Nutrition and Food Skills Education
For Adults with Developmental Disabilities

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ABSTRACT

Purpose: Individuals with developmental disabilities have poor eating habits and are at increased risk for cardiovascular disease, obesity, and osteoporosis. Needs and preferences for a nutrition education and foods skills program were explored in adults with developmental disabilities, agency managers, and support workers.

Methods: Twenty-eight adults with mild to moderate developmental disabilities participated in individual interviews; seven managers and 21 support workers took part in three focus group discussions. Concurrent data collection and analysis, data saturation, and a constant comparative method guided the research.

Results: All participants indicated a need for nutrition education and cooking programs for this population. Seven major themes emerged: poor eating habits, safety concerns, low transferable skills, social relationships, staff training needs, resource needs, and limited funding. Individuals with developmental disabilities also expressed feelings of self-efficacy in learning to cook healthy food.

Conclusions: There is a strong interest in and need for nutrition education and food skills programs for adults with developmental disabilities. The collaboration of multiple community partners in program implementation and delivery is essential. At the policy level, the needs of individuals with aging caregivers must be addressed and access to registered dietitians must be improved for this population.

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RÉSUMÉ

Objectif. Les personnes aux prises avec une déficience développementale ont de mauvaises habitudes alimentaires et présentent un risque accru de maladies cardiovasculaires, d’obésité et d’ostéoporose. Cette étude explore les besoins et préférences des adultes présentant une déficience développementale, des directeurs d’agences et des travailleurs de soutien en matière de programme d’éducation à la nutrition et de compétences alimentaires.

Méthodes. Vingt-huit adultes aux prises avec une déficience développementale légère à modérée ont participé à des entrevues individuelles; et sept directeurs et 21 travailleurs de soutien ont pris part à trois séances auprès de groupes de discussion. La recherche était guidée par une collecte de données et une analyse, effectuées en simultanée, par une saturation des données et par l’application en continu d’une méthode comparative.

Résultats. Tous les participants ont mentionné la nécessité de l’éducation à la nutrition et de programmes de cuisine pour cette population. Sept thèmes majeurs ont fait surface : les mauvaises habitudes alimentaires, les inquiétudes sur le plan de la sécurité, les faibles compétences transférables, les relations sociales, les besoins de formation du personnel, la nécessité de disposer de ressources et le financement limité. Les gens souffrant d’une déficience développementale ont également exprimé un sentiment d’autoefficacité lorsqu’il était question d’apprendre à cuisiner des aliments santé.

Conclusions. Il existe un fort intérêt de même que des besoins pour des programmes d’éducation à la nutrition et de compétences alimentaires chez les adultes aux prises avec une déficience développementale. La collaboration de multiples partenaires communautaires est essentielle en ce qui concerne la mise en place et la réalisation des programmes. Sur le plan des politiques, il est nécessaire de répondre aux besoins des gens pris en charge par des aidants naturels vieillissants et d’améliorer l’accès aux diététistes pour cette population.

(Rev can prat rech diétét. 2011;72:7-13)
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INTRODUCTION
Adults with developmental disabilities experience increased risk for cardiovascular disease (CVD), obesity, and osteoporosis (1,2). They eat poorly, have limited food preparation skills, lack nutrition knowledge (3), and have low levels of physical activity (4). They have limited opportunities to learn about healthy eating and food skills. Because increasing numbers of people with developmental disabilities are being transitioned from institutions to community-based living, food skills programs must be developed and implemented for this population.

Teaching nutrition and food skills to adults with developmental disabilities will foster independence and provide them with the knowledge, skills, and self-confidence to make healthy meals. Current literature indicates that by using different strategies, adults with developmental disabilities can acquire basic nutrition information (5,6), learn to shop for groceries (7,8), plan menus (9,10), and prepare food independently (11,12).

PURPOSE
Needs and preferences for a nutrition education and food skills program were explored in adults with mild to moderate developmental disabilities (“adult participants”), agency managers, and support workers. Study results may be used to inform the development of nutrition services to meet identified needs of people with developmental disabilities.

METHODS
Participants
Twenty-eight adults with mild to moderate developmental disabilities participated in individual interviews; seven managers and 21 support workers from five developmental services agencies in a southwestern Ontario city took part in three focus group discussions. The support workers consisted of full-time, part-time, and casual staff, as well as case workers, a residential counsellor, a program coordinator, and a case manager at the study sites. These people provide assistance with daily living skills and/or support the planning, delivery, and development of group-based activities.

Qualitative researchers deliberately seek out “participants or sites (or documents or visual material) that will best help the researcher understand the research question” (13, p. 185). For this reason, and because of this population’s characteristics, agency contacts with first-hand knowledge of their clients acted as gatekeepers and helped the researcher recruit individuals who they felt were able to provide informed consent and participate in the interview process. Purposive sampling captured substantial variability in participants’ demographic characteristics (Tables 1 and 2). Their ages led us to infer that a number of adult participants had older family caregivers.

Informed consent
Diligence was exercised to ensure that the adult participants understood and freely gave informed consent. A simplified consent form with pictorial representations of the questions was

Table 1
Demographic characteristics of participants with developmental disabilities (n=28)

<table>
<thead>
<tr>
<th>Variables</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>12</td>
</tr>
<tr>
<td>Male</td>
<td>16</td>
</tr>
<tr>
<td>Age (years)</td>
<td></td>
</tr>
<tr>
<td>20-24</td>
<td>4</td>
</tr>
<tr>
<td>25-34</td>
<td>9</td>
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<tr>
<td>35-44</td>
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<td>45-54</td>
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</tr>
<tr>
<td>55-64</td>
<td>4</td>
</tr>
<tr>
<td>Education level</td>
<td></td>
</tr>
<tr>
<td>Elementary</td>
<td>4</td>
</tr>
<tr>
<td>Basic adult education</td>
<td>8</td>
</tr>
<tr>
<td>Grade 12</td>
<td>9</td>
</tr>
<tr>
<td>High school</td>
<td>7</td>
</tr>
<tr>
<td>Living situation</td>
<td></td>
</tr>
<tr>
<td>Living at home</td>
<td>13</td>
</tr>
<tr>
<td>Living at lodge</td>
<td>15</td>
</tr>
<tr>
<td>Type of disability</td>
<td></td>
</tr>
<tr>
<td>Global developmental disabilities</td>
<td>21</td>
</tr>
<tr>
<td>Learning disabilities</td>
<td>2</td>
</tr>
<tr>
<td>Autism</td>
<td>2</td>
</tr>
<tr>
<td>Down syndrome</td>
<td>2</td>
</tr>
<tr>
<td>Fetal alcohol spectrum disorder</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 2
Demographic characteristics of managers and support workers

<table>
<thead>
<tr>
<th>Variables</th>
<th>Managers (n=7)</th>
<th>Support workers (n=21)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Education level</td>
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<td></td>
</tr>
<tr>
<td>College</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>University</td>
<td>2</td>
<td>9</td>
</tr>
<tr>
<td>Undergraduate</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Master’s degree</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not reported</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Length of employment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt;20 years</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>&gt;10 years</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>3-9 years</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>6 months-2 years</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>Not reported</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Demographic data were missing for five support workers.
used. Accommodation was also made for legal representatives to assist with this process; however, the participants were able to provide informed consent. The Brescia University College Research Ethics Board approved the study.

Data collection
Qualitative methods, specifically individual interviews and focus groups, were used. The strategy of inquiry involved a pragmatic approach for a real-world practice orientation (14). Interviewing adult participants allowed their voices to be heard in the process of planning programs (15).

Table 3
Sample questions in the interview guides*

<table>
<thead>
<tr>
<th>Sample focus group questions for managers and support workers</th>
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<tbody>
<tr>
<td>• What are your views about running a nutrition education and cooking program for this population?</td>
</tr>
<tr>
<td>• What kind of resources do you currently have to run such a program? What would you need?</td>
</tr>
<tr>
<td>• What kind of training do you need to help your clients learn to cook and eat healthily?</td>
</tr>
<tr>
<td>• What is the best way to teach your clients to perform a task?</td>
</tr>
<tr>
<td>• What kind of activities do you think they will enjoy doing besides cooking?</td>
</tr>
<tr>
<td>• What suggestions do you have for running such a program?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sample interview guide for individual participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>• What do you think of the idea of a healthy eating and cooking program here?</td>
</tr>
<tr>
<td>• Tell me about any experience you have had with a cooking program.</td>
</tr>
<tr>
<td>• Please tell me about cooking tasks that are easy/difficult for you to do?</td>
</tr>
<tr>
<td>• What kinds of foods do you eat regularly/are cooked at home?</td>
</tr>
<tr>
<td>• Do you wash your hands before you eat? What will happen if you don’t?</td>
</tr>
<tr>
<td>• How do you take a hot item out of an oven?</td>
</tr>
<tr>
<td>• Where should milk or chicken be kept?</td>
</tr>
</tbody>
</table>

Self-efficacy

If someone teaches you, do you think you could cook? Choose healthy food? Use kitchen appliances? Shop for healthy foods? Keep food clean and safe? Handle kitchen tools safely? (Possible answers were “yes, by myself”; “yes, with help”; or “no.”)

*Probes were used, as necessary.

Through the use of semi-structured interview guides, focus group participants were asked about the program model, resource needs, teaching strategies, and scheduling issues. The focus group interview guide for support workers was pretested with two clients from a non-participating agency. The interview guide for managers was reviewed by the manager of a developmental services agency and by a health promotion and communication specialist. Questions for both focus groups and individual interviews were developed on the basis of the literature and expert consultations.

Adult participants answered questions about their cooking experience, ideas for a cooking program, learning styles, food safety knowledge, and perceived levels of self-efficacy. A more structured format in the guide for adult participants was chosen to accommodate potential comprehension and communication challenges. The interview guide for adult participants was pilot tested with two individuals who were similar to the study participants. Revisions to the interview guides (Table 3) were made as needed.

In the interview sessions, visual prompts and cookbooks were used and questions were reframed and/or repeated, as needed, to ensure understanding. Each interview lasted approximately 30 minutes. Each focus group met for approximately 90 minutes. A note taker was present to observe and document the discussion. All interviews and focus groups were audio-taped and transcribed verbatim. Field notes documenting the researcher’s thoughts, impressions, and preliminary interpretation of the data were recorded following each session to provide context for the discussions and to guide the interpretation of the data.

Data analysis
Concurrent data collection and analysis, data saturation (the point at which no new information or themes are observed in the data), and a constant comparative method (where initial coding schemes are modified as the data warrant) guided the research (15-18). Responses from the managers, support workers, and adult participants were summarized according to the specific questions posed, topic areas such as the program model, resource needs, and teaching strategies. Responses to closed-ended questions posed to adult participants were summarized as descriptive statistics.

RESULTS
This study revealed a wide range of themes that describe preferences, needs, and concerns for nutrition education and cooking programs for adult participants. Figure 1 provides a visual depiction of all emergent themes. Key themes are represented by ovals and are linked to the source of research participant(s), shown as rectangles. For example, adult participants and support workers expressed safety concerns. All participants identified poor eating habits as being common in this population, and the need for nutrition education and food skills programs. Program funding issues influenced all groups. The significant themes drawn from the three
data sources were poor eating habits, safety concerns, low transferable skills, social relationships, staff training needs, resource needs, and limited funding. Responses to the self-efficacy questions are also reported.

**Poor eating habits**

All three respondent groups—participants, support workers, and managers—reported that poor eating habits were common among adult participants, with convenience food, fast food, and TV dinners being most frequently and regularly eaten. Of particular note was the concern expressed for individuals living at the lodging home. The managers reported that these individuals were so used to consuming unhealthy foods that changing their eating habits could be a real challenge. Support workers and managers verified this. One support worker said: “Most of our clients have poor eating habits. Prepared foods, soft drinks, cookies, and chips are the norm.” A manager stated: “One of the groups that I worry about the most is a group that doesn’t cook at all, the folks that live in lodging homes that we support. They don’t have the opportunity to cook, and they are filling up with highly refined carbohydrates at each meal.”

**Safety concerns**

Safety related to the use of kitchen equipment and utensils (e.g., stoves and sharp knives) was a concern for adult participants. One said: “Microwave is dangerous, not safe. I make my tea in the kettle. I won’t touch the oven. I won’t [go] near it!” Some adult participants reported that their parents never allowed them to use the stove, the oven, or sharp objects. Many support workers also reported that safety is a concern.

**Low transferable skills**

The managers and support workers reported that the individuals they support often have difficulty transferring skills from one environment to another. They felt that the ideal would be to teach clients the skills where they lived. One support worker commented: “Our guys usually [are] visual…. If we are using a kitchen at the [grocery store] across the street, with different equipment, they might not make that connection. It is going to be something that might not be so transferable.”

**Social relationships**

Some managers commented that many of these adults do not
have a network of friends; thus, an opportunity for socialization was seen as an important component of a cooking program. Many adult participants indicated that an ideal cooking program offers opportunities for social relationships: “An ideal cooking program is about fun, meeting different people, [meeting] a boy. Meeting new people would make me happy.”

Staff training needs
Managers and support workers strongly indicated that staff training would be important for success. Most support workers agreed that all residential care staff need training on nutrition and food safety: “…I would probably need to take the class [myself] rather than teach it. Seriously, I’m not in a position to teach any of these things.”

Resource needs
Managers and support workers identified resources as essential. Resources included pictorial grocery lists/recipes, menus, a cooking curriculum with teaching tips, and nutrition fact sheets. Compiling these items in a portable resource binder for each residential facility was also recommended.

Limited funding
A majority of the support workers and managers expressed concerns about funding this type of program. One of the managers mentioned constant battles with colleagues over limited funding. A support worker’s comment echoed the sentiments of her peers: “It would be ideal to have each person having an individualized program,… but cost wise, it is not a reality.”

Feelings of self-efficacy
More than 50% of the adult participants thought they could cook, use kitchen appliances, keep food clean and safe, and handle kitchen tools safely by themselves. Almost 50% of them felt they could learn to cook and choose healthy food with the help of others.

Some adult participants were not confident about their abilities to cook for themselves. This was apparent for one person who lives with his aging mother. He is in his 60s; his mother is in her late 80s and has deteriorating health. His mother has been his sole caregiver and he has never learned to prepare food for himself. When asked what he would prepare for a meal if his mother were not around, he reported that he was afraid of the oven and would not feel confident about making anything to eat. The support worker stated that this man will probably move to a nursing home with his mother when she is no longer able to remain in her home.

DISCUSSION
This study revealed a need for a nutrition education and food skills program for adults with developmental disabilities. Many of the adult participants reported poor eating habits and were observed to be overweight. Research has demonstrated that people with developmental disabilities are susceptible to many secondary conditions, such as obesity, CVD, and osteoporosis (1,2).

To provide a context for the results, themes are discussed in reference to individual, interpersonal, and organizational levels of influence within the social ecological model (19). Implications at the community and public policy levels are discussed briefly.

Individual level
At the individual level, attitudes, knowledge, and skills can influence health behaviours (20). For adult participants, addressing poor eating patterns, safety concerns, and low transferability of skills is important. Although no data exist on the eating patterns of Canadian adults with developmental disabilities, a report from elsewhere indicates that these adults often do not consume the recommended number of daily servings of fruit and vegetables (21), and that their nutrient intake tends to be high in saturated fat and simple carbohydrates (22). Adult participants in this study faced challenges in terms of eating a healthy diet, for example, a lack of nutrition knowledge, inadequate food skills, few opportunities to cook, and the availability of unhealthy food choices from vending machines. Nutrition education and food skills programs must be developed if adult participants are to enjoy health benefits throughout life.

Food preparation involves the use of knives, ovens, and stovetops and the handling of hot food items; therefore, knife safety, kitchen safety, and the proper use of basic equipment must be taught. Many instructional strategies that have been used to teach personal safety (23) could be applied to teaching food safety, such as modelling, rehearsal, praise, and “explicit behavioural training” (i.e., having participants actually perform or physically practise the skills they will be required to use, such as the operation of a stove). Building upon participants’ feelings of self-efficacy is important to support the teaching strategies employed.

Interpersonal level
Although the literature supports training in the natural environment to minimize barriers associated with generalization of skills across settings (24), staffing and budgetary constraints may prohibit programs from conducting lessons exclusively at participants’ homes. With training strategies such as general case programming (25), systematic prompting (26), role-playing, modelling, reinforcement, and corrective feedback, generalization of skills can occur even if training takes place in a community setting. Further, training conducted exclusively in the home setting limits opportunities for individuals to interact with others and meet new friends, an important goal in support strategies for this population. Researchers have identified that social relationships are important for adults with developmental disabilities (27). Many participants in the current study identified the need for more social events, friends, and
intimate relationships. Thus, at the interpersonal level, cooking classes offer opportunities for socialization, which can promote friendships and a sense of well-being.

Organizational level
The organizational level of influence in the social ecological model addresses factors in the private, public, and non-profit sectors to which individuals belong (19). Focus group participants clearly indicated the importance of staff training for the delivery of a successful program. Similar findings have been reported on limited awareness of safe food handling practices and nutrition knowledge among staff in community-based homes for adults with developmental disabilities (28–30). The results of the current study indicate the need for organizations to develop nutrition education resources and provide staff training to increase awareness of healthy eating. Registered dietitians’ (RDs’) involvement in nutrition resource development has been strongly supported in the literature (31), as well as by participants in this study. In terms of portable resources, a kit should be light, durable, and small. Ideally, the kit should be versatile and adaptable to accommodate different individual ability levels.

Community and public policy levels
To overcome limited funding, developmental services agencies need to explore different funding sources (e.g., grants, corporate funding) and pool their resources and expertise. Agencies may need to come up with other innovative measures (e.g., smaller-scale and less resource-intensive programming) to offset the major costs associated with new programming.

At the policy level, the needs of adults with developmental disabilities and aging caregivers have not been adequately addressed in terms of personal support services, home-delivered meals, home health care, and financial and legal assistance (32). Such supports will become increasingly important when an aging caregiver moves into long-term care, because there is a shortage of long-term care beds, and no policy to accommodate their dependent, developmentally disabled sons and daughters.

Given the fact that members of this population are at increased risk for several chronic diseases (1,2), have poor food and nutrition knowledge or skills (3), and have limited opportunities to learn such skills, their current level of access to RDs must be addressed. The complex needs of older adults with developmental disabilities will require competent nutrition specialists who can respond to their needs appropriately. Lodging homes for individuals with developmental disabilities may help address many nutritional concerns facing this population. The study results also highlighted the importance of developing policies that may address the consequences associated with the institutionalization of aging caregivers.

Dietitians who work in this area may need to increase their knowledge about this population’s learning needs. Dietitians can also play key roles in designing programs and services that enhance the quality of life for individuals with developmental disabilities. In addition, community and dietetic associations may advocate for appropriate and much-needed dietetic services for this population.

Study limitations
For participants who had difficulty answering open-ended questions, examples of possible responses were used for clarification. This may have introduced response biases; however, a systematic procedure was followed, which involved presenting participants with four possible responses and asking them to choose the one that described their response best. Because the same researcher conducted all the interviews, the bias was consistent and potentially controlled across all participants.

Participants with developmental disabilities in the study were pre-selected by the agency contacts, who acted as gatekeepers for the researchers. Many eligible participants may not have been approached for the study.

More than 50% of support workers in the focus groups came from the same agency; thus, the study would have been strengthened with more equal representation from all participating agencies. Managers and support workers were self-selected for the study; therefore, their desire for a cooking program would have influenced their expressed level of need for it. Although the interview guides were reviewed by a specialist from a university that specializes in health communication and research, pretesting of the guides with more people would have strengthened the study.

RELEVANCE TO PRACTICE
The current study represents one step in filling the research and service gaps in teaching nutrition and food skills to adults with developmental disabilities. It provides data to guide program planners in developing an effective nutrition and food skills cooking program for this population. The availability of nutrition education and food skills programs tailored for individuals with developmental disabilities may help address many nutritional concerns facing this population. The study results also emphasize the importance of developing policies that may address the consequences associated with the institutionalization of aging caregivers.

Dietitians who work in this area may need to increase their knowledge about this population’s learning needs. Dietitians can also play key roles in designing programs and services that enhance the quality of life for individuals with developmental disabilities. In addition, community and dietetic associations may advocate for appropriate and much-needed dietetic services for this population.

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