Loneliness.

Loss.

Isolation.

These words were written in the December 2011 journal article entitled ‘Unwrapping the Perfect Holidays: Tips for Staff Serving People with Intellectual Disabilities’ (before it was even called a journal) by Dave Hingsburger and Chanelle Salonia, followed by the statement that they are not often associated with the holiday season when we are inundated with images of happy families gathering around the dinner table, people opening gifts, and Hallmark movies where there is always a happy ending. They went on to say that, for many of the people we support, the holidays increase their sense of isolation, rejection, and exclusion due to a loss of close family ties and a lack of friends. Unfortunately, over the past couple of years, the association between these three words and the holiday season has grown not diminished for many with intellectual disabilities due to a world-wide pandemic. Even those who used to have regular visits with their families have had those replaced by phone calls and zoom visits, as they were required to isolate and limit interactions with others for the sake of their own health, others with whom they live, and those at risk of serious illness in the community.

As we are approaching another holiday season with uncertainty about what is safe for those we support, we want to offer a few suggestions of things you may do as a direct support professional (DSP) to make the holidays as enjoyable as possible. These ideas won’t work for everyone to whom you provide support, but our hope is that you will take the time to brainstorm ideas with your team which are individualized to the hopes, wants, and needs of each person you support.

Many of these ideas were in the original article, but we believe they bear repeating, as we have gained many readers since they were originally published:
1. Recognize that this can be a difficult time

It’s so easy to become wrapped up in our own lives and the endless list of things we need to do at this time of year, that we miss what’s happening with the people we’re supporting. They may not have a social calendar filled with family events or parties with friends to which they are looking forward. They may not have the joy and excitement associated with the anticipation of giving and receiving gifts. Watch for signs of sadness, or loneliness, or apathy. Resist the temptation to ‘cheer people up’ or attempts to cajole someone out of their low mood. Previous articles in this journal have discussed the importance of creating space for people to express how they’re feeling. Sometimes, just being there and providing the person with someone who will listen to them when they’re ready to talk is the greatest gift you can give them.

2. Think outside of the box

Many of those with whom you work may not be able to spend time with their family or friends, engaging in long-time traditions due to their own or other’s health-related issues. Perhaps, instead of exchanging gifts around a tree inside the house or lighting the menorah and singing songs, these traditions can be moved outside of the home. Invite family or friends over to decorate a tree in the yard and exchange gifts or set up the menorah on a table outside the home and sing traditional songs. Involve the people you support in holiday preparations, making cards or gifts for their housemates/friends/family members, decorating their home, menu planning, or baking.

3. Make time to review behavioural support plans

For those who have behavioural support plans or programs, this is a really good time to review them. Even if someone has been doing well for the past few months, the stress and heightened expectations which may not be met at this time of year can lead to the resurfacing of previous concerns or new ones. Refamiliarize yourself with the person’s triggers, warning signs, and escalation continuum, as well as the corresponding recommended responses from staff. This will allow you to be prepared and set the person up for success.

4. Avoid unnecessary stressors

By knowing the types of events and circumstances that cause someone to experience stress, we can make plans to avoid them or reduce the likelihood of their occurrence. For example, if someone has difficulty with bright lights, loud noises, and crowds, some stores offer sensory-friendly shopping times to make the experience less busy, less noisy, and less bright by controlling the number of people in the space, having no background music, reducing or eliminating bright or fluorescent lighting, renting or selling noise-cancelling headphones or earmuffs to block out noise, offering fidgets, and creating a sensory friendly map that shows which areas are quiet, calm, and less crowded. It is also possible to develop a Social Story (see volume 11 issue 10 of the journal) about what to expect in the situation. Another option is to go shopping early in the morning on a weekday when it is less likely to be busy. Check with the store prior to going to learn when their less busy times are. Shop online or offer to be their ‘personal shopper’ by taking a picture of the item they want to purchase and return later to buy it on their behalf.
5. Develop traditions

Often, the way in which the holidays are celebrated is dependent upon the traditions of the staff that are working that day. Learn about the traditions that are important to the people you’re supporting by talking to them and their families. Develop a ‘Holiday Traditions’ book where you write these down, so they can be carried out the same way every year for this person. Work with the people that live in the house to develop new traditions specific to the home in which all can participate and let them know they will continue to be carried on annually.

6. Dealing with family visits

When someone is anticipating going to visit their family for the holidays, it is naturally a very exciting time for them, which they will want to talk about with everyone. This can be a very painful experience for the person who is not going anywhere and may not even have a family they could see over the holidays. Speak to the person who is going home for the holidays, validate their excitement, and suggest it is something the two of you can discuss when you have one-to-one time to be sensitive to the feelings of those who do not have plans. Make plans in advance with the person not going home to be out of the house, so they have something to look forward to and don’t have to watch the other person being picked up by their family. Give the person the opportunity to choose something they really enjoy doing during that time to give them something exciting to talk about with the others when they return home. Take pictures of the activity that they can remember it by and share with others, particularly if they communicate through non-traditional means.

7. Be careful about what you communicate

Remember that people can hear you and may also pick up on your body language and mood. If you complain to a co-worker and appear sad or angry when you learn that you are working on a holiday that is special to you, the people you support will notice it and feel badly. Believing that you are personally responsible for ruining your staff’s holidays is a tough thing to deal with for anyone. Having these types of feelings is normal but saying or showing them in front of the people you support is unkind.

8. Choose entertainment/media carefully

Some of the old classic holiday movies that you grew up watching with your family like ‘It’s a Wonderful Life,’ ‘Love Actually,’ or ‘Miracle on 34th Street’ may bring back fond memories for you, but for someone who grew up in an institution or was shuffled from one foster home to another, it may evoke very painful memories of all that they missed in childhood. Let the person you are supporting choose movies and other forms of media that they want to watch. It’s ok if they want to watch the traditional movies but be cognizant of the fact that not everyone in the home may want to watch them. Give them the chance to opt out and engage in another activity they enjoy instead.

9. Take a breather…pace yourself

The holidays can be overwhelming with so much to do in our work and personal lives. Make a plan with other staff a few weeks in advance about everything that has to be done and divide it up between everyone. Make the most of people’s strengths and passions when you’re doing this. If someone really enjoys baking, give them the job of baking cookies with the people in the home. If someone loves to organize, task them with scheduling activities and ensuring there is staff coverage to get everyone to their
preferred events over the holidays. Pace yourself, take breaks, and plan days or shifts where there is downtime, and no one has to go anywhere.

10. Low impact holiday activities

So many holiday activities involve high energy, high volume, and high stimulation. Remember to include some low impact activities as well such as going for a drive to look at lights and decorations. Almost every neighbourhood has a house that’s known for having an incredible lighting display. Play some holiday music everyone enjoys and bring along hot chocolate to make it feel like an event. Allow it to be quiet, and low key but still quality time. There are many holiday events that are calmer and more intimate than malls and parties such as carol sings and candlelight services.

11. Self-care

The holidays can be a stressful time for everyone. We put so much pressure on ourselves to make everything perfect – the perfect gifts, the perfect decorations, and perfect food. If you’re responsible for providing this both at work and in your own home, it can feel overwhelming! Make time for yourself to do things you enjoy, even if it’s only a few minutes of quiet time to soak in a bathtub, or read a book, or meditate and feel the true spirit of the season. As Dave said, remind yourself of how fortunate you are to be able to make a ‘home’ twice over.

We’re hoping this article will give you some ideas or get you thinking about some possible ways to replace a tradition of ‘loneliness, loss, and isolation’ with a new tradition of ‘happiness’ for the people you support. It’s a big goal but even the smallest change in that direction is a start that you can continue building on year after year. Wishing you all a wonderful holiday season!

About the authors

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