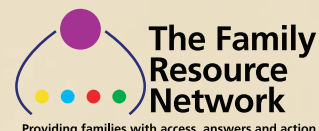




CENTER ON  
NUTRITION  
& DISABILITY



Providing families with access, answers and action




# CENTER ON NUTRITION & DISABILITY REPORT: THE STATE OF NUTRITION

For People With Disabilities in New Jersey





A portrait of a woman with dark, curly hair, wearing a light blue denim jacket over a white t-shirt. She is looking slightly to the right of the camera with a gentle expression. The background is a plain, light-colored wall. A solid purple rectangle is visible in the top left corner of the image.

*"You have what you are given. If you are given certain colors for a painting you have a choice to be upset that some colors are missing or you can choose what type of picture you want to paint."*

*- Lizzy*

*New Jersey*

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# ABOUT

An extension of the renowned Get FIT program, The Center on Nutrition and Disability is dedicated to creating an inclusive culture of health for people of all abilities through providing nutrition education, increasing access to healthy foods and supporting healthy dietary behaviors for people with disabilities. With funding from the Robert Wood Johnson Foundation, The Center on Nutrition and Disability engaged with people with

disabilities, family caregivers, direct support professionals, advocates, and additional stakeholders throughout the state of NJ to address nutritional concerns and the circumstances impacting the health of people with disabilities.

Through a series of interviews, it became clear that there is a need to improve and advance the current state of nutrition for individuals with disabilities. Acknowledging the impact that diet has on achieving a culture of health, the call to action for the Center on Nutrition and Disability is to decrease the barriers experienced by people with disabilities when accessing and maintaining a healthy diet. Through the development of a centralized access point for information, services, resources, training,

research and collaborative program development, The Center on Nutrition and Disability has the capacity to alleviate the barriers experienced by people with disabilities and their family caregivers when pursuing healthy lifestyles. This report provides an overview of data from various sources about the current state of nutrition for people with disabilities in the State of New Jersey.





# SUMMARY

Envisioning a Culture of Health for people of all abilities across the lifespan, this project will focus on one of the most vulnerable and diverse communities in New Jersey - people with disabilities. The numbers of individuals with disabilities are predicted to continuously increase over the years. As the US population ages, the disability population also increases; 35.4% of people over the age of 65 have a disability. By 2030, the number of adults with intellectual and developmental disabilities age 60 years and older is projected to increase from 641,860 in 2000 to 1.2 million.

Obesity is a significant risk factor in the development of chronic diseases including but not limited to, Type 2 diabetes, Cardiovascular disease, Osteoporosis, Hypertension, and Asthma. In NJ, 27.4% of adults, 15.3% of low income youth ages 2 to 4, and 31.7% of youth ages 10-17 are overweight or obese. In 2010, NJ had 607,689 diabetes cases and if significant changes are not made, diabetes cases are projected to reach 971,386 by 2030. As national obesity rates remain high, a disparate burden of obesity exists among the

disability population; adults with disabilities have a 58% increased risk of obesity and children with disabilities have a 38% increased risk of obesity, in comparison to those without disabilities. In 2015, 39.9% of people with disabilities in the US were obese in comparison to 25.4% of people without disabilities.

It is crucial for everyone to have a nutritious diet to avoid health conditions linked to obesity. It is especially important to focus on the effects of obesity linked conditions for people with disabilities. The effects of dental, intestinal, cardiovascular, and metabolic health can be debilitating especially for individuals who have a lack of access to healthcare.

New Jersey spends about \$14,489 per person with a disability on healthcare (CDC, 2012). Some of the treatments used for obesity related conditions could be reduced with a healthy diet in conjunction with physical activity.

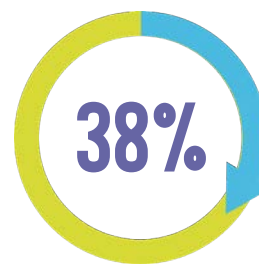


# CURRENT CIRCUMSTANCES

Obesity rates within the disability population are; 58% higher in adults and 38% higher in children (CDC).



Higher in Adults



Higher in Children



Higher Obesity Prevalence for Hispanics



Higher Obesity Prevalence for Non-Hispanic Blacks or African Americans

Obesity rates are significantly higher among racial and ethnic groups. Non-Hispanic Blacks or African Americans have a 51% higher obesity prevalence and Hispanics have a 21% higher obesity prevalence than non-Hispanic Whites (CDC).

In 2010, NJ had 607,689 diabetes cases and if significant changes are not made, diabetes cases are projected to reach 971,386 by 2030.

Individuals with disabilities are at a higher risk for obesity related and secondary chronic health conditions.

# 59.8%

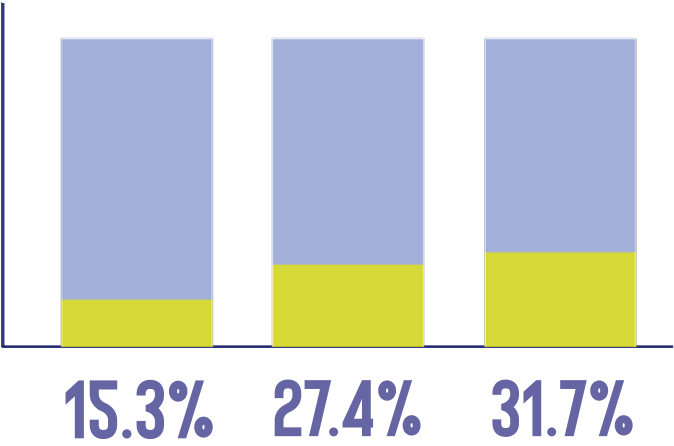
Increase in Diabetes Cases in New Jersey

Individuals with disabilities face the same or more challenges as everyone when trying to sustain a healthy lifestyle

Adults with disabilities are 3x more likely to have heart disease, stroke, diabetes, or cancer than adults without disabilities

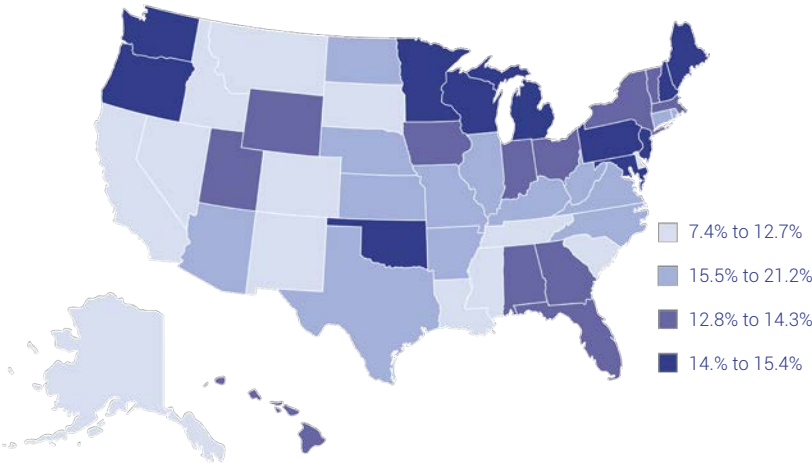
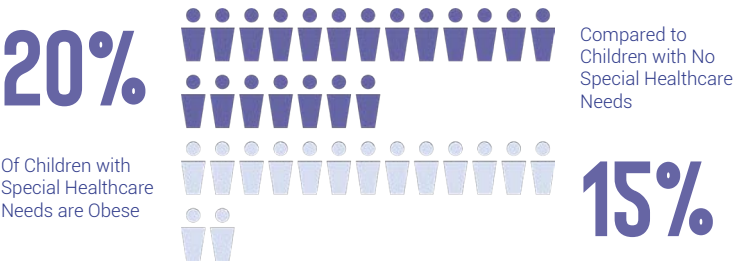
3x

More Likely to Have Heart disease, stroke, diabetes, or cancer than adults without disabilities



In NJ, 27.4% of adults, 15.3% of low income youth ages 2 to 4, and 31.7% of youth ages 10-17 are overweight or obese (State of Obesity, 2017).

20% of children 10 through 17 years of age who have special health care needs are obese compared with 15% of children of the same ages without special health care needs. (Child and Adolescent Health Measurement Initiative.)



In 2015, 39.9% of people with disabilities in the US were obese in comparison to 25.4% of people without disabilities; as indicated in the map below the gap in obesity percentage in NJ is significant, ranging from 15.5% to 21.2% (Kraus, 2017).

*“Frankie gained over 50 pounds since moving into the group home. He went from 145lbs to over 200lbs”  
- Kathy, Millstone , New Jersey*

The impact of nutrition-related chronic conditions such as obesity and diabetes on overall quality of life becomes increasingly compounded when coupled with the pre-existing limitations in activities of daily living experienced by an individual with a disability. Therefore, information on nutrition becomes doubly important in the development of a healthy lifestyle.

Furthermore many families with disabilities rely on social security benefits to support their child's disability needs. In order to build an inclusive culture of health, people with disabilities and their caregivers will require access to information and resources that allows them to pursue a healthier lifestyle. Experts in the field of dietary therapies are often expensive and are not locally accessible resulting in a tremendous gap in access to care. People with disabilities also experience a chronic lack of opportunity with accessing effective providers due to a limitation in the number of providers who have the necessary skill sets to assist them.

"Many individuals with disabilities live in group homes. Group homes provide many services that aid the individual in daily tasks like laundry, medication management, supervision, and housekeeping. Direct Support Professionals (DSP) have their hands full most of the day between running errands, teaching life skills, cleaning and much more... that cooking healthy nutritious meals gets placed on the back burner."

*"I know it is not an easy job and the staff does not receive adequate training, but it is also an issue we have to fix"*

*- Kathy, Millstone, New Jersey*





## New Brunswick, New Jersey

The W family consists of 4 loving and hardworking individuals. Sara and Jon are older parents who have a 17-year old son, Matt, and an older daughter, Ashley. Matt is diagnosed with Autism Spectrum Disorder and has been residing in a pediatric group home under the children's system of care for over a year. Matt and Ashley have an extremely close bond and she takes the time to communicate, train, comfort, and support her brother when she is available.

Matt is currently diagnosed with gastrointestinal issues which contribute to the distress and pain he feels but cannot communicate it. Sara shares with us that Matt rejects nutritious foods and prefers fried potatoes and meats because his menu is "the only thing he controls in his life and no strategic plan of food introduction is being implemented". In addition to poor diet, Sara adds "There is a lack of trained dentists that specialize in caring for people with special needs, many times worsening the quality of life for individuals by omitting visits to the dentist".

Matt is in the process of being moved down to Level 1 care because he is lightly medicated as opposed to heavily. Being moved down to level 1 care decreases the amount of care he is required to receive and concerns Sara and Jon on the outcomes of his progress.

With a fast turnover and shortage of staff, Matt's progress is not being monitored with consistency and his motivation declined over time. Activities of daily living such as shelving and assisting with pick-up and delivery to classrooms are some of the tasks that Matt is comfortable with and was making great strides in. "Matt is very observant and pays attention to detail, in one instance he showed a staff member where a key was that he remembers seeing another staff member put there" continued Sara.

***"We roll with the punches and do the best we can".***  
**- Sara**

# KELLY

## Egg Harbor, New Jersey

Kelly, is a bubbly 41 year old woman that resides in Egg Harbor NJ along side her Direct Support Professional, Kat. Kelly, excitedly expressed, "I do swimming for the Special Olympics and I like to play bocce ball" Kelly told us "I like my roommates, they have their own room". When asked what she liked to eat, she responded with "Ribs and spaghetti and I like to go to Red Robin and Applebees. I like to watch TV with my boyfriend Michael too". Kat shared that Kelly has gained about 20lbs and she is currently prediabetic. Kelly spoke positively about her experience with the healthcare system, sharing her excitement about learning the names of her doctors like endocrinologist, psychiatrist, podiatrist, cardiologist among many more.



# KATHY & FRANKIE

## Millstone, New Jersey

Kathy's son, Francisco, who also likes to go by the nickname Frankie, is a 51 year old male who has been living in a group home since 1994. Frankie is diagnosed with a rare genetic disorder called Cornelia De Lange Syndrome (CdLS). Due to this disorder, Frankie does not have his back teeth and in addition suffers from gastro-esophageal reflux disease with esophagitis, diaphragmatic hernia, and fecal urgency. Individuals with co-occurring conditions like Frankie's, require attention to nutrition, and nutrition is instrumental in improving quality of life and overall health.

A few staff members have successfully conducted 'group cooking' and healthy eating habits by cultivating a relationship with Frankie. By preparing home cooked meals, individuals with disabilities can practice their motor skills, social skills, and form meaningful relationships as well as improve their health simultaneously. Cookbooks, cooking utensils, pans, and a crockpot were provided by Kathy and were used by some staff members,

however, with a high staff turnover rate these positive strategies were not maintained or consistent.

"I know it is not an easy job and the staff does not receive adequate training, but it is also an issue we have to fix" Kathy shares. Staff has prompted Frankie with phrases such as "Where do you want to go out to eat today?", "Do you want to go to McDonalds?", "What drive thru should we go to?", "Want to go to the dollar store to get snacks?".

Kathy continues to voice her concerns as well as attempts to provide solutions by communicating to group home management, providing a list of foods Frankie likes, step-by-step taste tests, and a list of suggestions on how to engage with someone with a disability during meal time. Due to Kathy's growing concerns and communication with management and staff, she has been restricted from visiting her son without a 48-hour notice to the facility. She is afraid of retaliation if she continues to speak up about her concerns.

# BARRIER:

## BUDGET & PLANNING

Contrary to belief, it is not a shortage of food that creates malnutrition, it's the shortage of healthy food options. Accessibility and budget can make eating a nutritious meal a luxury for many individuals. The steep pricing of nutritious whole foods carries an additional burden for individuals. That is why budgeting and planning are crucial parts to achieving nutrition goals.

Budgeting is a balancing act between expenses and income. Through budgeting individuals are forced to take a look at their expenditures and better evaluate the importance of those expenditures. A Culture of Health can only be obtained when the importance of healthy living is highlighted and exhibited in day-to-day actions.



***"It is difficult to try to attempt something new when there are budget restrictions for the week."***

***- Danielle, Direct Support Professional,  
The Arc, Egg Harbor NJ***



## Egg Harbor, New Jersey

Shondel and Danielle, his Direct Support Professional engaged in an insightful discussion regarding the Get FIT program. Shondel enjoys participating in Get FIT's low impact exercises because it provides frequent breaks. Get FIT programs are tailored specifically to meet the needs and abilities of each participant. "After GetFIT, I like to eat sandwiches with ham and cheese" he jokingly added. "We are no longer buying junk food, we look for sales and Shondel is good at spotting them. It is hard because his roommate does not want to eat healthy and will get junk food that causes some disagreements. Also there are huge budget restrictions which only allow us \$40 per week. We try our best but it is definitely a challenge to eat healthy."



## Egg Harbor, New Jersey

Isabel had wonderful smile that lit up the room during her discussion with the Center on Nutrition and Disability. She was happy to share and talk about her daily activities and health behaviors. "I like riding my bicycle around the apartment complex, I like walking too" Isabel giggled "My favorite breakfast is canned tuna fish and coffee". Isabel shared that she enjoys swimming at the outdoor pool in the complex she lives in. She shared the array of foods she likes to make but expressed that sometimes it is hard to get all the ingredients with such a strict budget. "I like black beans and rice, grilled cheese sandwiches, broccoli, spinach, corn, peas, beets, and salad with buffalo wings on it!" she laughingly adds.

# KELLY

## Hamilton, New Jersey

Kelly is a 39-year old woman who resides in Hamilton New Jersey. She works for the New Jersey State Police and is involved with the Progressive Center as well as Project Freedom and the RWJ Wellness Center. She enjoys watching baseball, spending time with her family and friends, swimming, reading, and gardening to name a few.

Kelly was diagnosed with arthritis at age 2 and currently uses a scooter for mobility. She shared with us that she used to live with her ex-husband and they would share household chores, he would cook for them for the most part. Currently, she lives independently and mostly relies on pre-made meals from Shop Rite or Jersey Girl Café meal delivery. "I like the convenience of meal delivery but it can get expensive quickly equaling \$12 to \$14 a meal, I'd like to see an option for the disability community and I'd be interested in contributing to the planning of such programs".

Kelly enjoys cooking and usually makes a few large meals that last her the whole week. Kelly and her friends make it a point to cook together by contributing their own ingredients for salads. "We all engage in the process of cooking together and are more open to trying new things that way." Due to the amount of time that is needed to spend in the kitchen it makes it hard for Kelly to cook daily. "I'd really love to see some adaptive technology for cooking!" Kelly suggested "The biggest barriers would have to be time, budget, and pre planning."





# ROY & VALERIE

Roy is an exceptional bowler and track and field star for the Special Olympics. Roy also volunteers for the Salvation Army when he can. His Direct Support Professional made sure to share with us all of Roy's accomplishments since she has been with him. As we got into conversation about nutrition and meals, Valerie his DSP shared with us that they cook in large batches at the group home. "He helps cook the eggs, cut up onions, spinach and broccoli. We have to eat the same meals, one of our residents is diabetic so we have to be aware. We have an issue with people not liking certain things and you can never make everyone happy.





Bubbly, funny, and bright are some of the characteristics that many people would describe Elizabeth (Lizzy) and Maria. Two best friends who did not know that epilepsy would bring them together "People always assume I have no problems in my life because I teach yoga, I am fit, and I do not talk about epilepsy. They're wrong, I had to go through a lot and am still going through things" Lizzy shares."

Maria was diagnosed with generalized epilepsy as well as non-epileptic seizures at age 27. "I have been in the ER many times for cuts and falls but the hospital staff never followed up or checked for epilepsy until it had escalated", she continues.

***"Your medicine can fail at any second, what is important is to make your mind strong through your body"***  
- Maria

"The culture here is so diet motivated that people forget the importance of real foods. Going through these challenges has brought me closer to health."

Diagnosed at age 21, Lizzy said the diagnosis completely changed her life. "Prior to my diagnosis I did not care about my health. I ate what I wanted, partied, and did not sleep much" she adds, "Through my diagnosis I became more empathetic to people and even though it sucks I am the most health aware I have ever been." Books like The Body Keeps the Score, yoga practice, meditation, mindful eating, and health supporting podcasts were and are some of the tools Lizzy uses for her mind and body health.



*"I really like the concept of 'bite size' thinking, instead of thinking about the finish line; think about the small steps you can take today."*

*- Lizzy*

## KAREN

A New Jersey native, Karen, now living out of state, shared her day-to-day nutrition habits. Karen was born with spina bifida and walks with the assistance of a leg brace and crutches. She is 39-years old and has a passion for animals and is currently a full-time veterinarian.

"I do like to cook, eat lots of fruits and veggies, and I have been a vegetarian since high school. I am single and live alone so, when I cook I tend to make batches of things and eat the same thing for a few days. I do pack a meal to bring to work with me every day to avoid the temptations take-out" shares Karen. "There are a ton of food blogs and web sites that I use. Many are centered around healthy cooking and many are vegetarian. I also use WW recipes. Some of my favorite food blogs – Skinnytaste, Cookie and Kate, Oh My Veggies."

As the conversation progressed, Karen discussed resources and trainings on nutrition, with her preference leaning towards self-learning opportunities. "If nutrition isn't on someone's radar, you can't force it. I do like when there are recipes available in the grocery store, free magazines with seasonal things, online resources etc."

# BARRIER:

## SELECTIVE EATING AND RESISTANCE TO FOODS

Feeding difficulties such as food jags, refusal to self-feed and/or oral-motor are circumstances that many families and caregivers have to surpass to achieve proper nutrition. Food intolerances, allergies, chemical sensitivities, gastrointestinal disorders can result in nutritional deficiencies due to food selectivity.

Often, individuals with disabilities may be prescribed medication. The impact of medication interactions with certain foods are underrated and are rarely discussed among caregivers and providers. Caregivers are left to experiment with trial and error methods.

Eating practices such as food aversions, behavioral rigidities, resistance to new foods are all examples of behaviors associated with autism spectrum disorder. These findings prompt providers to take a deeper look into selective eating solutions.

### BEST PRACTICES FOR SELECTIVE EATING

- Plan meals, go shopping and prepare food together using fun utensils and gadgets (melon baller, blender for smoothies, cookie cutters for sandwiches)
- Pretend you are making a cooking show for TV
- Make snacks user-friendly (pre-cut veggies, small snack bags of pretzels, at eye level in cabinet/refrigerator)
- Create special names for food ("broccoli forest", "rainbow salad", "x-ray vision carrots")
- Prepare foods in different ways based on the individual's sensory preferences (e.g. vegetables can be raw and crunchy or cooked and soft; foods may be mixed or served separately)
- Serve in bright festive tableware
- Praise and reward even the smallest bite or interest in a new food
- Use age appropriate non-food motivators and reinforcers for positive behaviors

# ALYSON & OPHELIA

## Egg Harbor, New Jersey

Alyson is a resident of the Arc in Egg Harbor and Ophelia is her Direct Support Professional. Alyson, who has had experience with the Get FIT program, enjoyed the opportunity to participate. Despite participating in health and wellness programs, her father has expressed concern about her weight and activity levels. On a typical day, Alyson is not part of the meal preparation process, and like many of the residents in the group home, is not a fan of drinking water. "The residents request high carbohydrate meals and we try to put make it balanced by making pasta with veggies and no bread. Drinking more water is a huge goal for us because many residents do not drink enough water which can produce other health issues."

## Egg Harbor, New Jersey

Ernie is a quiet 62 year old who participates in programs at the Arc in Egg Harbor. He has participated in the Get FIT program for 3 years now – this is an impressive accomplishment for Ernie as his Direct Support Professional, Princess added that it is very hard to get him out of his room and out into the community. "He likes to play his PlayStation and drink diet soda in his room" Princess adds "He never drinks water, which is not good. His sugar is high too and he is diabetic." Ernie's experience is a common trend observed among many individuals with disabilities who are aging.

# ERNIE





# FAY & COLE

## Lacey, New Jersey

Cole is a happy 9-year old boy living with his mom Fay, younger brother Danny, and grandmother Carolyn. Cole was diagnosed with Autism Spectrum Disorder on his 2nd birthday when his mom recognized a few expressions like selective hearing and some other sensory processing behaviors. As Cole grew, Fay began to notice that he was very picky with food and certain food smells made him gag, even on some occasions vomit.

***“Food introduction takes months because of the long process of touch, feel, smell, put to lips, and then taste.”***

A Behavior Analyst visits Cole two to three times per week providing in home support like “packing snacks for school and practicing his address and name” Fay shares. “Cole is very picky and will only eat certain foods, like for breakfast he

likes pork roll, turkey bacon, and milk with ovaltine”. Cole then goes to school from around 8:20am to 3:45pm where he has an Independent Education Plan (IEP). For lunch he usually has variations between “chicken nuggets, pizza, fries, chips, or occasionally the school lunch staff will save him pork roll if available”.

Joining Fay and Cole during dinner time, Cole expressed his preference for McDonalds as a dinner option, stating “Donals, Donals” repetitively, and more specifically chicken nuggets, cereal, potato chips and McDonalds.

Fay expressed that these are routine conversations in their home, specifically with regards to Cole’s affinity to fast food for dinner. Fay expressed her positive experiences as an advocate stating “We get assistance from the New Jersey Personal Preference Program (PPP), Care Management Organization (CMO), Project Lifesaver to name a few. Cole is hooked up!”



## Hamilton, New Jersey

Stephanie is a bright, charming, and optimistic 27-year-old. "She has many different interests including music, instruments, sports, dogs, languages, writing, just to name a few" Lauren, her mom, shares.

Stephanie was born with compromised kidney function (kidney disease) and was diagnosed with Autism Spectrum Disorder at age 7. "Steph has struggled with being under weight and overweight because of a restrictive renal diet and the use of steroids. We know the importance of prevention and due to our efforts, Steph was able to make it without a kidney transplant until age 19" continues Lauren

Lauren is an advocate and has established connections with varying agencies over the years, yet it is still a challenge to access health and social services even when connections are present.

Lauren displays extensive knowledge about nutrition, how certain medications interact, and foods to eat with certain medications and to avoid with others. "The disability community is small, and having a child with disabilities has changed the trajectory of my life" Lauren shares genuinely.

***"Measuring foods, adding probiotics to control the effects of life long antibiotic use, managing acid reflux, and monitoring sodium and protein intake are some of the preventative measures we had to implement."***

***- Lauren***

**LAUREN & STEPHANIE**





# DREW

## Egg Harbor, New Jersey

Drew is a 38 year old male residing with the Arc in Egg Harbor City. Drew enjoys playing video games, swimming, dancing, participating in the Get FIT program, baseball, and trips to WAWA. During discussions pertaining to food preferences, Dan expressed "I wish I did not have to eat animals!" and "I wish I had a blender". Drew's ideal smoothie would include spinach and fruit. With some time, Drew felt comfortable discussing his favorite foods in addition to daily encounters with his direct support professionals.

## Egg Harbor, New Jersey

Joanie is a 30 year old woman who resides with the Arc in Little Egg Harbor. She was eager to share her positive experiences with the GetFIT program. "I worked at Applebees, putting together salads. Weighing lettuce and cheese." Joanie's favorite food is salad because she can add many different ingredients. "Joanie enjoys cooking but also enjoys going out to eat" Patti added (Joanie's DSP).

# JOANIE

Despite the many barriers that exist for accessing a healthy lifestyle, Get FIT and the Center on Nutrition and Disability have developed and demonstrated best practices that support healthy promoting behaviors for people with disabilities. Research indicates that small daily lifestyle changes can significantly impact the health trajectory of an individual irrespective of their abilities. The keys to successful nutrition and healthy eating habits entail motivation, education, and goal making. As outlined in this report, the Center on Nutrition and Disability aims to provide the resources, information, and safe space needed for improvements in nutrition.

**TAKE  
AWAY**

# CALL TO ACTION

The Center on Nutrition and Disability has built an online information center ([www.nutritionanddisability.org](http://www.nutritionanddisability.org)) that provides access to consumer-friendly resources and tools that have been developed and/or vetted by content experts and key stakeholders. Such tools include a picture-based Cookbook series ('The Nutritious Guide to Get FIT' and 'Frugal Bites') which was developed by the Center on Nutrition and Disability using universal design techniques so that visual learners may successfully prepare a healthy meal independently. Publishing these tools online through e-books allows individuals with visual impairments to access these resources. The Center on Nutrition and Disability is a central access point for credible information and access to experts.

Acknowledging the impact that diet has on accessing a culture of health, the focal point of action for the Center of Nutrition and Disability is to decrease the barriers experienced by people with disabilities

with accessing and maintaining a healthful diet. Through the development of a centralized access point for information, services, resources, training, research and collaborative program development, We have the capacity to alleviate the barriers experienced by people with disabilities and their family caregivers when pursuing a healthy lifestyle. Currently, we are working throughout the state with individuals with disabilities, caregivers, advocates, providers, and additional stakeholder to identify and address the gaps in care experienced by people with disabilities when accessing an inclusive culture of health. Through these efforts, The Center on Nutrition and Disability, in partnership with its stakeholders, has developed recommendations to advance the Public Health Strategy for the improvement of nutritional health for people with disabilities in the State of New Jersey.



# CENTER ON NUTRITION & DISABILITY