



Food for Thought: Persons with Disabilities and Healthy Eating

By: Jihan Abbas

Summary of Research Results

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Introduction

The following report outlines the results of research conducted with persons with disabilities on the issue of healthy eating. Both the research process itself (Participatory Action Research or PAR) and the results generated, shed light on this issue as well as the ways in which we can collectively come together to design and deliver community-based responses to this important and timely issue.

Project Overview

With funding provided by the Physical Activity and Healthy Eating Contribution Program – Centre for Health Promotion, Public Health Agency of Canada - Independent Living Canada, through the *Food for Thought* project is creating accessible tools on healthy eating. These tools include: program models exploring how food can also be used a vehicle to connect people and resources on physical activity and strategies to reduce social isolation and barriers to healthy eating.

Research is an important part of this initiative as it grounds our understanding of issues related to persons with disabilities and food, and allows us to connect with the community through PAR to identify barriers and solutions related to healthy eating and persons with disabilities. By tracking a select group of individuals with disabilities over the course of the initiative we will be able to gather their feedback on the issue and design supports based on their needs. Participants (referred to as ‘consumers’ within the IL network) are working with their local Independent Living Centres to test out various program models.

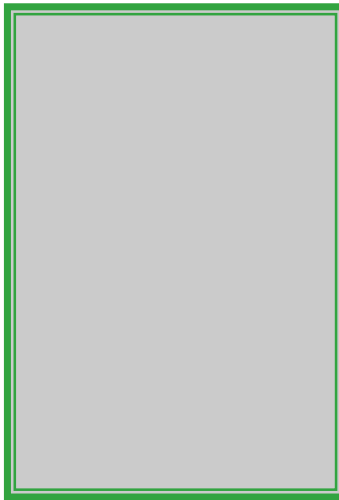
This research report reflects research conducted in the first phase of the project.

Research Methodology

Participatory Action Research (PAR) is a process which strives to ground itself in the lived experience of individuals and create positive social change based on research findings. PAR is unique as it

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includes persons with disabilities in the research process in ways and builds avenues to actively engage the community.



Within Independent Living Canada, PAR ensures:

- People with disabilities play an active role in the research process;
- Research reflects an accurate analysis of the social realities for persons with disabilities;
- Research findings shed light on the strengths, resources, and knowledge within the disability community;
- Research attempts to improve the quality of life for persons with disabilities and

promote the full inclusion of persons with disabilities.

In order to ensure research conducted for Food for Thought remained grounded in the principles of PAR, the following key commitments were made to participating individuals (administered through IL Canada and participating Independent Living Centres):

- Participants receive an honorarium for their participation in focus groups;
- Independent Living Canada provides regular updates on the project to participants (i.e., newsletter or poster updates);
- To thank participants for their ongoing engagement throughout the research process quarterly incentives are provided (for example pre-paid grocery cards, etc.);
- All participants are provided with the contact information to voice advice, concerns and/or feedback;
- A closing focus group will be held at each pilot site to gather feedback from individuals on the initiative (an honorarium will be provided).

In addition to these key commitments to individual consumers the following strategies were also used to ground the research process in PAR:

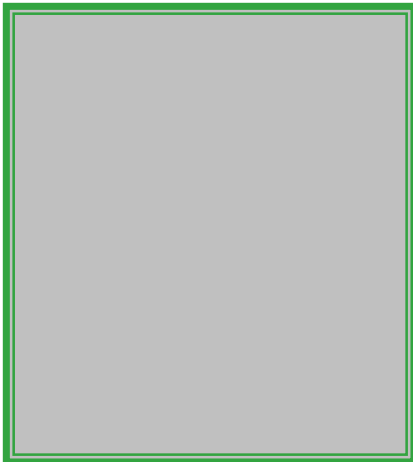
- Engage pilot Centres and local consumers through focus groups and individual surveys;
- Give consumers the opportunity to share their insights on the topic as well as give feedback on existing research;
- Provide consumers with the opportunity to discuss possible solutions linked to community expertise;
- Provided consumers with the opportunity to identify individual and collective strategies for change grounded in the every day lived experience of disability.

These spaces not only provide the opportunity for consumers to identify barriers but also to work together to design solutions, share information, and support each other through a peer support model.

Results

General Results

10 sites across Canada carried out focus groups and individual interviews with consumers. These sites include: Halifax NS, Shippagan NB, Montreal QC, Alfred ON, Kingston ON, Niagara ON, Calgary AB, Nanaimo BC, and Duncan BC.



These sites, because of their geographic (urban and rural) and linguistic (Anglophone and Francophone) diversity provided feedback which reflected realities in different communities with different kinds of supports. In total, 82 consumers provided feedback and represented a diverse cross section in terms of disability (i.e., sensory, mobility, learning and intellectual, etc.), age, living situation, and interest in and knowledge about healthy eating.

In general, feedback indicated that:

- ✓ Participants are very interested in the topic and enthusiastic about learning more about healthy eating;
- ✓ Participants were engaged in the research process;
- ✓ The focus groups provided opportunities for information sharing in a comfortable and supportive environment;
- ✓ The focus groups were empowering experiences for many, and provided peer support opportunities with respect to making changes.

It is important to note the impact of these social gatherings on the research process, as feedback overwhelmingly illustrates the importance of bringing people together to collectively address issues. These spaces not only provide the opportunity for consumers to identify barriers but also to work together to design solutions, share information, and support each other through a peer support model.

2. Choice-making

Choice-making with respect to persons with disabilities and healthy eating is important, as we recognize that, historically, persons with disabilities have not had access to the same levels of choice and control as many of their non-disabled peers. Our focus groups and individual questionnaires explored how consumers make their food choices.

The majority of consumers (a little over half) reported they do not receive assistance in making healthy eating choices. It is important to note that, with respect to choice, one's living situation is an important factor to take into consideration. Indeed, a majority of participants lived alone or with family members (parents, spouses, children, etc.), and this likely contributed to independence in choice-making. For those who live in a group home and/or a long term care facility (a minority of respondents), greater levels of assistance in choice-making were reported. For those who did report they received assistance, shopping for groceries and making healthy choices were the most frequently cited areas of assistance.

With respect to what informs individual choices about food, consumers noted advice from professionals, information on food labels, the cost of food, and information in magazines and commercials as informing their choices.

3. Consumers' Thoughts on "Healthy Eating"

We asked consumers about healthy eating and related concepts, and what these concepts meant to them. By doing this, we hoped to identify what these terms mean to the community itself and incorporate this insight into project activities. As well, communicating in plain and clear language is important within the Independent Living movement, and this exercise allowed us to gather terminology that is identifiable to the community.

Healthy Eating means the following to consumers:

- ✓ Eating foods from the four food groups in the Canada Food Guide and foods high in protein and low in cholesterol.
- ✓ "Eating things with all the vitamins and nutrition I need."
- ✓ A variety of foods including fruits and vegetables.
- ✓ Fresh and locally produced foods.
- ✓ Food that provides energy so the body can function.
- ✓ For some, "healthy eating" means "plain" or "bland" foods.

In general, consumers reported that healthy eating was about eating balanced meals, eating from all food groups, and avoiding foods that are generally thought of as unhealthy (fattening, salty, processed etc.).

Nutritious food means the following to consumers:

- ✓ Foods that are low in fat, sugar and salt;
- ✓ Foods that are good for your health and contain all the nutrients you need;
- ✓ Foods that are fresh rather than processed;
- ✓ "Foods that don't make you feel gross after you eat them."

A Balanced Diet means the following to consumers:

- ✓ More than one person noted that ‘balanced’ must be individualized, and what is balanced for some may not be balanced for others;
- ✓ Eating regular meals and foods from all food groups;
- ✓ Eating proper portion sizes;
- ✓ Including physical activity as a part of your routine.

Convenience food means the following to consumers:

- ✓ Foods that are more expensive;
- ✓ Food that are full of ingredients you can’t pronounce;
- ✓ Food from restaurants and fast food places;
- ✓ Pre-cooked or ready-made meals;
- ✓ Food that is fast, tastes good, and is easy to make.

In general, participants had a lot of feedback around convenience foods and mentioned these foods were often their choice because they did not have the time or energy to prepare other options.

As well, some participants noted that convenience foods gave them independence, as they were options that enabled choice and control. One participant noted that “no one can tell them not to” with respect to eating convenience foods. This point reminds us that we must remain aware of the lack of choice and control experienced by many persons with disabilities and thus ensure the supports and services we design and offer respect individual autonomy.

Unhealthy Food means the following to consumers:

- ✓ Foods that are high in cholesterol;
- ✓ Food with lots of salts, sugars and fats;
- ✓ Foods that are fried and processed;
- ✓ Foods with ingredients that are hard to pronounce.

With respect to unhealthy foods, many consumers noted frustration with respect to reading labels, as labels are often too small and difficult to understand. Consumers felt this made it more difficult to identify foods that may be unhealthy.

Other concepts consumers through were important with respect to healthy eating:

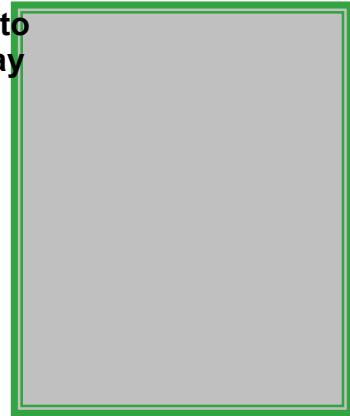
- ✓ Consumers felt the differences between 'good' fats and 'bad' fats was important to know;
- ✓ Consumers also felt it was important to understand the link between the foods you eat and the energy you get from these foods;
- ✓ Many consumers felt there were benefits to eating locally sourced foods (i.e., the 100 mile diet);
- ✓ Consumers felt food co-ops, community kitchens, and community gardens were all important concepts with respect to healthy eating.

In general, consumers were familiar with a number of different concepts and trends related to healthy eating, and were eager to discuss and share these ideas.

4. The Role of Canada's Food Guide

The research indicates that Canada's Food Guide was a resource many consumers know of, with just over 80% of consumers reporting they were familiar with the Food Guide. However, although many consumers noted they were familiar with the guide, within the focus groups several issues were noted that indicate consumers have concerns with the guide.

There is an important role for communities to play in helping individuals successfully incorporate the food guide into their every day routine.



The following barriers to using the Food Guide were all noted:

- ✓ Several consumers noted they did not know how to use the guide;
- ✓ Several other consumers noted they chose not to use the guide, citing concerns that it would be too costly or too difficult to meet the recommended daily servings from each of the food groups;
- ✓ Some consumers felt the guide did not reflect the kinds of foods they eat. Some participants felt dietary (i.e., vegetarians) and cultural needs were not reflected in the guide.

In general, it seemed that although many were familiar with the guide, there is a need for greater education and training on how to use the guide, and a need to present the guide as a more practical tool which can be adapted to individual circumstances.

Many participants noted that they had learned of the guide through health care professionals (doctors, dietitians, public health nurses and community health units). As such, it seems for many the Food Guide was presented as an isolated information source. With this in mind, it is clear there is an important role for communities to play in helping individuals successfully incorporate the food guide into their every day routine.

Cost is the most frequently cited barrier with respect to persons with disabilities and healthy eating.

5. Existing Barriers to Healthy Eating

The following identify the key barriers to healthy eating for persons with disabilities as noted by consumers through the focus groups and questionnaires.

Cost



Cost was the most frequently cited barrier with respect to persons with disabilities and healthy eating. Although this is not surprising given the higher levels of poverty within the disability community, it is certainly a significant barrier to keep in mind as it affects several aspects related to healthy eating.

For example, consumers noted cost acts as a barrier in all the following ways:

- The added cost of buying foods that are not in season, specifically fruits and vegetables;
- The cost of kitchen appliances that can make food preparation easier (i.e., steamers, slow cookers, etc.);
- The added cost of transportation that must be factored into the purchase of foods;
- General frustration among consumers that “bad” foods (i.e., overly processed, fast food etc.) cost less than “good” foods (i.e., organic etc.);
- Existing financial support for persons with disabilities fail to take into consideration the added costs associated with eating healthy.

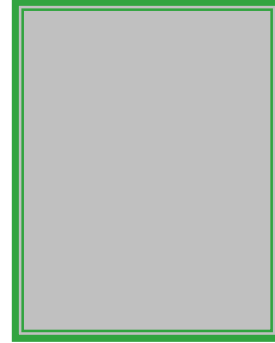
Choice & Independence

Reduced choice and independence among many within the disability community can act as a barrier to healthy eating.

Consumers note the following factors acting as barriers to their choice and independence in the process:

**Shopping,
preparing and
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alone.**

- Inaccessible transportation continues to prevent consumers from accessing tools and resources needed for healthy eating;
- Inaccessible food information on labels;
- Having to rely on others (who often lack training in healthy eating) to buy and prepare food;
- A lack of support within grocery stores to assist individuals in choice making;
- Health care professionals not taking the time to ensure consumers understand how they can eat healthier.



Disability Related

Participants noted that disability-related issues can make healthy eating more difficult in the following ways:

- Fatigue and/or chronic pain can make preparing meals from scratch more difficult;
- Additional food restrictions because of disability-related issues (i.e., dental conditions, different caloric needs, diabetes, etc.) can make healthy eating more complicated;
- Isolation because of bad weather and/or inaccessible transportation can make outings to get food and connect with others more difficult.

Social Isolation

Social isolation remains an unfortunate reality for many within the disability community. Participants confirmed this isolation also acts as a barrier to healthy eating as:

- You are more likely to make unhealthy choices and/or not eat regular meals when you are alone;
- Shopping, preparing and eating meals can be more difficult when you are alone.

Many participants noted that, although they feel alone, it is difficult to get out and connect and eat with others because of financial and transportation barriers.

In addition to the key barriers listed above, the following barriers were all identified by consumers and important to keep in mind.

Other Barriers:

- Not knowing about local resources that may be available to help;
- Not knowing individual rights (i.e., what support individuals are entitled to when they have special diets);
- Lack of choice in foods because of geographic location – in some areas of the country some foods are harder to access and more expensive;
- Lack of access to professionals and their resources;
- Complex needs due to other health conditions (i.e., diabetes, problems chewing, etc.);
- Transportation was noted throughout as a significant barrier in all aspects of healthy eating;
- Food is something all people have in common and we receive information from various sources – it is difficult to know what advice to follow;
- In addition to the choices we make about our meals, there is more and more information available about the ways in which foods are produced (i.e., genetically modified) and stored (i.e., toxic chemicals in plastic food containers) and how these things can affect our health. This is something all food consumers need more information and support with as well.

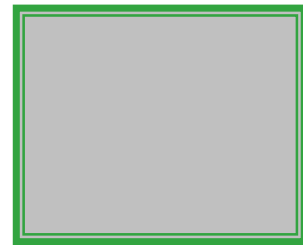
Find a shopping buddy and help support each other.

6. Community-based Solutions for Change

What emerges from the barriers listed above is the knowledge that the disability community needs a holistic approach to overcoming these barriers grounded within the community. The community-based solutions below, identified by consumers, illustrate some steps that can be taken individually and collectively to overcome these barriers. The following strategies for individuals, Independent Living Centres (ILCs), and communities illustrate the roles we all have to play with respect to healthy eating and persons with disabilities.

Individuals can do the following to work towards healthier eating:

- ✓ Plan menus in advance as this can help ensure healthier choices;
- ✓ Attend cooking classes and collect recipes and new ideas;
- ✓ Use flyers to find sale items and buy food staples when they are on sale;
- ✓ Find someone who can support you reading labels;
- ✓ When in doubt – ask your doctor for advice;
- ✓ Have others help review your shopping list for suggestions;
- ✓ Make sure you are accessing all the financial support you are entitled to;
- ✓ Volunteer at a food bank to learn more about what supports they can provide;
- ✓ Join a community garden or food club to have access to healthier foods;
- ✓ Find a shopping buddy and help support each other.



Independent Living Centres can provide the following supports:

- ✓ Continued community education and outreach to ensure all community members are aware of disability-related issues and their role in supporting the community;

Community education and outreach to ensure all community members are aware of disability-related issues and their role in supporting the community.

- ✓ Offer 'shopping programs' in local grocery stores – the programs can provide information and guidance specific to consumer needs;
- ✓ Partner with grocery stores to offer a 'shopping package' to get best prices for consumers with a disability – this can even be done in conjunction with extension agents and ILCs and other partners can work together to ensure shopping packages include foods from all food groups.
- ✓ Help identify and facilitate possible matches for those who want a shopping buddy;
- ✓ Using food outings to increase cultural understandings and provide social opportunities for consumers;
- ✓ Hold workshops for consumers on related issues (cooking, the food guide, how to shop on a budget, reading labels, etc.);
- ✓ Provide opportunities for consumers to access health care professionals who can speak directly to their individual dietary needs;
- ✓ Share project-related resources with the broader community (web sites, recipes, etc.);
- ✓ Provide meeting space for food clubs within ILCs and help facilitate peer support groups on the issue;
- ✓ Hold potlucks for consumers to try new foods, socialize, and learn about new meal options.

Communities can engage through the following activities:

- ✓ More education and training for those supporting people with disabilities so they can support healthy eating goals;
- ✓ More opportunities for workshops that persons with disabilities can access – being engaged makes people feel better about themselves;
- ✓ More opportunities to access dietitians and related resources;
- ✓ Suggestions from food banks on how to use/prepare the foods provided through food banks;

**More disability-friendly spaces
consumers' groups (i.e., community
gardens and food clubs.**

- s', it is important they share information about their needs (how foods are prepared, what is in them, and information on calories);
- ✓ Communities should provide a directory or clearing house on community resources related to healthy eating and active living;
 - ✓ More disability-friendly spaces for consumers' groups (i.e. community gardens and food clubs);
 - ✓ More accessible transportation and specific support in shopping (in some communities it was noted there are limits and restrictions with respect to packages that make shopping and using accessible transportation more difficult);
 - ✓ Food co-ops that will deliver to the home.



Conclusion

The barriers and solutions noted above illustrate that any approach to healthy eating for persons with disabilities must be a holistic one to engage all stakeholders (individuals, disability organizations, and communities). As well, we must work to facilitate opportunities to build partnerships and networks to enable a collective, community-based response to the healthy eating needs of persons with disabilities.

As there was overwhelming interest among those participating to access more information and opportunities on healthy eating and persons with disabilities, and participants were eager to learn more, now is the perfect time to move forward with these initiatives.

