

**Service, Support and Success:
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**Food For Thought:
What Food May Mean To People With Disabilities**

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Do you remember going to the grocery store with your parents and being told if you were good they would buy a chocolate bar? Or do you remember being old enough to go to the kitchen pantry to get your own cookies before going to bed? You were so proud that you were allowed to do it on your own, you might try a sneak a couple more, sometimes you got away with it and sometimes you didn't and you would be asked to put the extras back. Those are good memories, and when you remember them they bring a smile to your face. Food, for most of us was about fun and about family and the complex feelings that come out of those experiences.

For people with disabilities who lived in institutions, food came in delivery trucks, not from trips to the grocery store. Food arrived in huge heated carts, little was ever stored in a pantry, and what was available was kept under lock and key. Instead of at family tables, most ate in a large dining hall. Food was eaten fast all the while prepared to protect your food because you were afraid someone was going to steal your plate or have it taken away because meal time was finished? Instead of finishing, when all was done, eating was a race started by a bell and ended by a bell. It is terrible to think about, yet for many of the people we support this was a great part of their life. Even for those who may have grown up in community services, in many settings the food was monitored by staff, kept under lock and key and parceled out at the whim of the staff on duty.

Food for many of the people we serve came to be about survival. Gulping down great amounts of food was a functional behaviour in a dysfunctional environment. Adding to that dysfunction was the fact that food took on a much deeper meaning. It became 'paired with' being good, being acceptable, being liked. The dark side of using food as a reinforcer means that the denial of food means failure, means defeat, means that you just weren't good enough. For example; if your bed was made 3 days in a row out of 5 you got an extra cookie at snack time. However, if you messed your bed up a bit on day three, you were told, coldly, that there would be no cookies at snack time, you would have to work harder to meet an acceptable standard. Food given = I'm good. Food denied = I'm bad. This connection was made throughout services. Be it institution, be it group home, be it parental home – under the advice of others.

When the 'reinforcer was delivered' or, in plain language, 'the cookies were passed over'. You don't take your snack, sit and savor it, you are not going to chew it slowly and reap the reward of your hard work. No, you are going to take all those cookies and put all in mouth at the same time because you are

afraid that your room mate sitting beside you is going to try and steal them, or the bell will ring before you had a chance to finish and that extra cookie you work so hard for will be taken away because snack time is over.

We have all been taught to eat slowly, not to shove everything into your mouth, to sit at the table properly and maybe have a conversation about your day or what's ahead for the week. Unfortunately these rules did not apply to those we support. Having proper manners or proper etiquette, in an institution, is vastly different from what is considered acceptable in the community. Eating fast and furious meant you ate everything on your tray successfully, no one was able to steal anything from your tray or you finished before the bell rang; this was a successful meal time and you left happy.

Here is the challenge for those of us concerned about nutrition and diet for people with disabilities in community settings. We want to begin with diets and discussions about carbs and exercise. Sometimes we get blank looks because this is all so foreign to the people in our care. There are some basic things that need to be dealt with before we can even consider promoting good healthy lifestyles for people with disabilities. We must always remember to start at the beginning. We need to understand that people with disabilities have a different history and with that history come experiences, comes learning, comes ... baggage. So we've got some ideas for how you might want to slow down, think about food and what it means and what it doesn't mean to people with disabilities. Here are five things that should provide you with some food for thought:

- 1) **Safety:** People with disabilities need to learn that they are safe in their new environment. This means that they don't have to shovel food, because their food won't be grabbed away from them. This means that they need to come to see dinner time as a relaxing time of sharing and of conversation and even of laughter. Staff need to intentionally work to make dinner time a ritual wherein people can learn to slow down and enjoy their food. Harsh instruction will just alarm people – the automatic thought will be 'they are going to take my food away' and this will be counterproductive. So gentle reminders and conversational distractors can help bring a person to a realization that their meal is their meal and they can take time with it.
- 2) **Pairing Praise with Praise and Food with Nourishment:** The use of food as a reinforce is a powerful thing. However it was used in such a widespread manner. We may still need to use food as a reinforce but that should never be done without being in a formal behavioural programme. It should never be done in an ad hoc manner by staff. 'You won't get your dessert if you don't ...' are words that should never be said by a staff. The denial of food based on behaviour is a clinical issue and, therefore, a rights issue. We need to begin to separate food from the message 'I am good' and begin to teach people to recognize more social messages about performance and affection and worthiness. We've made a huge mistake, we need to undo damage. We all know how the same thing was done with cigarettes, we've stopped that now, but we've yet to realize that some food can be just as dangerous as ciggies.
- 3) **Develop New Routines:** Even with what was raised in the point above, we'd bet that there are people who will read this, nod their head in understanding and then say to someone an hour

later, 'I know, let's stop at Timmy's for a coffee on the way home, we both deserve a treat.' It wasn't just people with disabilities that had 'food' and 'treat' paired. Our habits become their habits. The whole point of stopping is to share time together. How about, 'Let's stop at the mall and do some window shopping.' Or "How about we take a walk around the park for a chat." Or, "How about we drive the long way home and see how far along they are on the new house they are building over there." Time together doesn't have to be coffee and donuts.

- 4) Community Living is a skill: When the institutions closed we welcomed people to their new homes. In those homes they had access to things that they never had before. The most interesting place? Kitchens full of unlocked food. Many dove at those kitchen cupboards with enthusiasm and desperation. Their life history told them that if they don't get it now, they never will get it at all. Often staff saw this behavior as a negative behaviour to be programmed and punished rather than a learned behaviour that was about survival. Often then, people were back into the 'reward' and 'punishment' aspect about food. Little teaching was done about 'how to live in a house with a kitchen.' And believe you me, we were all taught that as children. Probably everyone reading this had a mother or father who expressed, in no uncertain terms, their upset with you breaking rules in the kitchen. Not sharing. Eating someone else's saved piece of cake. Taking more than a fair share of the left overs. All small crimes that often met with huge parental reaction. We LEARNED how to be with food. We LEARNED how want something but not have it out of respect for another. We LEARNED these things. Yet we expect people with disabilities to just KNOW them. Community living is a skill ... where there is no skill, there will be behavioural difficulties. Maybe teach first!

and

- 5) Patience and Understanding: None of us will ever know the experience of living in a place where food means what food means in an institution. None of us will ever know what it is to see a chocolate chip cookie as a measure of our worth. None of us. We need to be cautious that in our zeal to help we forget that the journey that someone in our care is on, has taken them through some harsh times and some dark places. So, we need to approach all this with caution. What may be a simple 'diet' to you may represent a complete attack on self-hood and self-esteem. What may seem like simple information to you may seem like frightening information. We need, every day, to be aware of the fact that the people we serve need us to 'get' that their history matters, and that what they want from us, is to help them build new histories in which freedom is learned and experienced and treasured. This, takes, time.

As part of Vita's Clinical Team, the Nutritionist has to be very aware of the health needs of our members. However, that does not mean that the work cannot be done with sensitivity and understanding. More than just putting together a Menu, nutritionists need to make sure that the individual is considered, involved and cared for throughout the process. A nutritionist can help build a new history and create new memories upon which a new lifestyle can be created.