Position of the Academy of Nutrition and Dietetics: Nutrition Services for Individuals with Intellectual and Developmental Disabilities and Special Health Care Needs

ABSTRACT

It is the position of the Academy of Nutrition and Dietetics that nutrition services provided by registered dietitian nutritionists (RDNs) and nutrition and dietetics technicians, registered (NDTRs), who work under RDN supervision, are essential components of comprehensive care for adults with intellectual and developmental disabilities (IDD) and children and youth with special health care needs (CYSHCN). Nutrition services should be provided throughout life in a manner that is interdisciplinary, family-centered, community based, and culturally competent. Individuals with IDD and CYSHCN have many risk factors requiring nutrition interventions, including growth alterations (eg, failure to thrive, obesity, or growth retardation), metabolic disorders, poor feeding skills, drug-nutrient interactions, and sometimes partial or total dependence on enteral or parenteral nutrition. Furthermore, these individuals are also more likely to develop comorbid conditions, such as obesity or endocrine disorders that require nutrition interventions. Poor nutrition-related health habits, limited access to services, and long-term use of multiple medications are considered health risk factors. Timely and cost-effective nutrition interventions can promote health maintenance and reduce risk and cost of comorbidities and complications. Public policy for individuals with IDD and CYSHCN has evolved, resulting in a transition from institutional facilities and programs to community and independent living. The expansion of public access to technology and health information on the Internet challenges RDNs and NDTRs to provide accurate scientific information to this rapidly growing and evolving population. RDNs and NDTRs with expertise in this area are best prepared to provide appropriate nutrition information to promote wellness and improve quality of life.
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POSITION STATEMENT

It is the position of the Academy of Nutrition and Dietetics that nutrition services provided by registered dietitian nutritionists and nutrition and dietetics technicians, registered, who work under registered dietitian nutritionist supervision, are essential components of comprehensive care for all adults with intellectual and developmental disabilities and children and youth with special health care needs.

DEVELOPMENTAL DISABILITIES, including intellectual disabilities, are severe, lifelong disabilities attributable to mental and/or physical impairments manifesting before age 22 years and likely to continue indefinitely. They result in substantial limitations in three or more of the following areas: self-care, comprehension and language skills, learning, mobility, self-direction, capacity for independent living, economic self-sufficiency, and ability to function independently without coordinated services.[1] An intellectual disability is defined as a disability originating before age 18 years characterized by significant limitations in both intellectual function and in adaptive behavior.[1] Intellectual functioning refers to general mental capacity, including learning, reasoning, and problem solving. Adaptive behaviors comprise three skill areas: conceptual skills, social skills, and practical skills.[1]

The estimated total number of children and adults with intellectual and developmental disabilities (IDD) in the United States is approximately 1% to 3% (prevalence of 15.8 people per 1,000).[2] Of this, an estimated 600,000 to 1.6 million are elderly (aged 60 years or older) and this number is expected to grow to several million by 2030.[2]

Children and youth with special health care needs (CYSHCN) are "those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."[3] According to the 2009-2010 National Survey of CYSHCN, approximately 11.2 million children aged 0 to 17 years in the United States (15.1%) have special health care needs.[3]

The terms IDD and CYSHCN overlap but also diverge in a significant way. IDD encompass the lifespan, although the initial onset of the disability manifests

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itself during childhood. In contrast, CYSHCN is age-based, but includes a wider range of conditions, including IDDs, chronic diseases, health-related problems related to prematurity requiring extended follow-up, congenital defects, and medical issues that may be resolved through medical/surgical intervention by the time a child reaches adulthood.

The National Organization on Disability emphasizes that not all individuals with IDD use visible assistive devices, giving rise to terms like *invisible disability* and *hidden disability*. These disabilities can include hearing, cognitive, or psychiatric impairments or chronic, disabling diseases that may not be physically apparent.[4]

PUBLIC POLICY

In addition to private insurance, there are government programs, policies, and funding (Figure 1) available for individuals with IDD and CYSHCN that may provide coverage for medical nutrition therapy (MNT), enteral formula, or feeding equipment or cover the costs of support through therapy, nursing, or attendant care.

CHARACTERISTICS OF THE POPULATION, REVIEW OF SELECTED CONDITIONS, AND NUTRITIONAL RISK FACTORS

Life Expectancy

Improvements in medical care have led to increased life expectancy, with many CYSHCN and individuals with IDD living well into middle age and beyond. In addition to learning how to care for individuals who may experience early aging and worsening of cognitive and/or physical disabilities, chronic diseases must also be addressed in this population.[19]

The shift away from institution-based living toward home- and community-based living has changed how individuals access medical care, including MNT services.[20] The Center for Health Care Strategies Policy published a policy brief in 2012 recommending changes in provision of health care services in the rapidly changing health care environment.[21] Recommendations included lifelong planning for services and care, incorporating an individual's support network in decisions, and moving toward habilitation to maximize independence.[21]

Chronic Disease

Nearly 11 million individuals with IDD were enrolled in Medicaid (15% of total enrolled) during fiscal year 2011.[12] Medical expenses for Individuals with IDDs were disproportionate compared to the rest of the enrollees; that is, their expenses totaled 41% of Medicaid expenditures that year.[12] As people with IDD and CYSCHN age and become dually eligible for Medicaid and Medicare, the combination of cognitive and physical disabilities will significantly increase their medical expenditures; therefore, identifying new strategies emphasizing prevention and early treatment of comorbidities can help maximize future cost benefits.[22] An increased lifespan, along with the onset of chronic diseases such as coronary heart disease, diabetes mellitus, obesity, and hypertension will further increase the health care costs in this population.[22] This trend is not only noted in older individuals; there has also been a notable increase in hypertension, diabetes mellitus, and obesity in adolescents identified as CYSHCN.[23] The increased emphasis on preventive services, wellness promotion, disease prevention, and management of chronic disease with the passage of the Affordable Care Act (ACA) has the potential to give registered dietitian nutritionists (RDNs) additional opportunities to provide MNT in both individual and group settings.[22]

Figure 2 presents examples of nutrition diagnoses seen in selected syndromes and disabilities in individuals with IDD and CYSHCN. The Nutrition Care Process[24] was developed by the Academy of Nutrition and Dietetics to establish a standardized process of providing care, and to improve the quality and consistency of individualized care for clients. There are four steps to the process: nutrition assessment, nutrition diagnosis, nutrition intervention, and nutrition monitoring/evaluation. The nutrition diagnosis classifies and describes the nutrition problem that will require intervention from an RDN and nutrition and dietetics technician, registered (NDTR) (under RDN supervision). Figure 2 includes examples of nutrition diagnoses an RDN might use when working with this population; however, it is not exhaustive.

NUTRITION-RELATED ISSUES IN INDIVIDUALS WITH IDD AND CYSHCN

Oral Health Care

Individuals with IDD and CYSHCN have significant oral health care problems, including gingivitis, periodontitis, and caries[35]; however, complicating factors for treatment include significant difficulties in accessing care due to reimbursement, transportation, behavior issues, and lack of providers with expertise working with individuals with IDD and CYSHCN. Risk factors for poor oral health in this population include dependency on others for oral hygiene; oral aversions; dry mouth or gingival overgrowth as a medication side effect; a history of dysphagia; prolonged bottle feeding (in CYSHCN); or consumption of a liquid, puréed, or gastrostomy diet.[36] Oral health risk factors are important for the RDN to consider when performing nutrition assessments in this population.

Mealtime Assistance

Individuals may require a range of mealtime support: from minimal, such as cutting up food, to full support by a caregiver assisting with or providing a feeding, whether it is oral or enteral. A study by Ball and colleagues[37] found that as individuals with IDD got older, half required increasing levels of support at mealtimes, with 82% of individuals needing moderate to full support at mealtimes, and only 18% needing a small amount of support such as adaptive equipment or setting up a plate. The authors recommended including the individual and his or her caregivers when developing an interdisciplinary plan of care to address all aspects of mealtimes. Research has also found that individuals with dementia-associated dysphagia of Down syndrome and those with more severely involved cerebral palsy with limited mobility required more assistance at mealtimes.[37,38] RDNs should work with speech language pathologists and occupational therapists to include details such as texture modifications, pacing, encouragement, positioning, and behavior modifications in the feeding plan of care and work with caregivers to ensure and reinforce understanding.