

CHAPTER TWENTY SIX

COMMUNITY-BASED NUTRITIONAL SERVICES FOR PERSONS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

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Introduction

When compared to the general population, persons with intellectual and developmental disabilities (IDD) have significantly worse health outcomes and a shorter life expectancy (Krahn, Hammond, and Turner, 2016; Ouellette-Kuntz, 2005; Taggart & Cousins, 2014). According to a recent systematic study, persons with IDD are actually more likely to die 20 years sooner than the general population, and many of the reasons for mortality are preventable (O'Leary, Cooper, & Hughes-McCormack, 2017). Persons with IDD often experience health inequities related to access to care, genetics, social circumstances, and environmental factors (Krahn et al., 2016). Cardiovascular disease, type 2 diabetes, hypertension, osteoporosis, depression, overweight, and obesity are some of the key health hazards that are frequently mentioned for persons with IDD (Haveman et al., 2010; Rimmer & Yamaki, 2006; Taggart & Cousins, 2014; Yamaki, 2005). According to a four-year longitudinal study by Hsieh et al. (2014), persons with IDD had a greater prevalence of becoming obese (38%) than the general population (28%), with obesity being more common in this group. The long-term study also discovered a higher risk of acquiring obesity in women, persons with Down syndrome, those who engage in less physical exercise, those who consume more soda, and those who take weight-gaining medications (Hsieh et al., 2014).

Heart disease, type 2 diabetes, high blood pressure, stroke, liver and gallbladder disease, respiratory issues, and certain cancers, such as breast and colon cancer, are all common health consequences of being overweight and obese (Centers for Disease Control and Prevention, 2017). Being overweight or obese can be influenced by a person's behaviour, environment, and genetics. Nutritional intervention is often necessary for persons with IDD because they frequently have nutritional issues, such as metabolic disorders, drug-nutrient interactions, and poor feeding skills, and they may need to rely entirely or partially on enteral or parenteral nutrition (Griffiths et al., 2018; Van Riper, 2010). The type of diet that a person may have is influenced by their environment as well. According to Conner & Armitage (2002), O'Kane (2016), Rodriguez-Arauz, Ramirez-Esparza, and Smith-Castro (2016), a person's food choices are influenced by external factors such as

availability, affordability, accessibility, media attention, and cultural/religious customs. The environment is a significant determinant of obesity for persons with IDD, as evidenced by the significantly higher prevalence of becoming overweight or obese among persons with IDD who live in less restrictive environments, such as their own homes or group homes (Hsieh et al., 2014; Rimmer & Yamaki, 2006; Yamaki, 2005).

According to Yamaki (2005), there are three possible explanations for why persons with IDD who live in less restrictive environments may be more likely to gain weight or develop obesity: (1) Persons with IDD are typically from low socioeconomic status families and thus less likely to be able to afford healthy food options; (2) Persons with IDD who have moved into a less restrictive living environment are not used to the decreased supervision of their choices and therefore tend to choose to eat unhealthy foods; and (3) Persons with IDD who have IDD are more likely to Persons with IDD are frequently said to have poor diets because they lack nutrition knowledge, eat meals high in fat with few fresh fruits and vegetables, have low wages, and have trouble preparing food. Persons with IDD typically have little to no involvement in food shopping, meal planning, or meal preparation, despite the fact that there is little research on how they choose the foods they eat (Sisirak & Marks, 2014). For instance, individuals with IDD living in group homes often do not have a choice in what they eat since they are frequently excluded from grocery shopping, meal planning, and meal preparation because of organizational norms and safety guidelines (Rodgers, 1998). Additionally, prepackaged foods that are rich in calories and fat are frequently served due to time constraints on menu planning and food preparation (Nestle et al., 1998).

The health issues faced by persons with developmental disabilities are considerably more difficult than those faced by the general community, despite the fact that prevention efforts with the general population have not always been universally effective, well-focused, or well supported. Due to the higher risk of conditions related to their problem in the community, these persons are more likely to develop diseases that can be avoided. Researchers have discovered, for instance, that adults with Down's syndrome are more likely to be overweight (Rubin, Rimmer, Chicoine, Braddock, & McGuire, 2008). The frequency of risk factors for cardiovascular diseases, such as obesity and hypertension, is unusually high among persons with intellectual disabilities (Sutherland et al., 2012). According to the National Institute for Occupational Safety and Health (NIOSH), 2020, 1.5% of adults and 6% of school-age children in the United States each have a developmental disability. There is no comparable statistics available for Nigeria. Accordingly, 4.1 million adults and 4 million children in the United States live with a developmental disability, based on the 274 million persons that made up the population in 2000. According to the Office of Disease Prevention and Health Promotion (2000), 32% of persons with developmental disabilities also have high blood pressure, 24% have high cholesterol, and 30% of both the men and the women in this group are obese. These figures demonstrate that the demands of

those who live with developmental impairments are not significantly different from those of the general population when compared to the statistics of the general population previously reviewed.

The high incidence of health issues among adults with developmental disabilities is influenced by the extent of community-based health-promoting practices in person's life (Sutherland et al., 2012). Persons with developmental impairments are just as susceptible to risk factors like poor eating as the general public. Equal efforts should be made to address dangerous lifestyle variables in this population through community-based health promotion and preventive programs. In Nigeria, there is a clear need for research into potential community-based prevention and health promotion strategies, such as nutrition education, for persons with developmental disabilities because their health concerns are similar to those of the general population. Since research indicates that diseases like obesity and coronary heart disease, for which sedentary behaviour is a likely risk factor, are lifelong processes with origins during childhood and because physical activity (as well as nutritional) habits are established early in life and may persist into adult years, it is important to develop such a community-based health education programme.

In this paper, the writers expose the concept of community-based nutritional services for persons with intellectual and developmental disabilities, the paper briefly x-rays the historical perspective of nutritional services for persons with intellectual and developmental disabilities which began on the basis of institutionalization of persons with disabilities in the late nineteenth and early twentieth centuries on a commitment to educating persons with IDD, and evolved into centers of custodial care. Available community-based nutritional services will be discussed, which comprise of the health status of persons with intellectual and developmental disabilities, deinstitutionalization of persons with disabilities, new models, developmental disabilities health centre, differences in nutritional services among countries, and provider training and education. Other services will include integration, nutritional services delivery systems, standards and quality of care, and nutritional services financing. The paper will make suggestions.

Historical Perspective

Many medical practitioners of the 1950s and 1960s contemplated the health of persons with IDD through a disease orientation. In 1954, then President of the American Association on Mental Deficiency (today, the American Association on Intellectual and Developmental Disabilities), Dr. Arthur Hopwood, publicly opined that "medicine, not education, will find the answers" to care and treatment challenges experienced by persons with IDD. The person with IDD is, in such a "medical model," "sick," which was the basis of institutionalization for decades. Institutions (sometimes called "schools"), which were founded in the late nineteenth and early twentieth centuries on a commitment to educating persons with IDD, evolved into centers of custodial care. By the middle of the twentieth

century, the educational basis on which most institutions were conceived, had given way to a custodial, administrative model that was negatively referred to as the “medical model” (Feigelman, 2016). Ironically, persons with IDD lived far shorter lifespans and experienced far greater health disparities and inequities under the “medical model” than they do today in a community-based model. In 1962, US President John F. Kennedy (1917–1963), whose sister Rosemary was believed to have an IDD, created the National Institute of Child Health and Human Development within the National Institutes of Health. Kennedy’s efforts also included efforts to deinstitutionalize persons with IDD and move them to community, and encouraged the nation’s medical establishment to address the causes and treatment of IDD.

Available Community-Based Nutritional Services

1. Individuals with Intellectual and Developmental Disabilities' Health Status

Extensive research reveals barriers to effective dietary services and accompanying health disparities, which contribute to inequities in health status experienced by persons with IDD. Worse outcomes encountered by persons with IDD include:

- i. reduced access to preventative care and health promotion, as well as worse health with greater incidence of chronic illnesses, co-morbidities, and premature mortality;
- ii. inadequate oral, breast, and testicular cancer screenings as well as outdated vaccine information;
- iii. cognitive difficulties in identifying, interpreting, and self-reporting/communicating health issues that impact treatment compliance;
- iv. financial obstacles,
- v. inadequate financial incentives for those who provide feeding services to protect the health of persons with IDD;
- vi. sociocultural misconceptions, social and attitudinal hurdles, and mobility/access issues;
- vii. lack of research into the nutritional services requirements of those with IDD;
- viii. Lack of formal training for nutritional services professionals, particularly with the requirements of adults with IDD, which leaves the community short on skilled caregivers.

The American Association on Intellectual and Developmental Disabilities (AAIDD) stated "there is a marked disparity of health between persons with IDD and the general population" in 2006, and the United Nations Convention on the Rights of Persons with Disabilities was updated to state "the right (of persons with disabilities) to the enjoyment of the highest attainable standard" at around the same time (American Association on Intellectual and Developmental Disabilities, 2016):

- i. the same scope, caliber, and degree of free or reasonably priced nutritional services as is offered to others;

- ii. health care tailored to their disability, such as early detection and intervention when necessary, as well as services intended to reduce and stop subsequent disabilities;
- iii. health care services as close to the individual's community as possible, including in remote locations;
- iv. Care of the same caliber, especially on the basis of freely given and informed permission; education about the needs, human rights, and autonomy of persons with disabilities; adoption of moral guidelines for both public and private nutritional services; and
- v. When permitted by national law, the provision of health insurance and life insurance must be made in a fair and reasonable way, according to the 2016 United Nations Convention on the Rights of Persons with Disabilities.

2. Deinstitutionalization

Deinstitutionalization has long been viewed as a rejection of the “medical model” of care for persons with IDD (Yankauer, 2006). With large-scale movements of persons from institutions during the 1960s and 1970s, it was anticipated that the generic system of health services would be able to provide care for the persons with IDD moving into the community. Garrard (Garrard, 2008) described the relative absence of critically needed specialty health care, including neurology, behavioural neurology, psychiatry, and orthopedic services, needed by persons, which “could not be located in the community” (Garrard, 2008). Thirty years on, this challenge persists. However, Hayden and Kim (2015) found evidence to indicate that persons with significant medical conditions can be supported in typical community settings with medical support found in the community and that while the community-based nutritional services delivery system is in need of improvement, persons with IDD who have wide ranges of medical needs can be supported in the community.

3. New models

The growth of community health care delivery systems that offer access to high-quality care for persons with IDD has been slow but significant. In 2001, in some developed countries such as America, “Closing the Gap” programme outlined a number of “programmes and creative strategies” created to address the nutritional services needs of persons with IDD. Among those programmes, only two, New York City Premier Health Care Program and New Jersey’s Developmental Disabilities Health Alliance, were offering community-based, integrated primary care beyond pediatrics. The National Council on Disability’s (NCD) report on “the current state of health care for persons with disabilities” (National Council on Disability, 2019) cited only four “effective programmes” delivering health care to persons with IDD. No known similar services has been created in Nigeria to cater for persons with disabilities, though there are policies to take off this similar community-based services. Other models that have been developed more recently are in early stages of development. In these developed

countries like Colorado, for example, the Developmental Disabilities Health Center (DDHC) offers multidisciplinary, fully integrated primary health care to adults with IDD. This particular model, was conceptualized in 2007 through a meeting (Interagency Action Seminar: building as a system of health care for adults with developmental disabilities) that brought together local, national, and international experts on nutritional services and IDD to develop a model of integrated nutritional services customized to the needs of persons with IDD, was borne out of five core objectives:

- i. more widely accessible comprehensive dietary care;
- ii. increase the level of care given by local providers of nutritional services;
- iii. create materials for IDD sufferers to promote their health;
- iv. raise awareness of the needs for nutritional services among persons with IDD; and
- v. create a paradigm for the delivery of nutritional services that is adapted to the needs of persons with IDD.

4. Health Center for Persons with Disabilities

Though, no attempt has been made to a specific health centre for persons with disabilities in Nigeria, but provision for inclusive health services is recently made available some public health facilities across Nigeria. Efforts should be made to follow the patterns of American nutritional services services/ health centre like the one that was opened in 2011, the DDHC in Colorado Springs, Co, USA operates through a partnership of local and national organizations, including a major provider of case management and other traditional developmental disability services, the region's federally qualified health center (FQHC), the local public hospital, are habilitation hospital, and the region's mental health center. The DDHC offers integrated primary care that is customized to the needs of children and adults with IDD. This nutritional services delivery system is comprised of a number of key elements, including primary care that integrates acute and mental health, behavioural health services and consultation, on-site care coordination, allied health and other specialty care, health planning, and health education programmes for patients and their caregivers (National Council on Disability, 2019). The DDHC is also engaged in strategic research and practice partnerships with the University of Colorado, the Coleman Institute on Cognitive Disabilities, the National Center on Health, Physical Activity and Disability (NCHPAD), the Institute on Disability and Human Development (the UCEDD at the University of Illinois at Chicago), the University of Alabama at Birmingham, and the National Institute on Child Health and Human Development in Israel.

5. Varying Nutritional Services in Countries

It is important to acknowledge differences among countries in how health services are provided to persons with IDD and how nutritional services providers learn about IDD. In the UK, Australia, New Zealand, Canada, and the Netherlands,

for example, primary medical care to persons with IDD and their families is provided by general practitioners or family physicians and takes place in the community. Consultant specialists see patients on referral and provide most hospital care. Except for children with complex and severe disabilities who are near large hospital centers and specialists, the family physician/ general practitioner is the main medical provider. Developmental pediatricians in large hospital centers provide a large portion of primary care through a range of clinics (e.g., developmental clinic, complex care clinic, genetics clinic, Down syndrome clinic, Autism clinic, etc.). Other specialists, working out of the same facility are accessible (e.g., orthopedics, neurology, psychiatry, dentistry). For adults with IDD, with rare exceptions, there are no such focused resources. In the US, primary medical care may be provided by family physicians, general pediatricians, general internists, and, for women, even obstetricians/gynecologists. Consulting specialists work out of larger hospital centers, some providing continuing management for particular conditions related to their specialty. Special clinics for IDD are found in children's hospitals with variable emphases (general developmental clinics, syndrome-specific clinics, genetics clinics, etc.). Again, for adults with IDD, there are few focused resources, and the primary care physician, a family physician, or an internist, is expected to provide continuing, comprehensive medical care. While these and other emerging models are excellent examples of innovative approaches to caring for persons with IDD, there are few well-designed studies underway to test their impact.

6. Training and Education for Providers

There are few national standards, and what happens in a specific medical school around the world often depends on the presence or absence of faculty, who advocate for IDD content. Recently, in Canada, the National Medical Examination (Medical Council) has included IDD in both child-focused and adult-focused "learning objectives" as an expectation in undergraduate medical education.

In residency or traineeships, whether curricular programmes of primary care or consulting specialties, there are no national expectations. One exception is found in the UK where in psychiatry a 3-year programme (after already a specialist in psychiatry) will result in the sub-specialty of learning disability (in the UK this is the term for intellectual disability). In Canada, there is one post-residency fellowship in family medicine, and developmental disabilities, each year at Queen's University. In the Netherlands, the only IDD specialty training programme anywhere is 3 years long and offered to graduate general practitioners (Rotterdam, 2010). It is a reality that graduates of medical school anywhere have no accreditation-required curriculum in IDD. It is also the case that, except for pediatrics generally and psychiatry in the UK, no general practice/ family medicine or consulting specialty post-graduate programme offers a core curriculum in IDD. Yet in all world countries including Nigeria, persons with IDD look to general practitioners/ family physicians for their continuing, comprehensive primary

medical care. Some medical schools in Nigeria are beginning to offer undergraduate curriculum content in IDD, usually found in psychology, psychiatry, or pediatrics programmes, and are often community-based.

7. Integration

In health care generally, there are many effective integrated models of care. There are, for example, bi-directional referral systems, the least integrated and perhaps more properly named collegial, created out of health care provider relationships with other providers who may be located in another part of the same building, across the street, or across town. Location does not drive the connection, but a working relationship with a mutual interest in the well-being of the patient drives the referral process. This approach can develop informally and simply arises from both providers' efforts to develop a referral network. Co-location of health providers within the same building or clinical so emerges as a step toward integrating care. Providers exchange information about the patients they have in common on an as-needed basis. Referrals commonly flow from the physician to the mental health provider when signs of the need for mental or behavioural health support are noted during a primary care visit. More fully integrated care includes having both the mental health provider and physician in the same room with the client at the same time, a co-visitation model. The efficacy of this approach is well-documented (Funderburk, 2010; Naar-King, 2013). As our understanding of the health needs and experiences of persons with IDD advances, we find value in integrating not just the many potential elements of acute health care, but also in linking acute with behavioural health, long-term service, and support systems, and the community-based social and developmental support structures of the person with IDD. It is important to note that while a person may access all of these elements, it is only when all are fully integrated that optimal health becomes achievable. This approach emphasizes the need for careful care coordination, beyond traditional nutritional services models, to include all major aspects of a person's life.

8. Nutritional services Delivery Systems

These integrated delivery systems are cooperative networks that connect nutritional services providers in a coordinated, vertical continuum of services to a specific patient population or community (Enthoven, 2019):

- i. Appointments are extended, usually lasting up to 60 minutes, to provide the supplier of nutritional services enough time to get to know the patient.
- ii. To accommodate patients with problems with sensory integration, natural, non-fluorescent lighting is used (Colman, 2006; Fenton, 2005).

- iii. Wheelchairs and other adaptive equipment can be accommodated in the larger examination room (up to 224 ft², 21m²), which also allows the patient to be accompanied by whatever many persons they feel comfortable with.
- iv. The clinic was created by, for, and for persons with IDD and offers a variety of customized equipment options, including "high/low" examination tables, four different types of scales, including wheelchair and "grab bar" scales, as well as pleasant and friendly reception room.

9. Standards and Quality of Care

Sullivan, et al. (2011) highlighted that primary care providers are often the most consistently available health professionals involved in caring for persons with IDD and in interacting with regular caregivers. Their contribution is vital for disease prevention, early detection, and appropriate management. They can help to assess the need for referral to specialized and interdisciplinary health services when these are available. They also provide continuity and coordination of care. Reliable guidelines, however, are required to inform primary care providers about the particular health needs of persons with IDD and the best approaches to management. As long ago as 2003, the Dutch Society of Physicians for Persons with Intellectual Disabilities began formulating basic standards of care for persons with IDD. The resulting manifesto "Basic Standards of nutritional services for persons with intellectual disabilities (Meijer, 2014), "outlines five criteria for nutritional services for persons with IDD: that persons with IDD will use mainstream health services, that health professionals will have competencies in IDD, that health professionals who are specialized in the specific health needs of individuals with IDD are available as backup to mainstream service providers, that a multidisciplinary approach is indicated, and that a proactive, preventive, and anticipatory emphasis be placed on the delivery of nutritional services for persons with IDD. These promising approaches to establishing standards of care are important steps; however, more needs to be done to expand them globally. We highlight Horwitz, et al., (2000), who 14 years ago, recommended that guidelines be established to ensure the quality of care and raise nutritional services provider competence and confidence in providing appropriate, responsive nutritional services to persons with IDD. Such guidelines should be developed with substantial input from persons with IDD and their families, physicians and other nutritional services providers, researchers, and other nutritional services delivery system stakeholders.

10. Finance for Nutritional Services

In "Closing the gap," one of six core objectives is a systematic assessment of nutritional services financing. That nutritional services financing is complex and unnecessarily complicated is apparently the only point on which everyone can agree. In the US, nutritional services spending and the health status of Americans are not correlated. From private and public funding sources, payments are made in

relation to particular procedures rather than as incentives for health outcomes. For persons with IDD in the US, who rely heavily on publicly financed nutritional services (Medicaid and Medicare), the situation is exacerbated by below-market reimbursements to nutritional services providers, which has resulted in fewer and fewer providers who will accept Medicaid and Medicare patients. This leaves persons with IDD with a dangerously constricting set of quality nutritional services options. Bersani and Lyman (Bersani, 2019) offer a thorough outline of US government programmes that support persons with disabilities and particularly on the programmes available to support access to nutritional services (pp. 98-102). A core element of these programs is Medicaid, a federally funded, state-managed system that pays for nutritional services on a fee-for-service basis. Persons with IDD are, in the vast majority, eligible for and widely enrolled in Medicaid. In other countries, nutritional services financing systems vary. In the UK, Canada, Israel, and most other industrialized nations, equal access to nutritional services is assured through government-controlled universal coverage health services. While this assures access, quality concerns remain. Private insurance, either as primary funders of nutritional services services (as in the US) or as a supplement to universal coverage schemes (as in Israel, for example), are not a guarantee of access for persons with IDD nor are they correlated to the quality of the nutritional services provided or outcomes achieved. In the last decade, laws have appeared in a number of US states to mandate minimum coverage under private insurance plans that offer greater access to nutritional services for persons, particularly children with IDD. This has resulted in mandatory private insurance coverage, for example, such as applied behaviour analysis for children with Autism. Furthermore, the US Patient Protection and Affordable Care Act requires that individual and small private insurance group plans cover “rehabilitative and habilitative services and devices,” benefits that have previously not been widely available under private insurance plans. These important expansions of covered services through public and private insurance are steps in the right direction for persons with IDD and their families.

Conclusion

In the mid-1970s, the American Association on Mental Deficiency declared that the presence of an intellectual disability “is no justification for permitting any human life to be terminated through the withholding of life-sustaining procedures” (American Association on Intellectual and Developmental Disabilities, 2016). The need for such a statement at all implies what we know historically, that persons with IDD experience extremely limited access to quality health-care. Today, we celebrate longer life spans of persons with IDD, increased attention to the benefits of nutritional services that is responsive to their needs, and the development of important nutritional services delivery systems that are customized to their needs.

We also know that the growing body of research on health status offers incentive to continue developing nutritional services structures for persons with IDD by training nutritional services providers about the needs of persons with IDD, by establishing systems of care that integrate acute nutritional services with long-term services and support, by developing IDD medicine as a specialty, and by building health promotion and wellness resources to provide persons with IDD a set of preventative health supports that did not exist 25 years ago. These and other important advancements in our understanding of the health status and nutritional services needs of persons across the lifespan can only be characterized, against the backdrop of the realities for persons with IDD in the mid-twentieth century, as extraordinary.

Suggestions

The following recommendations are made:

- i. Expanded and codified standards of care for persons with IDD and their families are required; these standards should take into account the specific nutritional needs of persons with IDD, incorporate the concepts of self-direction and self-determination, reflect the need for and benefits of integration, and address end-of-life and palliative care issues.
- ii. In addition, special education and medical schools need to develop and formalize training that emphasizes communication skills and clinical experience, and establish residencies and post-residency fellowships in IDD medicine. Other health professions educational programmes similarly need to strengthen the curricula of their programs to include developmental disabilities.
- iii. While developmental and neurodevelopmental pediatric specializations are recognized, there are essentially no choices for analogous adult-directed specialty development, and board certification should be established and made available for physicians who wish to specialize in IDD medicine.
- iv. To increase access to high-quality care, nutritional services delivery systems that build on current models and adopt novel strategies to meet the requirements of persons with IDD are required.
- v. Although significant progress has been made in this area (Nehring, 2015; Taggart, 2014), more needs to be done to develop health promotion, wellness, and disease prevention initiatives that target health challenges specific to persons with IDD.
- vi. There is enough evidence to conclude that persons with IDD experience health disparities, but more research is needed to understand the relationships between health status and quality of life, the systems of nutritional services delivery and health status, and the advantages of health promotion and disease prevention on health status.

We can ensure that the accessibility to high-quality nutritional services for everyone will be improved by building on recent previous successes, paying

attention to these recommendations, and making other necessary improvements in our approach to nutritional services for persons with IDD.

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