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Building an Infrastructure for Down Syndrome Care

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A final project presented to the faculty of the
Instructional Design Master's Degree Program
University of Massachusetts at Boston

BUILDING AN INFRASTRUCTURE FOR DOWN SYNDROME CARE

An Action Research Project

Submitted by

Kate E. Martin

in partial fulfillment for the requirement of the degree

MASTER OF EDUCATION

April 27, 2023

Carol Sharicz

Approved by Dr. Carol Ann Sharicz, Faculty

Acknowledgment

I would like to thank the dedicated faculty members of the UMass Boston Instructional Design MEd Program for their inspiration, time, expertise, unique skills and understanding. I have enjoyed being a member of this supportive learning community. In particular, I would like to thank Dr. Carol Sharicz, my capstone project advisor and graduate program director. Carol, you believed in my crazy ideas when they were still a bit crazy and thanks to your guidance, they've come to be a reality. I will always be grateful for your detailed analyses of my papers, including my APA formatting! Thank you, Dr. Sharicz, and thank you to all of the program faculty for helping me reach the end of this journey.

Abstract

People with intellectual disabilities experience greater obstacles in attaining their full health potential. The most common identifiable cause of intellectual disability is Down syndrome. Established in September 2021, the Down Syndrome Program at The Kirk Kerkorian School of Medicine at the University of Nevada, Las Vegas (UNLV) aims to meet the healthcare needs of members of the Southern Nevada community with Down syndrome and their families. However, there is currently no infrastructure in place in Southern Nevada to provide Down syndrome care, or clinical services dedicated to individuals with the condition. This work discusses options that were explored to develop such an infrastructure. A series of educational workshops were recorded on the topic of nutrition in Down syndrome with the following instructional goals: (1) To describe the importance of Down syndrome care; (2) To list common conditions that co-occur with Down syndrome; and (3) To define care coordination as it pertains to individuals with Down syndrome. Modules were developed along with the videos to provide knowledge assessments, intended for current and future healthcare professionals interested in learning more about Down syndrome care.

Keywords: Down syndrome, intellectual disabilities, healthcare, educational workshops

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Background Information

The Kirk Kerkorian School of Medicine at UNLV Down Syndrome Program was established in September 2021 to meet the healthcare needs of members of the Southern Nevada community with Down syndrome, the most common identifiable cause of intellectual disability. People with intellectual disabilities experience greater obstacles in attaining their full health potential. They receive lower rates of preventative health care services like blood pressure checks, cholesterol tests, and diabetes screenings despite being at higher risk for chronic medical conditions. The program offers educational resources and research opportunities with a long-term goal to provide dedicated clinical services in the future.

The University of Nevada, Las Vegas (UNLV) has the following Top Tier Mission: "UNLV's diverse faculty, students, staff and alumni promote community well-being and individual achievement through education, research, scholarship, creative activities and clinical services. We stimulate economic development and diversification, foster a climate of innovation, promote health and enrich the cultural vitality of the communities that we serve. In addition, the vision of the Kirk Kerkorian School of Medicine at UNLV is "to create a world-class center of excellence and innovation for medical education, patient care, and research that prepares Nevada's physicians with the most advanced knowledge, treatments, and technologies while serving the health care needs of our diverse urban community." Taking these organizational priorities into account, providing clinical services dedicated to people with Down syndrome directly addresses the needs of the community and allows for an opportunity to educate students and resident physicians at the same time.

There are key stakeholders at the UNLV organization from the micro- to macro-level who are important to meet with, such as the medical school leadership team, i.e., Dean, CFO, vice dean for clinical affairs, etc. In addition, there are university stakeholders on other parts of the campus, such as the physical therapy department, as their faculty are research partners with the program, but also The Practice, which is a clinic at UNLV that provides mental health services and is not currently engaged with the program. There are likely several other opportunities for collaboration within the university that have not yet been explored.

Positionality Statement

All research has an underlying bias that can affect any stage of the research process (Smith & Noble, 2014). At its worst, that bias can falsely confirm a researcher's findings. However, viewed in a better light, bias can be reflected upon through the lens of positionality as a powerful tool to advance the knowledge of a particular topic. As Brian Bourke (2014) articulates, "Through recognition of our biases, we presume to gain insights into how we might approach a research setting, members of particular groups, and how we might seek to engage with participants" (p. 1). Bourke provides commentary on how he dealt with issues involving his own bias, focusing on aspects of positionality that were encountered during the completion of a qualitative research project. For example, he asked the question, "What role did my positionality as a White man studying issues of race in higher education play?" (Bourke, 2014, p. 2).

But, what exactly is positionality? Jafar (2018) offers the following definition for positionality: "The recognition and declaration of one's own position in a piece of academic work" (p. 323). With this description in hand, Jafar (2018) explained that he needed to place his "researcher self" in perspective when conducting a study that involved medical records as he acknowledged his own bias toward direct patient care over population-based epidemiology while viewing the results of his work due to his professional role in a clinical environment. (Jafar, 2018, p. 324)

My overarching research question is: What care coordination efforts have been implemented for adults with Down syndrome or intellectual and developmental disabilities (ID/DD)? A follow-up question to this is: What is the impact of care coordination efforts for adults with Down syndrome or intellectual and developmental disabilities (ID/DD)? Both of these questions carry significance for the impact they can have on the current and future care coordination services being offered for adults with ID/DD in my community of Southern Nevada as well as other places.

Positionality

I am a white female family medicine physician in my early 40s living in the state of Nevada, which ranks lowest in the nation in public spending for persons with ID/DD (Lulinski, 2019). I have been in some form of an academic setting my entire life, practicing academic medicine since the beginning of my professional career. In addition to obtaining a Bachelor's degree in biology and a Doctor of Medicine, I have pursued additional education, resulting in Master's degrees in public health, business and science with a specialization in aging services. I grew up in Southern Nevada alongside a sibling with severe intellectual and physical disabilities who encountered significant obstacles accessing healthcare services throughout his life until his untimely death two years ago at age 49.

While I can speak as a family member of someone with an intellectual disability, I cannot (and would not try to) speak for someone with ID/DD. In that regard, my positionality seems clear - I am someone who has witnessed a lack of coordinated care for adults with intellectual disabilities, in particular, a close family member. I think that positions me well to explore my research questions. I am also a physician, which represents one of my multiple identities that comes through during this reflection on positionality. As a result, I may want to reject an observation that healthcare services are not being administered properly, i.e, lack of coordinated care, but my "physician self" offers a lens of experience caring for people within a fragmented, at times broken, healthcare system. I also have expertise in aging services, so I am knowledgeable about what types of support can and should be offered to an aging population, including adults with ID/DD. Finally, based on my long track record in education, I may value training, teaching and related programs such as health literacy and patient navigation services at a high level. So, as much as I think care coordination is important, I need to ensure I am actually able to demonstrate its value through the available literature or identify a need for additional research on the topic. In summary, I am well positioned to pursue this inquiry as I am already a subject matter expert on intellectual disabilities from multiple vantage points.

Analysis Plan

One component of the needs assessment was a meeting with the leadership team at the Kirk Kerkorian School of Medicine at UNLV, which includes the Dean, Vice Dean for Clinical Affairs, Chief Financial Officer and Associate Dean for Finance and Facilities. The discussion centered around securing the resources required to add dedicated clinical services to the Down Syndrome Program, such as physical space, staffing, and information technology (IT) to support operations for the electronic health record and new patient registration and scheduling.

Philanthropy was explored as a possible funding source in the needs assessment process. A meeting took place with local donors (husband and wife) who have a grandson with Down syndrome. They spoke about the value of having a comprehensive network of services for their family member and expressed a desire to support that type of work for others in the community.

The following was communicated with them as part of a follow up / “thank you” message:

> Project: Specialized Down syndrome care in a physical space uniquely designed for and by people with Down syndrome and their families
>
> Annual health screenings for commonly occurring conditions with Down syndrome

- Atlantoaxial instability
- Cardiovascular disease
- Celiac disease
- Dementia
- Diabetes
- Osteoporosis
- Thyroid conditions

- Mental health screenings and services provided on-site
- Nurses trained in advanced phlebotomy skills to draw any necessary blood tests
- Telehealth: wider reach for individuals living in rural areas who cannot readily access providers and/or specialists and also at-home monitoring for anyone
- Physical, occupational and speech therapy screenings
- Collaboration with dental clinic for children and adults with Down syndrome

Another stakeholder identified in the needs assessment was The Practice, which is a clinic at UNLV that provides mental health services and is not currently engaged with the program. A meeting with the director of this clinic will be scheduled to discuss future collaboration opportunities.

Located in Southern Nevada, Opportunity Village is a unique resource for individuals with ID. It is the largest nonprofit, community-based, vocational rehabilitation program of its kind in the state. As part of this project, caregivers of persons with ID from Opportunity Village (OV) volunteered to be interviewed over a phone call. The caregivers are important communication partners as they help the individual with ID navigate any communication experience. A set of interview questions were asked to identify how caregivers communicate with a person with ID and to determine communication needs. Questions concerning accessing healthcare services were also discussed to assess any barriers experienced.

Other stakeholders including leaders from the Special Olympics (SO) Nevada were interviewed to discuss the needs of their athletes. Themes discussed included communication and access to healthcare. The athletes at SO are required to undergo sport physicals prior to participating in any events. In this program, practitioners are educated to provide care and screening for the SO athletes.

Care coordination involves organizing patient care activities and sharing information to ensure a patient's needs and preferences are met. Due to the variety of conditions associated with Down syndrome (Ds), the need for care coordination is greater for this population. Positive experiences of care coordination have been correlated with increased satisfaction with chronic illness care, primary care providers, and the overall organization of care (Wang, 2015). Wang and colleagues conducted three cross-sectional surveys of members of the managed care organization, Kaiser Permanente, who had been diagnosed with diabetes (Wang, 2015). This example in a population with a chronic condition could serve as a basis to suggest and confirm the same in a population of individuals with intellectual disabilities.

Care coordination has also been found to decrease the financial burden on families, the amount of illness-related school absences, and emergency department visits (Turchi, 2009). The authors of this study analyzed survey data from the 2005-2006 National Survey of Children with Special Health Care Needs (NS-CSHCN), looking for correlations between levels of satisfaction with care coordination and particular healthcare service outcomes. Parents who reported receiving adequate care coordination had decreased odds of having problems with needed referrals. Also, parents who reported receiving adequate care coordination had decreased odds of having two or more emergency department visits and of children missing more than six school days because of illness in the preceding year. These findings could be used to explore the value of care coordination for adults with special health care needs.

People with intellectual or developmental disability reported lower levels of satisfaction with the health care services they've received (Bowers, 2017). Bowers and colleagues studied the survey results of 442 members who were receiving care coordination services from a MMC state program with 100,000 enrollees with disabilities (Bowers, 2017). Members reporting a positive experience with the care coordination services reported fewer unmet healthcare needs and a higher appraisal of their health care. Members with mental health disabilities and intellectual disabilities, in particular, reported higher rates of unmet healthcare needs and so more attention to these populations to improve quality and access to care may be helpful.

It has been documented that children with intellectual and/or developmental disabilities (ID/DD) require specialized services involving the education and healthcare sectors. The authors, Boulet and colleagues (2009), analyzed nearly ten years of data obtained from the annual National Health Interview Survey (NHIS), spanning from 1997 to 2005, specific to children with developmental disabilities (DDs) and found that all measures of healthcare use (i.e., medical specialist, mental health, speech therapist) were higher for children with an ID/DD (Boulet, 2009). This rate of healthcare utilization increased even more in children with more than one ID/DD (Boulet, 2009). A similar trend was witnessed with special education, with 38.8% of children with 1 or more ID/DD receiving special education or early intervention services, increasing to 78.6% of children with 3 or more IDs/DDs (Boulet, 2009).

Grieco and associates (2015) published a review article mainly on children with Down syndrome, although they also discussed the functional capacities of an individual's life, from childhood through the adult years. Specifically, there are some significant takeaway points regarding adults with Down syndrome, including the topic of self-monitoring, in which it was noted that individuals with Down syndrome have poor monitoring of their verbal comprehension or are unable to execute or create a plan to request clarification of instructions (Grieco, 2015). This could help justify the provision of care coordination services for these individuals.

A preliminary search of the literature showed that there were sparse results for care coordination efforts for people with Down syndrome. For example, a scoping review on quality indicators for Down syndrome did not find any specific information on Down syndrome so the authors expanded their research to include intellectual disabilities (van den Driessen Mareeuw, 2017). They concluded that quality indicators specific to Down syndrome care had not been published and there was also little information available on the medical care for people with intellectual disabilities (van den Driessen Mareeuw, 2017). Starting with Down syndrome could be a way to document successful care coordination programs, which could be expanded to others with intellectual disabilities.

Of the few studies on care coordination for people with Down syndrome, none were focused on the adult population. The most closely related study found during this preliminary literature search was a scoping review focusing on families' needs for care coordination for their children with Down syndrome (Skelton, 2021). Although this study stated that care coordination is beneficial in improving health management outcomes, the results are limited to children (Skelton, 2021).

Analysis Report

At this time, the medical school does not have funding to bring an initiative like a Down syndrome clinic to bear. Although such a clinic was viewed by the medical school leadership group as a cost neutral or possible profit-producing service line, there is no startup money to get it up and running.

An introductory meeting with potential donors (husband and wife) to discuss funding for the Down syndrome clinic went well. They expressed interest in staying in touch and having additional future conversations. Most recent correspondence received from them encouraged collaboration with a community organization that has put forward similar goals for clinical care, which doesn't help the funding challenge.

The Family Quality of Life (FQOL) Scale was administered to facilitate the interview process (Beach Center on Disability, 2016) with caregivers of people with Down syndrome (see Appendix A). The FQOL is a 25-item inventory that measures several aspects of a families' perceived satisfaction in terms of family quality of life. It is rated on a 5-point Likert type-scale. The five domains measured are family interaction, parenting, emotional well-being, physical/material well-being, and disability-related support.

In addition to family members and other caregivers, athletes from Special Olympics Nevada were interviewed to obtain a first-person perspective on their thoughts about accessing healthcare. Ten athletes were interviewed with the supervision of SO staff. Questions were asked about their satisfaction with accessing healthcare services in their area and also their experiences with the SO Healthy Athletes program.

Key Research Findings

After speaking with caregivers from Opportunity Village, a persistent issue emerged.

Specifically, there was a discrepancy between receiving approval for equipment or devices needed. These devices are necessary to meet the needs of individuals with ID, such as ambulatory equipment. Persons with ID qualify for Medicaid and their treatment and devices must be pre-approved under the state-funded insurance program, which can be complex to navigate. In addition, persons with ID often have chronic conditions that affect them from childhood through adulthood. Unfortunately, increasing age can affect coverage qualifications for certain treatments as well. Conditions often progress with age, but the Medicaid coverage for expensive services and equipment does not always keep pace with those needs.

Questions concerning accessing healthcare were asked of caregivers. Overarching themes were continuity of care and finding resources and services in the area. The biggest concern was the lack of a centralized location to provide accurate information about services available for individuals with ID. Because of the changing availability of resources, a centralized listing of services and resources would need to be continually updated.

<u>SO Leaders</u>: During the interviews with the leaders of SO Nevada, the topic of accessing healthcare services was discussed. Up until 2016, there were only about 3-4 full time staff in the SO Nevada Healthy Athletes' program. In 2020, they had 10 full-time staff. Their future goal is to build a robust referral network, educate as many practitioners as they can, and certify as many clinical directors as possible for the Healthy Athletes Program. The leaders at SO Nevada feel that it is important for more practitioners to receive specific training in healthcare management of persons with ID. Things like building patient relationships are very important to foster a more supportive environment and make it inviting for the individuals with ID. Certain aspects such as athletes being able to communicate problems effectively to a practitioner and have access to follow-up care are areas that can be improved.

SO Athletes: The consensus among the athletes was very positive concerning their experiences with the Healthy Athletes Program. Many positive responses were centered around being able to socialize with their teammates during their sports physicals. One of the main findings was the need for better management, overall, for those with ID in terms of follow-up care.

The literature review findings highlight the importance of care coordination by theme (communication, information, utilization) due to the often co-occurring conditions an individual with Down syndrome experiences. Since these conditions are chronic in nature and do not resolve in adulthood, the findings could help support how a similar approach to care coordination would be essential for adults with Down syndrome, too.

This research set out to better characterize the clinical service support system required for Down syndrome care due to the lack of infrastructure currently in place for it (problem statement). The target audience for this work encompasses the local healthcare community, including healthcare providers in training and other educational programs.

Learning/Performance Objectives

Program participants will be expected to complete educational modules that align with the instructional goals identified during the Analysis phase.

The instructional goals are as follows: (1) To describe the importance of Down syndrome care; (2) To list common conditions that co-occur with Down syndrome; and (3) To define care coordination as it pertains to individuals with Down syndrome.

Instructional Strategy

The overall instructional and assessment approach is based on the constructivism learning theory as the participants are encouraged to reflect on their experiences in a clinical environment to construct meaning from this educational module series. The modules will be delivered via the Canvas online learning management system.

Instructional Materials

Educational content includes video recordings of informational workshops with accompanying quizzes that assess achievement of the objectives.

Development of Materials/Intervention(s)

Informational small group workshops held on the Zoom online platform were recorded for later playback. The topic of the workshops focused on nutrition areas important to people with Down syndrome and their caregivers (see Appendix B). They were led by a registered dietician who is also a current doctoral student in the School of Integrated Health Sciences at the University of Nevada, Las Vegas (UNLV). Participants included undergraduate pre-health students at UNLV. The videos were captioned with English and Spanish subtitles so they could be uploaded to the Down Syndrome Program website and shared broadly with anyone with an interest in the topic; they were approximately 30 minutes each in duration.

Quizzes were developed using the Learning Management System, Canvas by Instructure, corresponding to the video topics. Each video workshop represented a module about a nutrition topic important to people with Down syndrome (see Appendix C).

Implementation and Evaluation

The pilot plan offers these nutrition modules to medical students and resident physicians enrolled in training programs at the Kirk Kerkorian School of Medicine. Successful completion of the associated assessments (achieving 100% correct results) would result in receiving a certificate in Down syndrome care for nutrition. If the program is well received, it can be expanded to other areas of focus such as fitness/exercise, cognitive/brain health and heart health.

Formative evaluation will be conducted using the Kirkpatrick model, applying the following four levels of evaluation:

Level 1: Reaction

Feedback from learners who have interacted with the modules, including those who did not successfully complete or finish them will be requested via e-mail or an online survey within 24 hours of starting the module.

The following questions will be asked:

- Did you understand the module objectives? Yes/No;
- Do you feel like you can quickly apply what you learned? Yes/No;
- Were the course materials easy to navigate? Yes/No; and
- Do you feel like your learning experience was enhanced by the workshop facilitator? Yes/No

Level 2: Learning

The module quizzes can be used in a pre-test/post-test manner, such that the learner is asked to take the quiz ungraded prior to watching the video and then again, graded after viewing the video, and the differences in scores can be compared. Alternatively, one of the questions can be sampled for the same purpose so the learner is asked to complete only one question in advance to pique their interest without causing confusion or frustration.

Level 3: Behavior

A delayed survey (3-6 months later) will be sent to learners who have successfully completed the modules, asking the following questions:

- Were you able to apply what you learned during the modules? Yes/No
- Do you feel like the modules were worth the time and energy you spent on them? Yes/No

Level 4: Results

The ultimate goal of this project is to build an infrastructure for Down syndrome care in Southern Nevada, which would include healthcare providers who are knowledgeable in the conditions and special care considerations for these individuals. With that in mind, a long-range survey, i.e., yearly, would be distributed to healthcare providers in the area to assess their comfort level caring for this population to look for an upward trend over time.

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Appendix A

Family Quality of Life Scale - Scoring & Items

The FQOL Scale uses satisfaction as the primary response format. The anchors of the items rated on satisfaction are rated on a 5-point scale, where 1 = very dissatisfied, 3 = neither satisfied nor dissatisfied, and 5 = very satisfied.

Items

There are 25 items in the final FQOL scale. Below are the items keyed to each of the first sub-scales domains:

Family Interaction:

- My family enjoys spending time together.
- My family members talk openly with each other.
- My family solves problems together.
- My family members support each other to accomplish goals.
- My family members show that they love and care for each other.
- My family is able to handle life's ups and downs.

Parenting:

- Family members help the children learn to be independent.
- Family members help the children with schoolwork and activities.
- Family members teach the children how to get along with others.
- Adults in my family teach the children to make good decisions.
- Adults in my family know other people in the children's lives (i.e. friends, teachers).
- Adults in my family have time to take care of the individual needs of every child.

Emotional Well-being:

- My family has the support we need to relieve stress.
- My family members have friends or others who provide support.
- My family members have some time to pursue their own interests.
- My family has outside help available to us to take care of special needs of all family members.

Physical / Material Well-being:

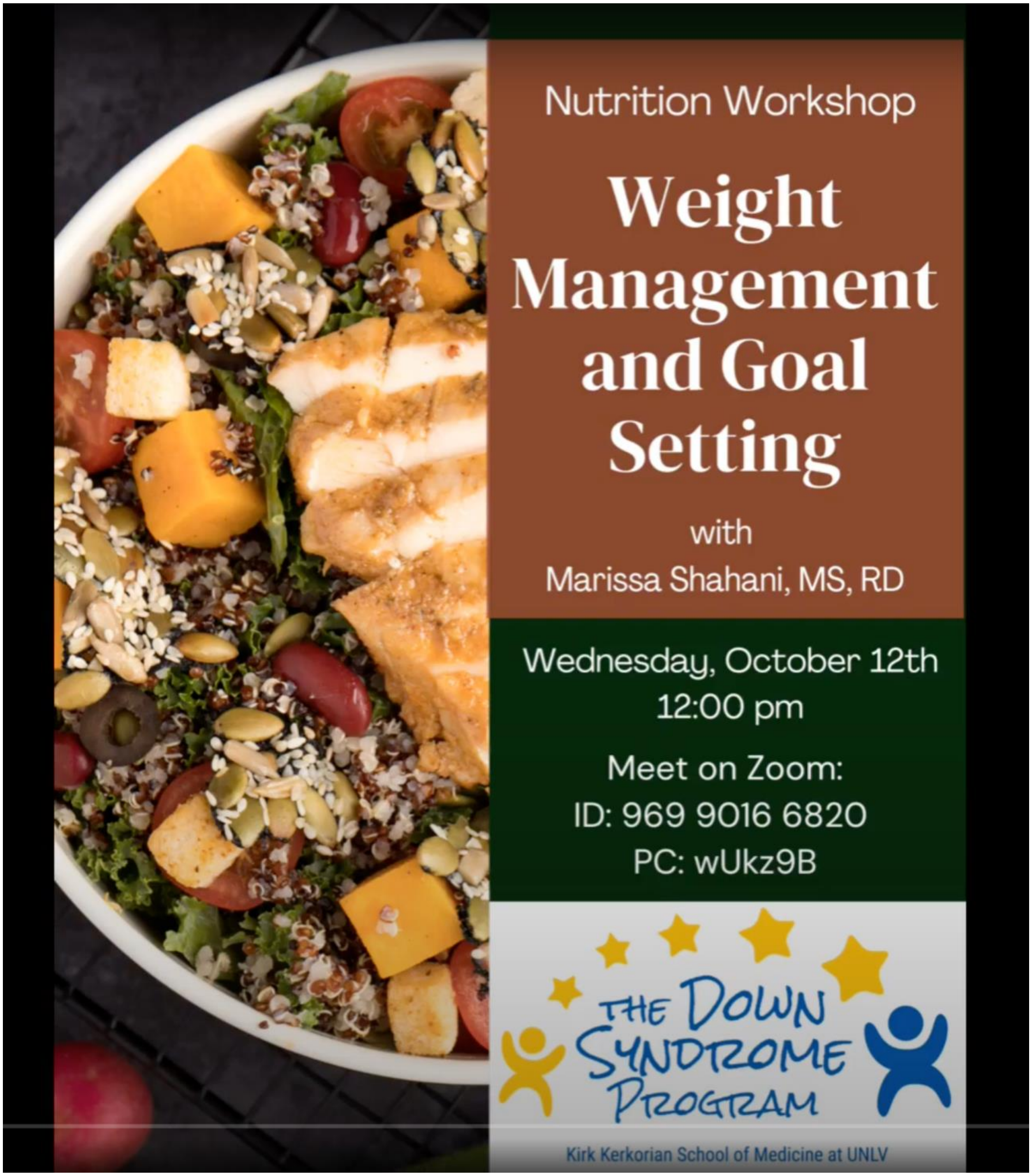
- My family members have transportation to get to the places they need to be.
- My family gets dental care when needed.
- My family gets medical care when needed.
- My family has a way to take care of our expenses.
- My family feels safe at home, work, school, and in our neighborhood.

Disability-Related Support

- My family member with special needs has support to make progress at school or workplace.
- My family member with special needs has support to make progress at home.
- My family member with special needs has support to make friends.
- My family has a good relationship with the service providers who work with our family member with a disability.

Appendix B

Nutrition Workshops - Opening Screenshots



Nutrition Workshop

Weight Management and Goal Setting

with
Marissa Shahani, MS, RD

Wednesday, October 12th
12:00 pm

Meet on Zoom:
ID: 969 9016 6820
PC: wUkz9B

The Down Syndrome Program

Kirk Kerkorian School of Medicine at UNLV

Figure B1. Workshop #1 - Weight Management and Goal Setting

Common Sensitivities and Restrictions - 11.9.22

SENSITIVITIES & FOOD RESTRICTIONS

Marissa Shahani MS, RD

Figure B2. Workshop #2 - Sensitivities & Food Restrictions

Safe Supplement Use Workshop - 12.14.22

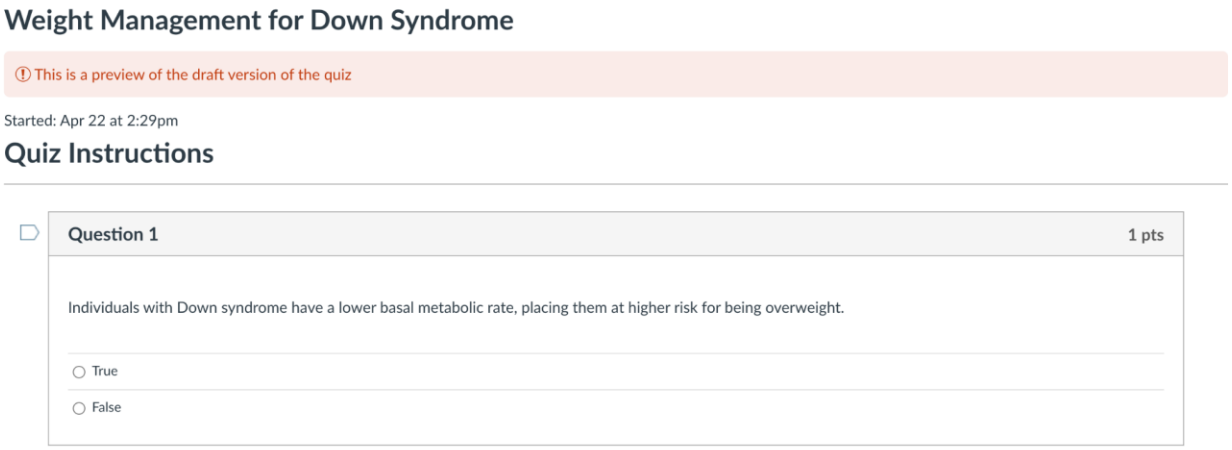
SAFE SUPPLEMENT USE

Marissa Shahani, MS, RD

So today I wanted to talk about safe

Figure B3. Workshop #3 - Safe Supplement Use

Appendix C



Weight Management for Down Syndrome

ⓘ This is a preview of the draft version of the quiz

Started: Apr 22 at 2:29pm

Quiz Instructions

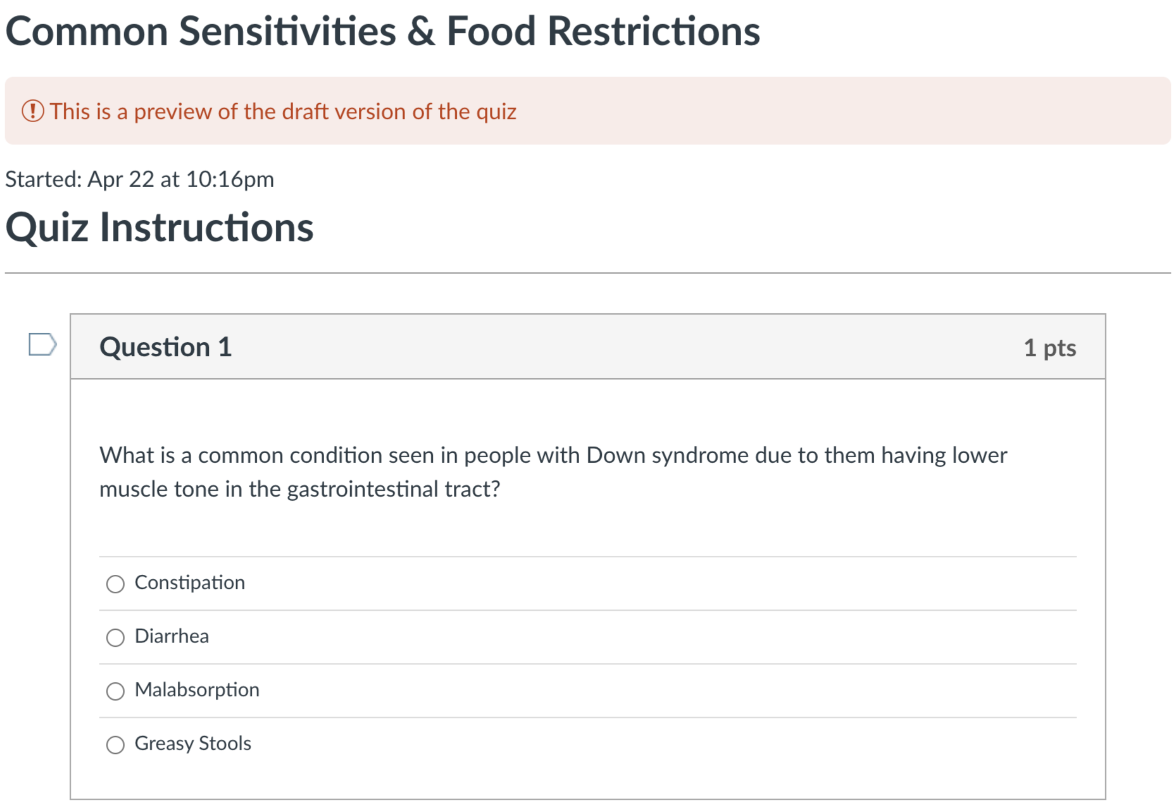
Question 1 1 pts

Individuals with Down syndrome have a lower basal metabolic rate, placing them at higher risk for being overweight.

○ True

○ False

Figure C1. Sample Question from Quiz #1 - Weight Management for Down Syndrome



Common Sensitivities & Food Restrictions

ⓘ This is a preview of the draft version of the quiz

Started: Apr 22 at 10:16pm

Quiz Instructions

Question 1 1 pts

What is a common condition seen in people with Down syndrome due to them having lower muscle tone in the gastrointestinal tract?

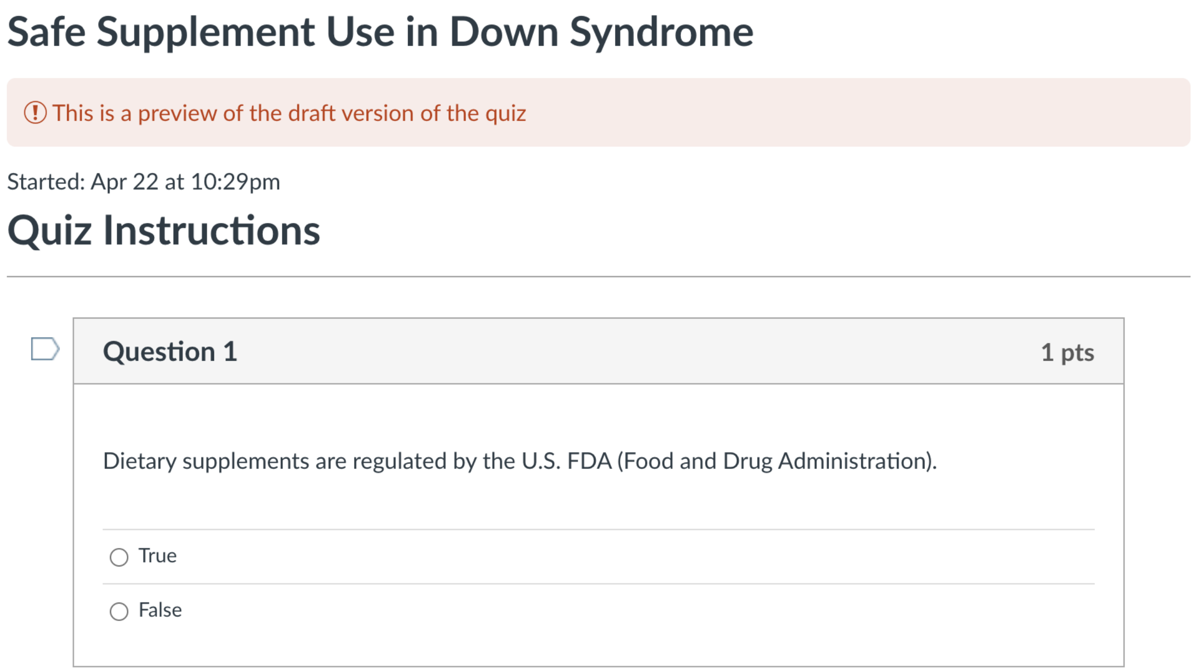
○ Constipation

○ Diarrhea

○ Malabsorption

○ Greasy Stools

Figure C2. Sample Question from Quiz #2 - Common Sensitivities & Food Restrictions



Safe Supplement Use in Down Syndrome

This is a preview of the draft version of the quiz

Started: Apr 22 at 10:29pm

Quiz Instructions

Question 1 — 1 pts

Dietary supplements are regulated by the U.S. FDA (Food and Drug Administration).

○ True

○ False

Figure C3. Sample Question from Quiz #3 - Safe Supplement Use in Down Syndrome