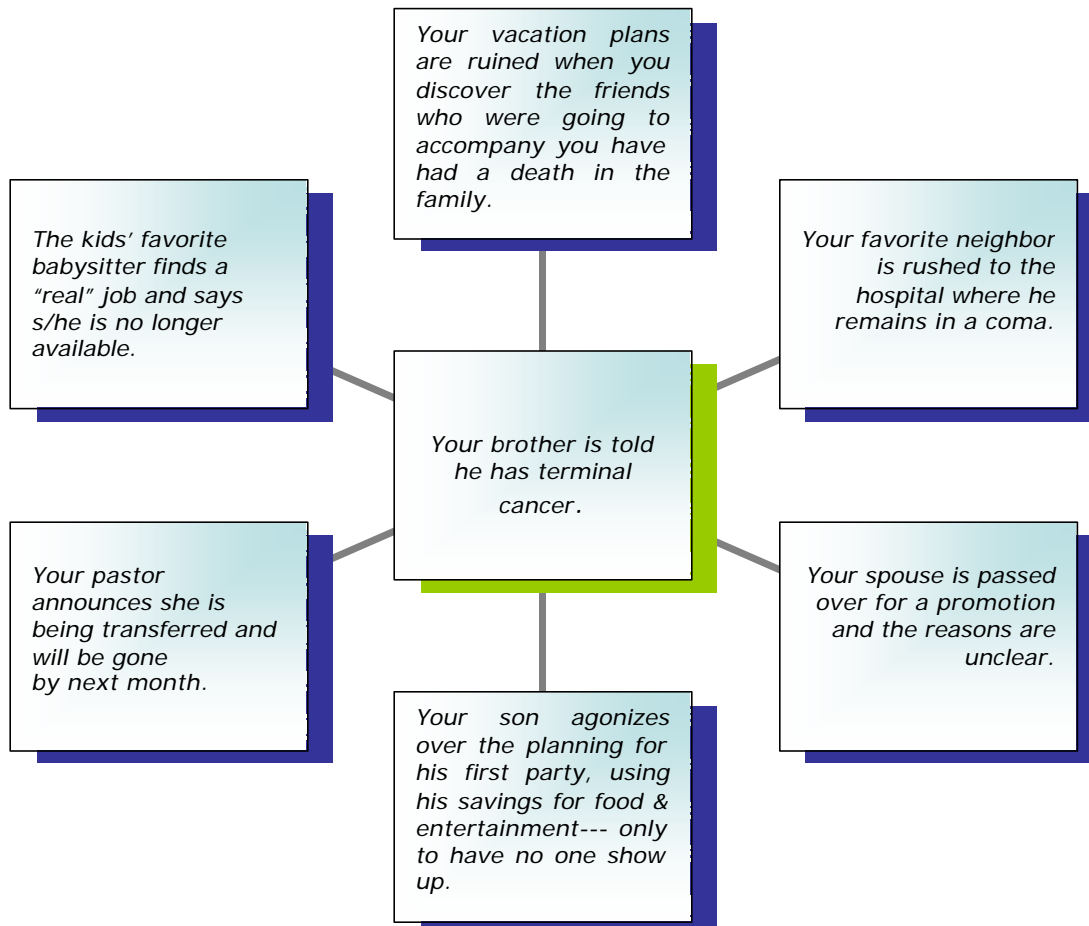


## EXPERIENCING LOSS IN UNEXPECTED PLACES



If we were asked to measure the degree of pain to the people involved in each of the above situations, we may not attribute the greatest severity to ourselves. However, we would undoubtedly be affected, in some cases profoundly, by the impact of these life experiences. When someone we care about is saddened or becomes less present in our lives through death or absence,

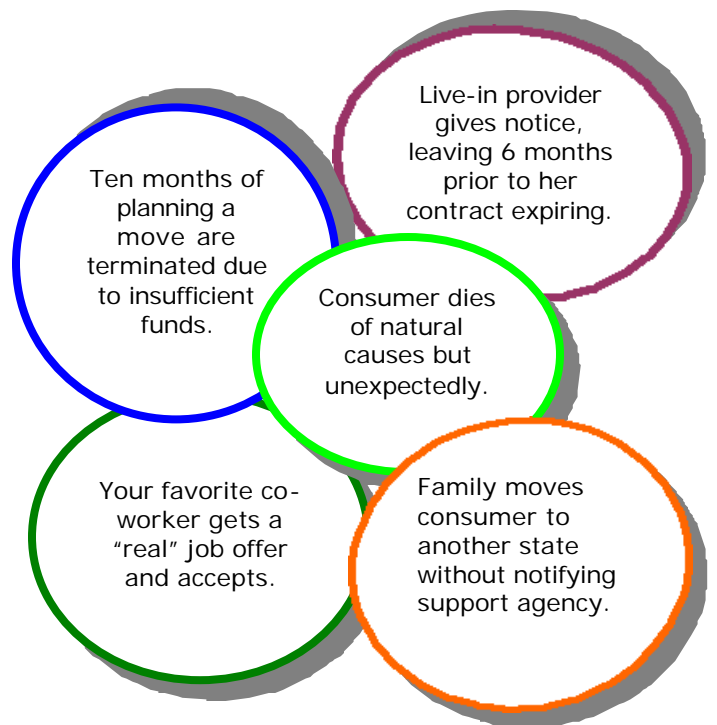
we are affected. How deeply we feel the impact depends both on the level of intimacy in the relationship and on our individual response and capacity to grieve those things that injure us. We know that these experiences have an impact on the people involved. We take it for granted that the people in each scenario have a meaningful relationship to one another.

Those of us in the developmental disabilities network encourage, and try to nurture the formation and duration of strong relationships among direct service workers, the people with whom they work and their family and friends. The critical importance of building relationships to make direct support work more than a series of personal care tasks and business transactions is discussed more fully elsewhere. However, we *assume* that relationships are the foundation on which to build a strong, respectful, and meaningful service delivery system and work environment.

We believe that **relationships are fundamental to delivering assistance that people with disabilities need**. Interestingly, this presents a workplace challenge unique to our service system. **When meaningful relationships are formed, they will also dissolve**, and subsequent feelings of loss and sadness will follow. Grief in the workplace is to be expected in our system whereas elsewhere it is not the norm. If we do not address the very strong impact that loss plays in our daily lives, we will have a difficult

time retaining a workforce that doesn't burn out, give up, feel isolated, or retaliate against an onslaught of unaddressed emotions.

Everyone in the work of supporting people, which includes managers, direct service workers, county administrators, families and consumers themselves have to assume that there is sadness and loss in the work as well as gifts. In the examples below, think about how the outcomes would be different were the people (workers/families) engaged in simple transactions rather than friendship and involvement.



A person's experience of separation, termination, or disappointment is determined by the depth and closeness of the relationship. The more you invest in a relationship, the stronger your feelings and sense of loss when the relationship is severed.

Because staff is paid to support an individual does not in any way diminish the quality of the relationship that may have developed. In some cases staff may only be a supplement to family caregivers but relationships have all sorts of degree of interaction. When families and providers partner, a higher level of safety and quality exist for the person being supported. In those cases, losses may be shared and acknowledged. However if, for instance, family response is different than the worker expects, or the worker's response is different than the family's, tensions can interfere with the grieving process. It is easy to imagine that neither party would be able to validate the feelings or perspective of the other when the other person's reactions are those not liked or understood.

Families, as well as supervisors, agency staff, and colleagues, don't

always recognize the extent to which a worker has attached, and neglect to recognize that when difficult things occur, the worker is grieving and/or hurt as well as the family and/or their member with a disability. Conversely when workers leave a situation where the family has invested heavily in creating a relationship for purposes of quality and continuity, it can be devastating for not just the person being supported but the family members as well.

Because we know that it is easier to experience grief, change, death, and disappointment if people talk about it, it is important to have mechanisms in place so that loss is not overlooked in the interest of getting on with the work or assuming people will recover on their own.

Even an anticipated loss can result in surprise at the range, scope and depth of our feelings about the loss. Sudden or unanticipated changes in relationships can be even more surprising but also perplexing. Upon the death of a man known for a relatively short but intensive amount of time, a worker stated, "I felt gutted!" Upon the departure of a valued live-in provider, the mother of

a vulnerable young woman with disabilities echoed these sentiments by stating, "I felt like my life was no longer going to be my own. I was overwhelmed with feelings of betrayal, anger, loss and fear for my daughter."

Loss can be disturbing in that we all react and respond to it differently. If there is no venue to grieve – such as not being included in plans for a departure, or not being part of the rituals around death – the loss can be that much more difficult to experience as well as from which to recover.

**W**e know quite a bit about loss but not a lot about supporting people that experience loss in the work we share. There are many points at which we feel loss; it affects support workers, people with disabilities, their families and friends. For workers, loss comes with life and relationships-- something we strongly encourage! Accepting and understanding loss will increase the richness of our experiences and allow us to maintain commitments over the long haul.

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**W**hether or not people know to label their feelings as sadness, loss or grief, we need to know they are experiencing it. The experience will be different for every person. We can only look for our own answers, try to support people in their discomfort, losses and struggles, and try to encourage people to find their own answers as well.

*It is important to have conversations about how the workplace can respect differences among people's experiences but also adopt rituals to support people with disabilities, their workers and families. Rituals such as organizing activities to acknowledge the departure of workers, taking the time to attend funerals, holding a special ceremony at the workplace, establishing a memorial, paying tribute, are all ideas to think about. Embracing, acknowledging and understanding through conversation and opportunities will go a long way toward nurturing this aspect of our unique work environment.*

**"EXPERIENCING LOSS," CONCEIVED, WRITTEN AND EDITED BY**

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