take vacation or are off work for extended periods of time, Sarah becomes stressed that they will never return, often losing sleep. Recently, after Sarah shared with her social worker that she is scared everyone will leave her, the social worker asked Sarah if she would like to write a letter to George and visit his grave.

### *Reflection Questions*

- Why was the letter writing exercise a helpful therapeutic step in Sarah's grief journey?
- What made visiting the grave meaningful to her?
- What could staff members do to ease Sarah's fear that they will not return?

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Juan is 45 years old and does not use spoken communication; he uses adaptive communication through an iPad. He has lived with his mother, Roberta, his entire life, and they have a close bond. While Roberta is usually able to identify Juan's wants and

needs, lately Juan has become aggressive and distraught, and Roberta is uncertain as to why. A neighbor told Roberta that their dog, Trixie, recently was euthanized and asked how Juan was doing, since he would often watch and wave at their daily walks past his room. Roberta realized Juan was distraught wondering where Trixie was and why she wasn't going on her usual walks. Roberta and the neighbor told Juan of Trixie's death and allowed him the chance to communicate any questions that he had. Juan asked several questions using his iPad, and Roberta and the neighbor answered what they could to the best of their abilities and gave him links to websites about older animals and euthanasia. After a few weeks, Juan contacted the neighbor and, using his iPad, asked if they could hold a small memorial for Trixie. The neighbor was appreciative of the chance to recognize her own grief over Trixie's death, and they proceeded to hold a small ceremony where Juan was able to place a stone on the spot where she was buried.

#### *Reflection Questions*

- How did Juan's mother and neighbor help Juan with his grief?
- Why are animal deaths disenfranchised?
- What is the significance of ritual in this case?

Reference: Doka, K.J. (1989). *Disenfranchised grief: recognizing hidden sorrow*. 347.