

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 IDD, 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 CYSHCN 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 Process²⁴ 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 caries³⁵; 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 colleagues³⁷ 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.

Program and background	Population served	Role of RDNs and/or nutrition-related services that may be offered and/or provided
2004 Individuals with Disabilities in Emergency Preparedness Executive Order ⁵	IDD and CYSHCN	RDNs may be involved in ensuring individuals with IDD and their families have a plan in place for disasters and emergency situations, including adequate food, water, enteral and parenteral nutrition, and supplies.
Child Health Act of 2000 ⁶ created the National Center for Birth Defects and Developmental Disabilities within the Centers for Disease Control and Prevention and the Healthy Start Initiative. Expanded state surveillance, national education, and prevention through the Centers for Disease Control and Prevention. National Institutes of Health authorized to perform research on cognitive disorders and neurobehavioral consequences.	CYSHCN up to age 21 y	RDNs involved in research
Child Nutrition and WIC ^a Reauthorization Act of 2004, Section 204 ⁷	Children aged 0-5 y are eligible for WIC services based on need Children in kindergarten through 12th grade are eligible to participate in the school wellness programs	WIC provides formula and food packages in addition to nutrition assessment, education, and counseling, for children based on need. This law mandates local school wellness programs to help increase physical activity and improve nutritional intake in an effort to reduce childhood obesity RDNs involved in school menus, wellness programs.
CYSHCN Program; Title V of the Maternal and Child Health Program ⁸	CYSHCN	RDN consultation services for MNT. ^b Other covered services may include enteral formula, enteral feeding supplies, feeding equipment, nutritional supplements, and thickener.
Early Periodic Screening, Diagnosis, and Treatment Program. ⁹ Children and adolescents receive preventive dental, mental health, developmental, and specialty services and referrals	Children younger than age 22 y who qualify for Medicaid, including CYSHCN	Services covered under Medicaid found to be medically necessary to treat, correct, or reduce any conditions or illnesses found during screening are required to be covered. This may include RDN consultation services for MNT, based on state definitions of medically necessary services.

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Figure 1. Programs and services available for individuals with intellectual and developmental disabilities (IDD) and children and youth with special health care needs (CYSHCN) and the role of registered dietitian nutritionists (RDNs). ^aWIC=Women, Infants, and Children. ^bMNT=medical nutrition therapy.

Program and background	Population served	Role of RDNs and/or nutrition-related services that may be offered and/or provided
Early intervention authorized by Part C of the Individuals with Disabilities Education Act. ¹⁰ Services address developmental needs of children aged 0-3 y with disabilities. Includes transition planning to preschool programs for ages 3-6 y if CYSHCN are eligible.	CYSHCN aged 0-3 y States have the option to provide services for children older than age 3 y or add additional criteria to include at risk children	RDN consultation services for MNT provided in a home-based environment.
The Individuals with Disabilities Education Act ¹¹ for children and youth (aged 3-21 y) requires free, appropriate public education in the least restrictive environment appropriate to each child's needs, regardless of their disabilities. Schools are required to develop Individualized Education Programs for each child to outline specific educational and related services needed.	CYSHCN	Goals related to nutrition therapy, feeding support, feeding therapy, or other nutrition-related goals may be included in Individualized Education Programs.
Medicaid, Title XIX of Social Security Act. ¹² Individual states administer Medicaid under federal guidelines. The Affordable Care Act ¹³ has allowed states to choose to expand Medicaid.	Low-income and medically eligible individuals	Covered services may vary by state. RDN consultation services for MNT may include medical care, enteral formula, enteral feeding supplies, feeding equipment, nutritional supplements, and thickener.
Olmstead vs L.C. ruling, US Supreme Court, 1999 ¹⁴ New Freedom Initiative 2001	IDD and CYSHCN	Adults with IDD were transitioned to community-based living from institution-based living. RDN involvement in implementation of MNT in community-based group homes, menu planning, and staff and client training.
The Patient Protection and Affordable Care Act of 2010 ¹³ expands private health insurance options and provides individual states the option to expand Medicaid with the goal of universal coverage. Medicaid-Medicare Coordination Office created to coordinate care for individuals eligible for both programs (commonly referred to as duals, individuals with multiple chronic conditions, such as developmental and physical disabilities, and very low income) to help streamline care and reduce costs.	IDD and CYSHCN	The Community First Option has been expanded to offer services for individuals who would otherwise live in an institution without services. Attendant services may be provided for activities that can include instrumental activities of daily living, such as grocery shopping. Items needed by an individual to set up a new home when moving from an institution into community living may also be provided. There is potential for increased RDN involvement in all areas, such as preventive services, wellness promotion, disease prevention, and management of chronic disease.
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Figure 1. *(continued)* Programs and services available for individuals with intellectual and developmental disabilities (IDD) and children and youth with special health care needs (CYSHCN) and the role of registered dietitian nutritionists (RDNs). ^aWIC=Women, Infants, and Children. ^bMNT=medical nutrition therapy.

Program and background	Population served	Role of RDNs and/or nutrition-related services that may be offered and/or provided
Project Head Start ¹⁵ federally funded preschool program	Low-income children aged 3-5 y. 10% of national enrollment targeted to serve CYSHCN	Provides nutrition services to preschool children from low-income families, including family education and nutrition screening.
State Children's Health Insurance Program, ¹⁶ Title XXI of the Social Security Act, to provide insurance for children in families whose income exceeded Medicaid limits and could not afford private health insurance. States design their own programs under federal guidelines.	Children	Covered services may vary by state and may include nutritional supplements, enteral formula, enteral feeding supplies, thickener, and recreational activities to increase activity level.
US Department of Agriculture National School Lunch Program ¹⁷ Healthy, Hunger-Free Kids Act of 2010 ¹⁸	CYSHCN	Alternate meal choices must be made available for CYSHCN with medical or other dietary needs (including food allergies) by schools if a child cannot eat the school breakfast or lunch. A physician's order must be provided for the alternate dietary requirements. RDNs at district or school level will assist school/families to develop procedures to safely prepare and serve alternate meal choices, including reading labels. Requires local wellness policy implementation, including nutrition promotion, nutrition education, physical activity, and other wellness promotion activities.

Figure 1. (continued) Programs and services available for individuals with intellectual and developmental disabilities (IDD) and children and youth with special health care needs (CYSHCN) and the role of registered dietitian nutritionists (RDNs). ^aWIC=Women, Infants, and Children. ^bMNT=medical nutrition therapy.

Dysphagia

Factors that may influence an individual's nutritional status, such as food aversions, oral motor problems, food allergies, and dysphagia are important to include in MNT provided by RDNs or NDTRs (under RDN supervision) who can educate caregivers and train them to recognize signs and symptoms of dysphagia that may be observed during mealtimes.³⁸ Monitoring weight records for unintended weight changes can indicate onset or worsening of dysphagia, because the individual may be unable to consume adequate intake to maintain or gain weight. In an aging population, a stroke

or the onset of dementia can result in or exacerbate dysphagia.³⁸

An interdisciplinary team evaluation of dysphagia can provide information on an individual's safety for oral feedings that can be incorporated into the plan of care.³⁹ When there is no evidence of aspiration on a videofluoroscopic swallow study and oral feedings are safe, an RDN and NDTR may work in collaboration with therapy providers (eg, speech, language, and occupational therapists) and caregivers to implement the plan of care. Texture modifications, thickening liquids, oral nutritional supplements, or self-feeding equipment may all be included in a plan of care to help an individual

maximize feeding independence when safe to do so. RDNs determine appropriate food choices that follow the dysphagia recommendations and educate the individual and/or caregivers to implement the plan. RDNs may review and discuss enteral feeding options with individuals with IDD, CYSHCN, their families, and/or their caregivers when oral feedings are not safe.

In CYSHCN, possible signs of dysphagia and feeding problems include very prolonged feeding times, not self-feeding when developmentally expected to, food refusal, frequent vomiting, respiratory distress as a meal progresses, irritability during meals,

Syndrome or developmental disability	Nutrition diagnosis	Etiology and/or signs and symptoms
<p>^aASD</p> <p>ASD is a group of developmental disabilities that are characterized by delayed speech and language development, ritualistic or repetitive behaviors, and impairments in social interactions. Individuals may also have delays in feeding skills and the ability to self-feed.²⁵</p>	Inadequate energy intake	Limited food choices Medication side effects affecting appetite
	Limited food acceptance	Sensory processing issues Avoidance of foods/food groups
	Inadequate intake of calcium/vitamin D/iron/other nutrient(s)	Limited food choices; avoidance of foods/food groups Complementary and alternative medicine treatments, such as vitamin B-6 supplements, following a gluten-free, casein-free diet may place child at risk for nutrient deficiencies ²⁶
	Underweight	Inadequate energy intake BMI ^b <5th percentile for children aged 2-20 y Medication side effects affecting appetite Limited food choices secondary to behaviors
	Overweight/obesity	BMI >85th percentile for children aged 2-20 y Use of food for behavioral interventions Estimated excessive energy intake Medication side effects affecting appetite Sedentary activity level Limited food choices that are excessive in calories
<p>Cerebral palsy</p> <p>A nonprogressive disorder of muscle control or coordination that affects different parts of the body. This results from an injury to the brain during fetal, perinatal, or early childhood development. The severity is variable. Intellectual disability is often present.²⁷</p>	Increased energy expenditure	Unintended weight loss
	Excessive energy intake	Increased body adiposity Reduced energy expenditure secondary to treatment with medication to reduce muscle tone Hypotonia Weight gain greater than expected Changes in mobility status Enteral nutrition provides more calories than measured/estimated energy expenditure
	Inadequate oral intake	Unintended weight loss Inability to self-feed due to lack of coordination Poor dentition, presence of cavities, and/or abscesses Gastroesophageal reflux disease Oral motor dysfunction/dysphagia Medications affecting appetite Failure to thrive Malnutrition
	Inadequate fluid and fiber intake	Constipation Inability to independently consume fluid and food Dysphagia

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Figure 2. Common nutrition-related issues in individuals with intellectual and developmental disabilities and children and youth with special health care needs with suggested nutrition diagnosis terms. Adapted from Figure 1 of 2010 Academy position on developmental disabilities and special health care needs and references 24 and 26. ^aASD=autism spectrum disorder. ^bBMI=body mass index. ^cGI=gastrointestinal.

Syndrome or developmental disability	Nutrition diagnosis	Etiology and/or signs and symptoms
		Altered thirst sensation, inability to communicate thirst
	Swallowing difficulty	Abnormal swallow study showing aspiration and/or oral/pharyngeal dysphagia Coughing, choking, prolonged chewing, pocketing of food, regurgitating, and facial expression changes during eating Reduced food intake Unintended weight loss Prolonged feeding times, lack of interest in food, food avoidance, mealtime resistance
	Altered GI ^c function	Constipation Gastroesophageal reflux disorder, delayed gastric emptying Medication side effects
	Food—medication interactions	Constipation related to antispasticity medications Increased risk of osteopenia/osteoporosis related to antiseizure and antigastroesophageal reflux disease medications Risk of B-12 deficiency related to antigastroesophageal reflux disease medications
	Underweight	BMI <5th percentile/age in children aged 2-20 y Reduced muscle mass, muscle wasting Inadequate energy intake to promote weight gain compared to estimated or measured needs Hypertonia, dystonia
	Overweight	BMI >85th percentile/age for children aged 2-20 y Excessive energy intake Sedentary activity level Hypotonia
Cystic fibrosis An inherited disorder of the exocrine glands, primarily the pancreas, pulmonary system, and sweat glands, characterized by abnormally thick luminal secretions. Blockages in the pancreas prevent pancreatic enzymes from being available for digestion of	Increased energy expenditure	Unintended weight loss Malnutrition
	Inadequate fat soluble vitamin intake	Reduced vitamin levels
	Altered GI function	Abnormal digestive enzyme and fecal fat studies Growth stunting or failure
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Figure 2. (continued) Common nutrition-related issues in individuals with intellectual and developmental disabilities and children and youth with special health care needs with suggested nutrition diagnosis terms. Adapted from Figure 1 of 2010 Academy position on developmental disabilities and special health care needs and references 24 and 26. ^aASD=autism spectrum disorder. ^bBMI=body mass index. ^cGI=gastrointestinal.

Syndrome or developmental disability	Nutrition diagnosis	Etiology and/or signs and symptoms
fats and proteins, leading to poor weight gain and growth as a result of malabsorption. ²⁸		Evidence of vitamin and/or mineral deficiency Steatorrhea Constipation Gastroesophageal reflux disease
Drug exposed and fetal alcohol spectrum disorders Physical, behavioral, mental, or learning disabilities that occur when a fetus is exposed to drug and/or alcohol during development. Growth may also be affected. ²⁹	Food–medication interaction	Side effects of medications affecting appetite
	Overweight/obesity	BMI >85th percentile for children aged 2-20 y Estimated excessive energy intake Sedentary activity level
	Self-monitoring deficit	Altered self-regulation Overweight/obesity Underweight
Down syndrome A genetic disorder that results from an extra chromosome 21, resulting in developmental problems such as congenital heart disease, cognitive delay, short stature, gastrointestinal problems, and decreased muscle tone. ³⁰	Inadequate oral intake	Dementia Swallowing difficulty Unintended weight loss
	Breastfeeding difficulty	Feeding difficulty with weak suck Poor weight gain
	Altered GI function	Constipation (related to hypotonia, low activity, and/or low fiber intake) Celiac disease ³¹
	Overweight/obesity	Increased body adiposity Estimated excessive energy intake Reduced energy needs related to hypotonia BMI >85th percentile/age for age 2-20 y
Genetic or inherited metabolic disorders Genetic conditions that result in a deficiency or defective enzyme in a metabolic pathway. Some of these, such as phenylketonuria, can result in significant lifetime intellectual and developmental disabilities. Others can cause death if not properly treated.	Imbalance of nutrients Impaired nutrient utilization Altered nutrition-related laboratory values	Food and nutrition knowledge deficit of dietary changes related to new diagnosis Nutrient restriction due to metabolic disorder
	Unintended weight loss	Poor appetite due to metabolic disorder Inadequate energy intake Lack of adequate insurance coverage for low protein foods/special metabolic formulas, limited access to formula Food and nutrition knowledge deficit of dietary changes related to new diagnosis
	Unintended weight gain	Excessive energy intake
Orofacial Cleft A birth defect that occurs when the lip and/or the roof of the mouth does not form or close	Swallowing difficulty	Abnormal swallow study showing aspiration and/or oral/pharyngeal dysphagia Inadequate oral intake Frequent respiratory infections/pneumonias

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Figure 2. *(continued)* Common nutrition-related issues in individuals with intellectual and developmental disabilities and children and youth with special health care needs with suggested nutrition diagnosis terms. Adapted from Figure 1 of 2010 Academy position on developmental disabilities and special health care needs and references 24 and 26. ^aASD=autism spectrum disorder. ^bBMI=body mass index. ^cGI=gastrointestinal.

Syndrome or developmental disability	Nutrition diagnosis	Etiology and/or signs and symptoms
properly, resulting in a cleft lip and/or cleft palate. ³²		Coughing/choking with foods/liquids Cleft lip/cleft palate
	Breastfeeding difficulty	Inability to form proper latch Inadequate oral intake
	Underweight	Inadequate energy intake Increased energy expenditure
Prader-Willi syndrome A genetic disorder resulting from a deletion in chromosome 15. Hypotonia in infancy can result in failure to thrive before onset of hyperphagia. Common medical issues include obesity as a result of hyperphagia; short stature, and varying levels of intellectual abilities. ³³	Breastfeeding difficulty Inadequate oral intake	Feeding difficulty with weak suck Poor weight gain
	Excessive energy intake Overweight/obesity	Increased body adiposity BMI >85th percentile/age at age 2-20 y Reduced energy needs Self-monitoring deficit
	Limited adherence to nutrition-related recommendations	Inability to limit or refuse foods offered Lack of social support for implementing changes
	Undesirable food choices	Intake inconsistent with diet quality guidelines Unable to independently select foods consistent with food quality and energy controlled guidelines
	Intake of unsafe food	Food obsession Hyperphagia Eating serves a purpose other than nourishment Pica
Spina bifida (myelomeningocele) A neural tube defect resulting from incomplete closure of the spine during early pregnancy. This results in nerve damage, including neurogenic bowel/bladder and paralysis. Other common medical issues include Arnold Chiari II malformation, hydrocephalus, growth hormone deficiency, and learning differences. ³⁴	Increased protein needs	Chronic, nonhealing wounds
	Swallowing difficulty	Abnormal swallow study showing aspiration and/or oral/pharyngeal dysphagia Frequent respiratory infections/pneumonias Coughing/choking with foods/liquids Presence of Arnold Chiari II malformation of the brain
	Altered GI function	Low fluid and fiber intake Neurogenic bowel Constipation
	Overweight/obesity Unintended weight gain	Increased body adiposity BMI >85th percentile/age for age 2-20 y Estimated excessive energy intake Self-monitoring deficit Limited mobility Reduced energy needs related to altered body composition, short stature

Figure 2. (continued) Common nutrition-related issues in individuals with intellectual and developmental disabilities and children and youth with special health care needs with suggested nutrition diagnosis terms. Adapted from Figure 1 of 2010 Academy position on developmental disabilities and special health care needs and references 24 and 26. ^aASD=autism spectrum disorder. ^bBMI=body mass index. ^cGI=gastrointestinal.

frequent gagging and/or coughing, and poor nutritional status.³⁹ Closely monitoring growth records and trends in CYSCHN can indicate overall adequacy of energy intake to promote growth velocity and prevent weight loss.

Enteral Feedings

Any individual with IDD or CYSCHN who has significant dysphagia with aspiration or who is unable to maintain appropriate weight or hydration with oral feedings can benefit from enteral feedings. Anthropometric measurements, enteral feeding provision, and tolerance are closely monitored by RDNs to make necessary adjustments to prevent overfeeding or underfeeding. RDNs ensure individuals with IDD, CYSCHN, and caregivers are involved in planning the enteral feeding schedule and trained on how to implement enteral feedings and troubleshoot problems with enteral feedings.

Medication Use

Polypharmacy. As individuals with IDD age and develop multiple comorbidities, multiple medications may be prescribed by several medical providers. A study by Hobdon and colleagues⁴⁰ found an increased risk of polypharmacy in individuals with a dual diagnosis of IDD and a psychiatric diagnosis than in those without a psychiatric diagnosis. Sixty-two percent of the study participants⁴⁰ had a dual diagnosis, and almost one-half of the study participants were taking two or more psychotropic medications. RDNs should review the medication list of all individuals with IDD and CYSCHN, evaluate the nutrition-related implications of the medication regimen, and recommend any necessary changes such as adjusting timing of psychotropic medications to reduce effects on appetite.⁴¹

Food-Drug Interactions. Many individuals with IDD take multiple medications for treatment of chronic conditions for extended periods of time, increasing the risk of drug–nutrient interactions. Drug–nutrient interactions are commonly seen with use of anticonvulsants, stimulant medications, medications for treatment of gastroesophageal reflux disease, and antipsychotics. Studies have shown that long-term use of antiepileptics in CYSCHN and adult women with IDD⁴²

can affect bone metabolism and lead to a higher fracture risk. Stimulant medications can interfere with appetite, slowing down the rate of growth and weight gain in children and resulting in weight loss or failure to gain appropriate weight in adults.⁴³ Gastric pH is altered by medications to treat gastroesophageal reflux disease, which may result in small bowel bacterial overgrowth (eg, bloating, flatulence, and diarrhea), vitamin B-12 deficiency, or increased risk of fractures when taken for more than 1 year.⁴⁴ Motility medications (eg, bethanecol chloride, erythromycin, and metoclopramide) can alter digestion and the absorption rate of nutrients and medications. Finally, antipsychotic and tricyclic antidepressant agents for depression and behavior issues can cause dry mouth, taste changes, nausea, vomiting, and increased appetite and weight gain.⁴⁵ RDNs will recognize potential drug–nutrient interactions, optimize micronutrient intake, and monitor for vitamin and mineral deficiencies when indicated and recommend replacement supplements if necessary.

Wellness

Recommendations for wellness and disease prevention for individuals with IDD and CYSCHN are similar to those for the general population (eg, physical activity, nutrition, access to health care, clinical preventive services, dental care, mental health, and family care giving). Healthy People 2020 (www.healthypeople.gov) is a comprehensive set of national public health objectives that include:

1. eliminating preventable disease, disability, injury, and premature death;
2. achieving health equity and eliminating health disparities;
3. creating social and physical environments that promote good health for all; and
4. promoting healthy development and healthy behaviors at every stage of life.

Furthermore, the following objectives were included for people with IDD, stating that people with IDD should:

- be included in public health activities,
- receive well-timed interventions and services,

- interact with their environment without barriers, and
- participate in everyday life activities.

Without these opportunities, individuals with IDD and CYSCHN will continue to experience health disparities compared with the general population. It is important to utilize RDNs and NDTRs (under RDN supervision) to help meet these objectives.

Other groups are working to improve health care in wellness. The Centers for Medicare and Medicaid Services have set forth a health care reform initiative referred to as the triple aim: improving health care experience, improving health outcomes, and reducing cost.⁴⁶ Individuals with disabilities and special health care needs are at high risk for comorbidities, resulting in poor outcomes and increased health care costs. Care provided throughout the lifespan, beginning at birth, by an RDN is essential to accomplish the objectives set forth in the triple aim.

PEDIATRICS

Nutritional Risk Factors

Altered physical growth rate and body composition are often seen in CYSCHN. The prevalence of obesity in CYSCHN is almost twice that of the general population, because nearly half of adolescents with autism spectrum disorder (ASD) and Down syndrome are overweight, and 25% with ASD and 31% with Down syndrome are obese.²³ In most CYSCHN, these rates of obesity are often attributed to poor eating habits and low levels of physical activity. In children with Down syndrome these rates may also be attributed to limited mobility, short stature, and reduced muscle mass. Only one-third of CYSCHN participate in physical activity regularly.⁴⁷ Overweight and obesity, as well as short stature, limited mobility, and inappropriate eating practices such as pica, are often seen in individuals with Prader-Willi syndrome. The use of growth hormone has improved linear growth and final adult height, as well as improvements in body composition, with few side effects in individuals with Prader-Willi syndrome.⁴⁸ Because there are currently no recommendations specifically for overweight/obese individuals with CYSCHN, RDNs working with this

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Figure 3. Current resources that provide detailed, peer-reviewed information for registered dietitian nutritionists and nutrition and dietetics technicians, registered, working with individuals with intellectual and developmental disabilities and children and youth with special health care needs.

population may use evidence-based protocols for typically developing youth, such as those included in the Academy of Nutrition and Dietetics Evidence Analysis Library (www.andevidencelibrary.com) to promote appropriate growth velocity and prevent excess weight gain. In CYSHCN, these protocols need to be individualized, because CYSHCN may require specialized care. RDNs will work toward finding the best strategies to promote proper growth and prevent excess weight gain in CYSHCN.

On the opposite side of the weight spectrum, underweight can be a significant risk factor for some CYSHCN, for instance those with Rett syndrome, cerebral palsy, and cystic fibrosis.⁴⁹ Guidelines by Mehta and colleagues⁵⁰ present a method of defining and classifying pediatric malnutrition, including the use of z score changes for anthropometric measurements to more accurately assess growth below the fifth percentile for age. CYSHCN may meet the criteria for chronic, moderate-to-severe malnutrition due to their underlying diagnosis if their z scores are -2 or lower.⁵⁰

Advances in Genetics/Genomics and Neonatology that Affect IDD

The field of genetics has evolved rapidly since the completion of the Genome

Project in 2003. During the past decade, advances in genetic research have enabled genome-wide discovery of chromosomal copy-number changes and single-nucleotide changes in persons with IDD and CYSHCN (www.ncbi.nlm.nih.gov/About/primer/genetics_cell.html). Chromosome microarray analysis, recommended as a first-line test in the genetic workup of children with developmental delays, ASD, or congenital anomalies, provides a molecular diagnosis in 15% to 20% of cases.⁵¹ As the data from genomic research continues to accumulate, the understanding of genes, pathways, and molecular mechanisms will continue to evolve and translate into better diagnosis, prognosis, and therapies—including MNT—for these developmental disabilities. RDNs may be involved in many of these endeavors.

Neonatology is a specialty area of medicine and nutrition that deals with the medical care of newborn infants, particularly ill or premature newborns. According to the March of Dimes, the 2013 rate of preterm births in the United States was 11.5%, 2% higher than its goal.⁵² The high rate of premature births and the increased survival of low-birth-weight infants results in more babies with emergent needs as critically ill newborns, as well as developmental delays. Preterm birth is a leading cause of death in the first months of life, and infants who survive

have an increased risk of serious health problems such as pulmonary/respiratory problems, feeding difficulties, temperature instability, jaundice, delayed brain development, and an increased risk of IDD and other disabilities.⁵³ RDNs must closely monitor growth velocity in premature infants. The Centers for Disease Control and Prevention recommend adjusting for gestational age up to age 36 months for premature infants.⁵⁴ Many premature infants are seen in specialty follow-up clinics for monitoring of growth and development and management of chronic conditions. RDNs can work with medical providers as part of an interdisciplinary team, including RDNs working in early intervention, to provide MNT as part of long-term follow-up at all levels of care.

Select Issues for CYSHCN

Frequently encountered issues in nutrition assessment are specialty measuring techniques/equipment, specialized growth charts, and sensory processing or food selectivity issues. Instructions on special measuring considerations and equipment, as well as specialty growth charts, are available from the Health Resources and Services Administration (<http://depts.washington.edu/growth/>). Specialty growth charts are available for some diagnoses; however, their use in

nutrition assessment remains controversial, because most were developed using small populations with old or retrospective data and do not include all growth parameters. The American Academy of Pediatrics recommends using growth charts from the World Health Organization for children younger than age 2 years and the Centers for Disease Control and Prevention for children older than age 2 years, for all children with or without disabilities. The expectation is to have each child grow at his or her own potential and follow his or her own growth curve, even if it is below the curve. RDNs monitor the growth curves and use this information in their assessment of a child.

CYSHCN can be highly selective eaters, with very restricted repertoires of food acceptance. Food selectivity and concerns about dietary adequacy are common reasons to refer children for nutrition services.⁵⁵ Although various factors can contribute to food selectivity, sensory processing disorder is common in CYSHCN. Sensory processing disorder is an under- or over-reaction to certain experiences of touch, smell, taste, sound, and sight, often resulting in an observable aversion or negative behavioral response to certain stimuli. Sensory sensitivity may contribute to difficulty with food textures, frequently seen in children with ASD.⁵⁵ It is important that RDNs and NDTRs (under RDN supervision) identify any food aversions or sensory sensitivities and work with the individuals, their care givers, and other health professionals to slowly overcome these aversions or find ways to provide an acceptable and nutritionally adequate diet.

Successful transition from the pediatric systems of health care to the adult systems is important because individuals between ages 16 and 21 years often become ineligible for the services that they have used and depended on throughout life. Successful transition is one of the outcomes used to measure success of community-based systems of care for CYSHCN.⁸ However, in the 2009–2010 National Survey of Children with Special Health Care Needs, only 40% of CYSHCN met the core performance outcome for transition to adult care, with loss of health insurance reported as a primary factor in failing to meet the performance outcomes.⁵⁶ However, the implementation of the

ACA and the end to preexisting condition discrimination and lifetime caps on benefits means individuals with IDD and CYSHCN will have more options for quality health insurance.⁵⁶

ADULTS

Weight Status

As adults with IDD have left institutional care to live in group homes or supported living arrangements, they have adopted the physical activity and dietary intake characteristics of the general population, and in turn, have shown increasing rates of overweight and obesity.⁵⁷ The prevalence of obesity in adults with IDD is approximately twice that in the general population.⁵⁸ These high rates of obesity combined with lower levels of fitness and poor diet quality result in an increased risk of heart disease, diabetes, and hypertension.⁵⁹ Furthermore, overweight and obesity in individuals with IDD can place an extra demand on caregivers when an individual is dependent on physical assistance for activities of daily living.⁵⁷ The prevalence of obesity is a major health problem that requires further research from individuals, including RDNs working with this population. Evidence-based protocols for weight management, such as those included in the Academy of Nutrition and Dietetics' Evidence Analysis Library should be used, which include reduction in energy intake for weight maintenance, daily aerobic exercise, food monitoring procedures, and an interdisciplinary approach for behavior modification. However, as in adolescents, these protocols need to be individualized for each person with IDD, particularly with diagnoses such as Prader-Willi syndrome, cerebral palsy, and spina bifida. Furthermore, RDNs should consider factors such as age, disease state, body composition, mobility status, and diagnoses when determining appropriate weight goals for persons with IDD.

Although not as prevalent, some adults with diagnoses such as cerebral palsy and Rett syndrome, and those who have developed Alzheimer disease, are at risk for being underweight.⁶⁰ Mobility impairment and underweight status are two factors that increase risk for pressure ulcers, specific nutrient deficiencies due to inadequate intake, and further weight loss

if ill and unable to eat. The Academy of Nutrition and Dietetics' Evidence Analysis Library has protocols for unintended weight loss in older adults and wound care that may be used as a guide for the RDN when individualizing the plan of care; however, these protocols are not specific for persons with IDD.

Unique Issues for Nutrition Assessment

Two frequently encountered issues in nutrition assessment for adults are collection of dietary intake data and determining energy needs. Although the need for nutrition assessment and monitoring is high in adults with IDD, there are inherent challenges in collecting dietary intakes data due to compromised cognitive functioning, poor memory, and a shortened attention span.⁵⁷ Due to the significant barriers in collecting valid data, there is not a validated method for dietary assessment in adults with IDD, although research suggests that the use of proxy-surrogate or digital imagery may improve dietary recall for analysis.⁵⁷

Assessing nutrition and energy requirements is challenging because the nutrition and energy requirements vary depending on the disability diagnosis, the severity of the disability, mobility status, age, medications, and feeding problems. When determining energy requirements, RDNs may individualize the requirements based on all of these considerations, as well as monitor the individual and make changes to the plan of care as needed.

Special Considerations for Adults with IDD

RDNs and NDTRs who work with adults with IDD should be aware of challenges that affect that person's nutritional status, such as high levels of food insecurity due to lack of financial support; higher rates of medical and functional problems at age 50 years or younger, including dementia and Alzheimer disease; and the need for specialized diets.^{61,62} Furthermore, RDNs and NDTRs need to consider each individual's living situation, because many adults with IDD live in group homes or have live-in caregivers and may have less control over their available food choices.

CONSUMER AND HEALTH CARE TRENDS

Services Received

The Individuals with Disabilities Education Act¹¹ requires that students with IDD be educated to the maximum extent possible with students who do not have IDD (ie, mainstreamed); however, many students remain in special education classrooms and are educated by special education teachers and related personnel. As students transition out of adolescence, the Individuals with Disabilities Education Act requires schools to provide transition services to adulthood to prepare for continuing education and/or employment.

Adult services vary by state policy and are typically provided by state funded agencies. Services provided may include community-based day services, adult training facilities, supported housing, and in-home support.

Medical Home

A patient-centered medical home is a cultivated partnership between the patient, family, and primary provider in cooperation with specialists and support from the community. The patient/family is the focal point of this model and the medical home is built around the patient/family.⁶³ In a medical home, individuals and families can expect that physicians and staff will know and remember them; respect their ideas, customs, and beliefs; and help them coordinate care and information among multiple professionals and services.⁶² RDNs and NDTRs who work with individuals with IDD and CYSHCN, and who are not affiliated with that individual's medical home provider, may obtain necessary releases of information to ensure that MNT provided is part of coordinated and effective care provided for each individual. The Academy of Nutrition and Dietetics has resources for involvement of RDNs in patient-centered medical homes (<http://www.eatright.org/pcmh/>).

Technology for Teaching

Computer technology is increasing in the education of individuals with IDD. Computers have been successfully used in education and training for individuals with IDD across the age

spectrum, as well as a communication device for those individuals who have hearing and speech impairments.⁶⁴ For example, computers, tablet computers, and smart telephones have been used to teach individuals with IDD and CYSHCN to communicate, identify and write numbers, understand emotional expression and improve social skills, perform daily life skills, and monitor their physical activity and diet intake.^{64,65}

COMPONENTS OF COMPREHENSIVE NUTRITION SERVICES

Nutrition Services

RDNs are responsible for the nutrition assessment of individuals with IDD and CYSHCN. Assessment is multifactorial, including a review of medical diagnoses, anthropometrics, nutrition-focused physical exam, biochemistries, clinical data, dietary intake, feeding skills, functional abilities, cognitive skills, environmental factors, social factors, and economic resources. This thorough assessment is used to determine nutrition diagnoses and develop intervention plans. Services may be provided, depending on local and state regulations, in a variety of settings, including a family home; school; day program; group home; intermediate care facility; or any other type of living, social, or health care environment. This population requires RDNs to be trained and knowledgeable of the nutrition needs and have the ability to modify traditional treatment approaches. RDNs will be involved in training other interdisciplinary team members, individuals with IDD and CYSHCN, and/or caregivers in food selection and preparation as part of the intervention plan.⁴¹

Protocols and Standards of Care

Although there are currently no evidence-based practice guidelines for nutrition services specifically for individuals with IDD and CYSHCN available in the Evidence Analysis Library, many of the comorbidities such as pediatric and adult weight management, diabetes type 1 and 2, and hypertension that occur in this population do have evidence-based practice guidelines available. The Academy of Nutrition and Dietetics Standards of Practice

and Standards of Professional Performance for Registered Dietitians (Competent, Proficient, and Expert) in Intellectual and Developmental Disabilities published in 2012 defines the skills needed by RDNs to address nutrition-related issues present in individuals with IDD and CYSHCN.⁴¹ Development of best practices for individuals with IDD and CYSHCN will be key in advocating for reimbursement for RDN services in the future.

Education of RDNs and NDTRs for This Population

Webinars, educational conferences, dietetic practice groups, subspecialty groups, and clinical settings offer specialized training for RDNs and NDTRs who work in the area of IDD and CYSHCN to increase their knowledge about this population. Several programs are available to train professionals to work with individuals with IDD and CYSHCN. The Association of University Centers on Disabilities (www.auccd.org) is a network of training programs that includes training for RDNs to increase the availability of nutrition services for CYSHCN. The Association of University Centers on Disabilities provides and promotes a national network of university-based internship and training programs, such as The University Centers for Excellence in Developmental Disabilities (UCEDD) and Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs.

UCEDDs are funded by the Administration on Intellectual and Developmental Disabilities (www.acl.gov/Programs/AIDD/Index.aspx) and partner with state governments, local communities, and private agencies. Their four core functions are: interdisciplinary preservice preparation and continuing education, research, information dissemination, and community services. Many RDNs have been trained through UCEDDs and now lead programs, conduct research, and provide MNT to individuals with IDD and CYSHCN. Because UCEDD programs are affiliated with universities, they bridge a crucial gap between academia and community.

LEND is a graduate-level training program funded by the Maternal and Child Health Bureau that operates in collaboration with a UCEDD or other health care facilities. LEND provides

fellowships in ASD and neurodevelopmental disabilities for practicing, graduate, and postgraduate individuals from various health care professions to prepare them for future roles in areas such as research, clinical practice, and student teaching. Leadership roles and interdisciplinary competency are key components of LEND training.

Additional resources for RDNs and NDTRs are listed in [Figure 3](#).

Collaboration with Other Professions

Individuals with IDD and CYSHCN have nutrition needs across their lifespan, such as increased risk of comorbidities, feeding/mealtime issues, and food insecurity, which can be further complicated by lack of insurance. RDNs are an integral part of the interdisciplinary team, which may include the primary care providers/medical home, speech language pathologists, occupational therapists, physical therapists, mental health providers, therapeutic recreation specialists, and caregivers. For example, implementation of MNT for management of obesity in a child with spina bifida may involve not only an RDN, but also the child's physical therapist and physical education teacher at school to ensure all components of the plan are in place.

Health Insurance and Payment for Health Services

In 2012, before the implementation of the ACA, more than 47 million Americans were uninsured⁶⁶ and during 2009-2010, 3.6% of CYSHCN were uninsured and 34.3% of CYSHCN had inadequate insurance coverage.⁶⁷ The goal of the ACA is to reduce the number of uninsured individuals through expanding Medicaid or subsidizing insurance coverage. Uninsured individuals are less likely to receive preventative care and services for major health conditions and chronic diseases. Individuals with IDD and CYSHCN require specialty and preventative care in addition to a primary care provider/medical home. Care coordination to reduce duplication of services and increase efficiency will be an important consideration to reduce costs and provide quality care as the health care environment changes in the future.⁶⁶

Roles and Responsibilities

The updated Standards of Practice and Standards of Professional Performance for Registered Dietitians (Competent, Proficient, and Expert) in Intellectual and Developmental Disabilities provides guidance for RDNs when developing screening, assessment, and monitoring tools. RDNs individualize MNT according to an individual's needs and includes input from the individual as well as his or her family, caregivers, and medical providers.⁴¹

Developing proper MNT requires understanding an individual's functional abilities, cognitive abilities, literacy, communication abilities, and level of understanding.⁴¹ Educational materials should be appropriate both for the individual's cognitive function and chronological age (ie, materials designed for children are not appropriate to use when educating adolescents or adults).⁴ Appropriate communication methods, necessary accommodations, and assistance are used by RDNs and NDTRs (under RDN supervision) when developing and providing education.

Person-Centered Language

Person-centered language places the emphasis on the individual, not the disability (eg, "person with a disability" not "disabled person" and "person with autism spectrum disorder" not "autistic"). RDNs and NDTRs can engage an individual by speaking directly to him or her, using age-appropriate language for their cognitive abilities, showing respect, and offering choices for education to be effective.⁴

Recommendations

Adults with IDD and CYSHCN have multiple 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.^{40,41,45,55,68} Comorbid conditions such as obesity or endocrine disorders that require nutrition interventions are also more likely to develop as the population ages.²² Poor nutrition-related health habits, limited access to services, and long-term polypharmacy are considered significant health risk factors.^{57,68} RDNs and NDTRs are vital in providing

comprehensive care to these individuals. However, to provide comprehensive nutrition services for adults with IDD and CYSHCN, the Academy of Nutrition and Dietetics recommends that RDNs and NDTRs do the following:

- work to obtain reimbursement for MNT as part of comprehensive health care for persons with IDD and CYSHCN;
- advocate activities for nutrition services to be included in services provided for persons with IDD and CYSHCN throughout the lifespan;
- develop and implement best practice and MNT protocols to address the unique needs of persons with IDD and CYSHCN;
- develop and provide specialized interdisciplinary nutrition training for practicing RDNs and NDTRs to address the unique health issues of persons with IDD and CYSHCN;
- promote and provide timely and cost-effective nutrition services, including ongoing nutrition monitoring, as an essential component of health care programs for persons with IDD and CYSHCN throughout the lifespan;
- support programs, particularly inclusive ones, that provide wellness promotion and preventive services throughout the lifespan for persons with IDD and CYSHCN;
- collaborate with health care providers to ensure policies are in place to promote family-centered, interdisciplinary, coordinated, community-based, and culturally competent nutrition services for persons with IDD and CYSHCN; and
- support and participate in medical/nutrition research and publish in primary and secondary areas of disease risks for persons with IDD and CYSHCN.

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