

Down Syndrome News

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NEWSLETTER OF THE



NATIONAL
DOWN SYNDROME
CONGRESS

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“Follow Your Dreams.”

That is actor Zack Gottsagen’s advice to others as they pursue their goals and what has made the 34 year old actor a trailblazer his entire life.

Zack Gottsagen was the first child with Down syndrome to be fully included in the Palm Beach (FL) School District. He was also involved in an early court case involving the Americans with Disabilities Act (ADA), resulting in mandatory training of all Little League coaches nationwide regarding the inclusion of children with disabilities. But it is his latest star-making role in “The Peanut Butter Falcon” that has catapulted Gottsagen into the national spotlight.

The role was made for Zack – literally. Filmmakers Tyler Nilson and Michael Schwartz wrote the script with Gottsagen in mind, including his interest in wrestling. In the film, Gottsagen plays the role of Zak, a young man with Down syndrome living in a nursing home. Eleanor, a young social worker, played by Dakota Johnson (“Fifty Shades of Grey”) is assigned to care for Zak. In the opening scene, the audience learns that Zak’s will may be a little more than Eleanor can handle as he and his friend Rose Mary scheme an escape plan for Zak. Rose Mary and Zak’s plan fails but Zak is determined. With the help of his roommate Carl, Zak finally escapes from the nursing home and is on his way to fulfilling his dream of making his way to the wrestling school run by his favorite professional wrestler, Salt Water Redneck, played by Thomas Haden Church

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We are honored to have Zack Gottsagen deliver a keynote speech at next June’s 48th Annual NDSC Convention, in New Orleans. Much as in “The Peanut Butter Falcon”, attendees can expect to learn valuable lessons while building lifelong relations. And, following the “First Rule” of Gottsagen’s character, Zak, you should plan to “PARTY!”



Letter From the President



Dear Families,

It is hard to believe that we are preparing to wrap up 2019. This has been a big year for NDSC and 2020 promises to bring even more excitement as we prepare to take the 48th Annual NDSC Convention to New Orleans, Louisiana. We will be bringing "Lagniappe in the Big Easy!" Are you asking yourself what in the world I am talking about? Lagniappe is a word that originates from the Louisiana French that was introduced to the area around New Orleans by the Spanish Creoles. It means "a small gift given to a customer by a merchant at the time of a purchase" (such as a 13th doughnut on purchase of a dozen). So yes, NDSC will be bringing lagniappe, "a little something extra" to New Orleans next June 25th – 28th.

This convention also means a changing of the guard. Each year at the annual convention we elect new members to the Board of Directors who serve a three-year term. My term as NDSC President will come to an end with this election. I am honored to have served as your NDSC Board of Directors President. I will not be leaving though, as I will remain on the board serving in the capacity of Immediate Past President.

As we are in the planning phase of the 48th NDSC Convention, we invite you to get involved in the convention. We are currently accepting proposals for speakers for workshops and pre-conferences. Although we only physically see most of you at the "Greatest Family Reunion" each year, we want to remind you that we are here for you 365 days a year to provide resources and support.

I wish you and your family a very happy holiday season and a prosperous and healthy New Year! It is indeed my pleasure and privilege to serve you and your family.

All my best,

Kishore

Lagniappe in the Big Easy



NATIONAL
DOWN SYNDROME
CONGRESS

48TH ANNUAL CONVENTION

Lagniappe: /lan'yap/ Noun: a bonus or extra gift

The NDSC 48th Annual Convention, June 25–28, 2020, in New Orleans.

What is Lagniappe in the Big Easy?

Lagniappe is a word used primarily in the region influenced by New Orleans and therefore customary of the Louisiana French culture. The word lagniappe is pronounced LAN yap and means a small gift or bonus given. We think it is the perfect word to describe the NDSC 48th Annual Convention.



The Call for Speakers for the 48th Annual NDSC Convention is Open.

If you have an interesting and engaging presentation we welcome you to submit a workshop proposal for consideration. All proposals will be reviewed and considered by the NDSC Convention Planning Committee (CPC). Due to the volume of submissions, space, and balance in programming, not all proposals will be accepted.

More information, including tips and suggestions to getting your proposal noticed, can be found on the NDSC website under the Convention tab, Call for Speakers, General Convention Workshops. Submissions for General Workshop Speaker proposals are due by 3:00 PM EST on Friday, January 3, 2020.

Follow Your Dreams continued from page 1

(“George of the Jungle”). Along the way, Zak develops a lasting relationship with Tyler, played by Shia LaBeouf (“Transformers”).

Praised by critics for his authenticity, comedic wit and timing, Gottsagen has also caused buzz among Academy Award voters. But the best story may be the one that happened behind the cameras – a true friendship between Gottsagen and LaBeouf. In recent interviews, LaBeouf has credited Zack for saving him after he hit a personal low during the filming of the movie. When LaBeouf’s addiction issues impacted his work, Gottsagen told LaBeouf that he was disappointed in him. Those tough, but honest, words have stayed with LaBeouf and he says they are keeping him sober.

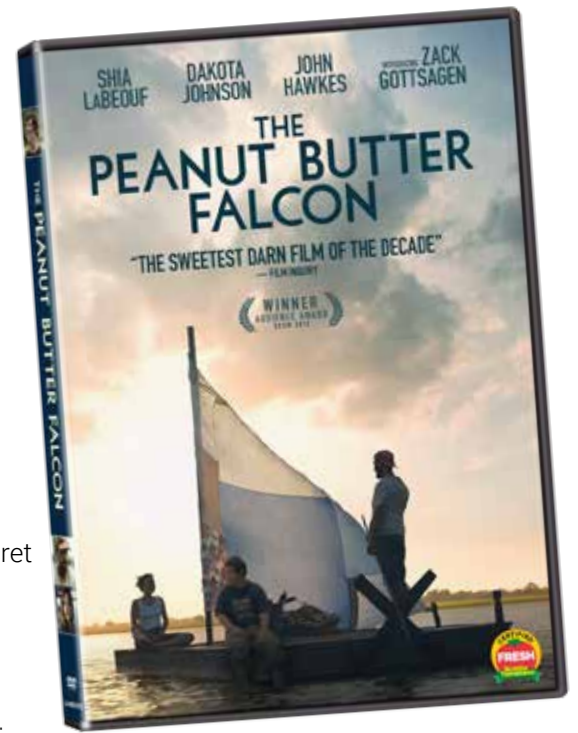
For his part, Gottsagen shared that “there were long days on the set and long nights in the hotel practicing with Shia” and that the two spent “every single week practicing and watching wrestling together.” Zack told NDSC Engagement Director, Rhonda Rice, that his favorite moment with Shia was learning their secret handshake – “one only for buds, dudes, friends.”

Gottsagen also talked about his relationship with his other co-star, Dakota Johnson, noting that she “is sweet, kind and generous. We love being together.” Gottsagen notes that one of the film’s pivotal scenes involving the three main actors is when LaBeouf’s Tyler tells Johnson’s Eleanor “that while she’s been doing paperwork, he and Zak have been doing something called living.” For Gottsagen, though, his favorite scene with Johnson is “the one where we are dancing” and his favorite scene of all is “the wrestling scene.”

As is the case with most successful people, Gottsagen’s success didn’t happen overnight. When asked by Rice when he first knew that he wanted to be an actor, Gottsagen replied, “I was three. I knew very young.” The story is corroborated by his mother, Shelly, who recalls that her son took his first role – that of a frog – very seriously, and together they practiced his lines for hours. Later, Gottsagen auditioned for the Middle School of the Arts and Dreyfoos School of the Arts, where he was accepted, attended as the first fully-included student with a disability, and graduated with honors.

Later, when cast in the lead role of “Artie” at the Royal Playhouse, Gottsagen said he was “hesitant at first” because it was a live performance. Like every other role, though, Gottsagen took this one by the horns as he learned not only his lines, but everyone else’s, eventually assisting other actors as they rehearsed. Gottsagen was featured in the highly acclaimed award-winning documentary, “Becoming Bulletproof”, and has had several movies with Zeno Mountain Farms. It was during a summer camp at Zeno Mountain that Zack met “The Peanut Butter Falcon’s” producers, Nilson and Schwartz, who were camp counselors at the time.

Zack Gottsagen looks at life with a confidence that few have. When asked if he was nervous about working with such stars as Shia LaBeouf and Dakota Johnson, he replied, “Nope, I was just excited to meet them.” He wants to encourage others, no matter their goal. As for other young actors, he says to just keep working, stating, “It will come. You will get the parts.”



Sponsor Opportunities in the Big Easy!

The National Down Syndrome Congress Convention is the largest single disabilities event in the world hosting nearly 4,000 individuals with Down syndrome, their families and the professionals that serve the community. Sponsorship of the 48th Annual Convention provides a high-value, cost-effective way to feature your company or organization and support the work of NDSC. Choose from one of our sponsor levels or customize a package to fit your organization’s visibility and budget requirements. For more information call us at 770-604-9500.

SELF-ADVOCATE SPOTLIGHT

Maggie Erickson



Photo: Arc Value Village

Maggie Erickson was elected by her peers to sit on the National Down Syndrome Congress Board of Directors last June at the 47th annual NDSC convention. Maggie is a young woman who leads a very active life working, spending time with friends, and volunteering.

Maggie grew up in St. Paul, Minnesota as an only child so she is the light of her mother's eye and a super-duper friend to many.

Maggie attended Highland Park High School where she made a lot of friends, was involved in Girl Scouts, participated in choir and attended regular classes. She was also on the gymnastics team and earned 2 varsity letters. Maggie graduated from high school in 2009 and soon began her post-secondary education as a student in the BUILD program at Bethel University.

Maggie says that she loved the experience at Bethel. She met new friends, lived in a dorm for 2 years, and liked being independent and on her own. Maggie was on the Bethel dance team, was a manager for the girls' softball team, had an internship at Special Olympics Minnesota, and worked while attending school. She is a 2017 graduate of the BUILD program at Bethel and very proud of her accomplishments.

Maggie is a very active community volunteer. She is a past member of the Board of Directors of the Down Syndrome Association of MN, a current member of The Arc of

Minnesota's Self-Advocacy Committee, and spokesperson for Arc's Value Village, as well, she is an avid Special Olympics supporter and athlete and involved in Best Buddies International.

Maggie loves being independent and has had a job since she was 19 years old. She has worked at for the Minnesota Twins baseball team for 8 years in Premium Guest Services and at US Bank Stadium with the Minnesota Vikings football team in guest services for 4 years. She formerly worked as a research Data Entry Specialist at the University of Minnesota and currently volunteers in this field at the nearby courthouse and also does some modeling. You can see her in many Arc Value Village promotions and Minneapolis St. Paul magazine. She works with Moore Creative agency (Affinity Plus Credit Union) and has also appeared in The Volk Magazine. Needless to say, Maggie is a busy woman!

Some other fun facts that we learned about Maggie, are that she was crowned Minnesota Miss Amazing, she is a Bowling champion with Adaptive Sports, and is related to King Henry the 2nd and is part of that royal bloodline. What we really learned is that Maggie is an amazing woman and that National Down Syndrome Congress is fortunate that she is a leader of our organization.



NDSC to Partner on the 2020 Disability Policy Seminar

NDSC is excited to announce that we are partnering with The Arc, AAIDD, NACDD, SABA, UCP and the Autism Society to host the 2020 Disability Policy Seminar, to be held March 23- 25, 2020 in Washington, D.C. The Disability Policy Seminar offers the opportunity for passionate advocates, self-advocates, experts, and professionals in the field to come together and learn about key issues affecting people with intellectual and developmental disabilities. The event features two days of informative sessions led by experts in the field

and offers opportunities for participants to discuss key issues with others from their same state. On the third day, attendees go to Capitol Hill to speak with their legislators. For more information, please visit disabilitypolicyseminar.org.



National Down Syndrome Congress is excited to announce that we are partnering with the U.S. Census Bureau to support the 2020 Census. As a National Partner, we will be working to make sure our community is accurately represented in the upcoming decennial count.

The census counts everyone in the United States and it is critical for people with Down syndrome (or anyone with a disability) to be a part of the count as not being included would negatively impact services, supports, and even funding that directly affects support for people with disabilities.

Census results are the basis for congressional representation and help determine how more than \$675 billion in federal funds is distributed each year to support vital programs in states and communities across the country. These funds shape local health care, housing, education, transportation, employment, and public policy. As the 2020 Census approaches, we will continue to share information about how you can make sure our community is fully represented. Visit 2020CENSUS.GOV anytime to get the latest news.

NDSC Hosts Policy Event in D.C. in Collaboration with American University Law School

On Monday, November 4, 2019, the NDSC Policy Team, in collaboration with American University Washington College of Law, hosted an event entitled "It's Never Too Early to Prepare: A Discussion of Pathways to Workforce Readiness and Employment." During this event there were panel discussions about the laws and policies that successfully prepare students for the transition to competitive integrated employment from early school age through adulthood. The panels, comprised of policy experts, as well as self-advocates, reviewed the current state of disability employment policy and proposed future changes. Self-advocates from around the county also participated in a poster session where they shared about their life and employment history. Close to 100 people were in attendance.

Thank you to our sponsors, Landsman Law Firm, Michael Orleans (NFP), Down Syndrome Association of Delaware, Chesapeake Down Syndrome Parent Group, F.R.I.E.N.D.S., Down Syndrome Network of Montgomery County.

We would also like to send a special thanks to Mitch and Julie Rothholz, the event Gold Level Sponsor.





Communication Skills in Adults with Down Syndrome

Libby Kumin, Ph.D., CCC-SLP

There is very little published information about communication skills in adults with Down syndrome and how those skills relate to activities of daily living and employment. It is often assumed that adults have mastered all of the language, speech, and social communication (pragmatics) skills and that there is no possibility for further growth and development. That is not true. There is no plateau on communication skills. There can be further learning and mastery of skills in adults with Down syndrome. As with all people, experiences, relationships, travel, reading, new environments, and jobs lead to further growth and development in adulthood.

Within school settings, speech-language pathologists work with children with Down syndrome, but they are rarely still working with children in middle and high school. Parents are told that the child's language level is commensurate with that child's measured IQ, so the SLP can no longer work with the child. Most IQ tests are strongly language based, so it would make sense that there would be a high correlation between the language level and IQ score. When you are told that, request that your child be tested with a nonverbal IQ test so that cognitive and language skills can be assessed separately.

The speech-language pathologist has an important role to play with the individual in middle school, high school and beyond. The speech-language pathologist (SLP) can analyze individual needs and provide information to families, community support workers, employers, and job coaches about speech, language, and communication skills. This information is valuable in planning for appropriate and successful employment. It is especially important that an assessment and treatment plan be included in the transition plan written at age 14, implemented at 16, and addressed until age 21. For example, we know that individuals with Down syndrome generally learn well visually and that they have difficulty following verbal instructions. The SLP can test to determine if that is the case for your child. If so, accommodations under the Americans with Disabilities Act can provide visual supports customized for work and home settings with repetitions and reminders such as posted rules, e.g. sign in, complete tasks, follow the schedule.

What do we know from the research? Adults with DS may have difficulty telling what happened to them when you ask. That kind of communication is known as complex narratives. In speech therapy, we can teach a model for remembering and stating complex information. This can be helpful within a daily living setting, as well as at work. Research asking adults with DS to tell a story after watching a wordless picture story "Frog Where are You." found that the adults expressed more plot line and content, and greater detail when describing the frog's adventures than TD controls matched for mean length of utterance (MLU) and mental age. Research has documented that adults with DS have shorter conversations and often take fewer turns in a conversation. Based on my clinical experience, adults who have many social contacts, often through Special Olympics, Best Buddies and other group activities have better conversational skills. Executive functioning including planning, organization and memory may be difficult. Auditory memory is difficult, and following spoken directions may be difficult, especially if they are long or complicated. Vocabulary is more advanced than grammar and sentence structure. Sociability is strong, but the adult may need help with social skills and navigating social interactions. Research demonstrates that many adults have good social reasoning skills, and could identify inappropriate social behavior in others, and describe why the behaviors were inappropriate. There is a wide range of skills in speech intelligibility with some adults being easy for listeners to understand and others being more difficult to understand.

What are examples of adult communication skills? The following list can be used by families in several different ways. It can be used as a checklist to evaluate the skills your adult child has mastered and the skills s/he needs to work on. For the SLP, it can be used to assess skills and develop treatment plans, or plans for transitioning to adulthood. If your adult child communicates well, it can be used as a checklist to document communication skills for employment and independent living. This is a list I have developed based on research findings and my clinical experience. You can add to the list for your child. If you observe other related skills, please send me suggestions, and together, we will add to the list so that it can be even more useful.

Pragmatics

- Conversational skills
- Social skills at work
- Social skills ADL
- Social reasoning skills
- Narrative discourse skills
 - Retells a story
 - Relates what happened during the day
- Communication breakdowns and repairs
 - Aware when another person is not understanding his/her message
 - Requests clarifications when she/he is not understanding instructions
- Topic introduction, maintenance, and closure
- Able to have a longer conversation
- Knowing which activities and requirements includes choices and which are non-negotiable
- Interactive language including both verbal and nonverbal skills,
- Use of appropriate gestures and body language
- Use of appropriate proxemics
- Decoding body language in others
- Compliments/criticizes appropriately
- Perspective taking

Receptive Language

- Maintains appropriate eye contact
- Understanding and following simple verbal directions
- Understanding and following complex verbal directions
- Verbal comprehension
- Auditory memory
- Listening skills
- Reading comprehension
- Understands time concepts
- Understands humor

Expressive Language

- Organization of thoughts for language encoding
- Formulating a message
- Vocabulary

- Morphosyntax (structure and grammar of language)
- Asks questions to gather information
- Asks questions for clarification
- Can provide reasons or excuses
- Can express feelings
- Can use scripts
- Can express humor
- Can describe object, person, or event

Speech

- Speech intelligibility/clarity
- Articulation
- Voice
- Resonance
- Fluency

Communication and related skills for employment

- Writing resumes
- How to find a job
- Interviewing skills
- Can use different registers-boss, coworkers
- Appropriate social skills, rules, greetings, farewells
- Appropriately getting attention, thank you, and apologies
- Appropriate proxemics
- Sequencing of daily living activities.
- Executive functioning skills
- Electronic communication/technology quotient
- Time management
- Money management
- Communication skills needed in the workplace
- Asking questions to understand required tasks at work
- Understanding the reason for the task and the value of the task at work
- Being able to visualize the tasks and uses visual supports
- Can remember and follow sequential instructions
- Needs ADA accommodations-models and visual directions and cues

Dr. Libby Kumin is a professor of Speech-Language-Hearing Sciences at Loyola University Maryland. She is active in giving presentations to local and regional family support groups, and frequently speaks at the NDSC Convention.



A Year in Review

NDSC's Center for Outreach & Education provides individuals with Down syndrome, their families, and the medical and educational professionals that serve them, with meaningful and interactive programs.

Over the course of the last 12 months we've reached more than 20,000 people, across the country and beyond, through our Rural Outreach programming, Adult Sibling trainings, Parent Webinars, First Responders trainings, Educators Conferences, and Medical Outreach.

Our Programs & Partnerships team has traveled up, down and all around - working with local, national, and international Down syndrome support organizations. We've also forged a successful partnership with local groups in our area to work on various programs as the Georgia Down Syndrome Consortium. With the help of many expert presenters and self-advocates we've helped put on one-day conferences in underserved areas and trained educators on best practices for including children with Down syndrome in the classroom. We've exhibited at medical conferences, providing accurate and up-to-date information where it is needed most.

By taking all of the resources and programs that the NDSC currently offers, and delivering them directly to populations across the country, we can truly make an impact on the lives of everyone who needs, and requests, this vital outreach and education.

To learn more, visit the "Outreach & Education" tab on our website.



LuMind IDSC Research Rally Follow-up

Last June at the 47th Annual NDSC Convention Lumind IDSC hosted the 2019 Research Rally and Breakfast. The event featured a panel of experts including Dr. Brian Chicoine of Advocate Health, Dr. George Capone of the Kennedy Krieger Institute, Dr. Mary Pipan of the Children's Hospital of Philadelphia, and Dr. Brian Skotko of Massachusetts General Hospital and Harvard Medical School.

The panel discussion was moderated by Dr. James Hendrix, the Chief Scientific Officer of LuMind IDSC.

The rally had approximately 400 people in attendance and more than 200 questions were submitted to the Research and Medical Care Q&A Panel. The time allotted for the event did not allow for all questions to be addressed at the rally. LuMind IDSC and the panelists have collaborated to produce a FAQ to include all unanswered questions covering topics such as Alzheimer's and Dementia, Inflammation and Autoimmune Disease, Regression, Hearing Loss, Lifestyle, and the Latest Research to name a few. The complete write-up and video of panel introductions are available on the LuMind IDSC website at www.lumindidsc.org.



In 2020 the Hyatt Regency New Orleans will be home to the **NDSC 48th Annual Convention**.

This 1,193 room, world-class hotel blends historic Big Easy style with contemporary design. Centered downtown near Champions Square, just steps from the Mercedes-Benz Superdome, and minutes from the historic French Quarter, Arts District, and Mississippi Riverfront, you will be able to take in all of the cultures of New Orleans offers. There is no better place from which to explore the history and eclectic vibrancy of New Orleans.

The hotel block will open with Convention registration in early April of 2020.

Lagniappe in the New Year



GIVING TO THE NSDC

Lagniappe: /lan'yap/ Noun: a bonus or extra gift



A Little Something Extra for the New Year!

This past year has been one of tremendous growth for the NDSC. In 2019, with the addition of the new NDSC Center for Outreach & Education, we have provided resources to communities across the nation and abroad. We have served more individuals with Down syndrome and their families where they are than ever before. Online we have hosted webinars on a variety of topics and our Policy & Advocacy Team has worked diligently to influence legislative change and hosted the first-ever NDSC Policy Seminar in Washington, D.C. We have hired new staff and continue to make strides to upgrade our flagship event, the annual NDSC Convention.

Lagniappe (pronounced LAN yap) is a word used primarily in the region influenced by New Orleans and therefore customary of the Louisiana French culture. It means "a little something extra given as a bonus or gift". We hope that when making your year-end contribution you will consider giving "a little something extra" so that we may continue providing resources and valuable programming through the NDSC Center for Outreach & Education in 2020.





Celiac Disease and Down Syndrome

Celiac disease is a chronic digestive condition where the body reacts to combat a protein called gluten. Gluten is found in foods such as wheat, barley, and rye. People with Celiac disease will show signs of an immune reaction against gluten that affect a person's ability to digest nutrients.

In the typical population, approximately 1 out of 100 people may have CD. This number is increased in the population of people with Down syndrome to approximately 10 out of 100.

Many times the symptoms of Celiac disease go untreated or the diagnosis of Celiac disease is not determined initially. Misdiagnosed symptoms or delayed diagnosis of Celiac disease can lead to malnutrition, decreased growth, and complications such as lymphoma. Since Celiac disease is more common in children with Down syndrome, early screening is important. Many doctors who regularly treat patients with Down syndrome will recommend Celiac disease testing. It is important for parents to be aware of the symptoms of Celiac disease and to share with their child's doctor if they notice the symptoms.

When symptoms are present initial testing usually involves ordering a blood test that detects Celiac disease antibodies. If screening test results are positive for the Celiac disease antibodies more testing will be needed to confirm the diagnosis. The next step after receiving a positive blood test is generally to follow with an upper endoscopy. This procedure requires anesthesia. During the procedure, a gastroenterologist uses a lighted, flexible camera to examine the intestines and digestive tract. A biopsy, or tissue sample, will be taken and examined to determine if Celiac disease is present.

If the diagnosis of Celiac disease is determined the best treatment is adopting a 100% gluten-free diet. This means removing all wheat, barley, and rye from a person's diet and avoiding cross-contamination with these foods as well.

Adapting to a gluten-free diet can sound a little overwhelming at first but simple changes and learning to read labels will soon become second nature. Begin by educating yourself about gluten-containing foods, and incorporating naturally delicious gluten-free grains and foods into the diet. Eliminating most processed foods and instead opting for whole food choices such as fresh fruits and vegetables is important to the management of Celiac disease. It is important to note that one should be cautious of cross-contamination in prepackaged, processed foods.

Symptoms of Celiac disease most commonly include:

- Stomach pain or bloating
- Diarrhea
- Constipation
- Growth failure
- Anemia
- Behavioral problems
- Personality changes such as irritability

Many naturally delicious gluten-free foods are available and include:

- All fruits including berries, banana, mango
- All vegetables
- Beans, seeds, and nuts including nut butters
- Eggs
- Potatoes
- Lean, non-processed meats, poultry and fish
- Most low-fat dairy products including yogurt, cow, almond, soy, and rice milk
- Cold or hot cereal (made from puffed rice, quinoa, millet, amaranth, teff, or other GF grains)
- Corn tortillas
- Other things that can be added to foods include cinnamon, maple syrup, hummus, cream cheese, salsa, guacamole, and bean dip.

Grains, starches or flours do not have to be completely eliminated from the diet of someone with Celiac disease. Those that can be consumed in a gluten-free diet include:

- Amaranth
- Arrowroot
- Buckwheat
- Corn and cornmeal
- Flax
- Gluten-free flours (rice, soy, corn, potato, bean)
- Hominy (corn)
- Oats (although inherently gluten-free, oats are often cross-contaminated with wheat or barley during harvesting or processing. Only certified gluten-free oats should be consumed on a gluten-free diet.)
- Millet
- Quinoa
- Rice
- Sorghum
- Soy
- Tapioca (cassava root)
- Teff

There are different varieties of wheat, all of which contain wheat gluten. Wheat flours also have different names based on the milling process. All of the following kinds of wheat and flours have gluten and should be avoided:

- Durum
- Einkorn
- Emmer
- Enriched flour with added vitamins and minerals
- Farina, milled wheat usually used in hot cereals
- Graham flour, a coarse whole-wheat flour
- Kamut
- Self-rising flour, also called phosphate flour
- Semolina, the part of milled wheat used in pasta and couscous
- Spelt

With a surge of people choosing gluten-free diets more gluten-free foods are now more readily available. Foods that are labeled gluten-free, according to the Food and Drug Administration, must have fewer than 20 parts per million of gluten. In order for foods to include the gluten-free labels they must include:

- Naturally gluten-free foods
- Prepared foods that do not have a gluten-containing ingredient
- Food that has not been cross-contaminated with gluten-containing ingredients during production
- Food with a gluten-containing ingredient that has been processed to remove gluten

Many gluten-free processed foods that are available include gluten-free breads, pancakes, waffles, and French toast, muffins, and pastas.

Making significant lifestyle adjustments can be challenging. Some may find it necessary to consult a specialized Registered Dietitian to assist with their unique dietary needs. Joining a support group may benefit others and always rely on your doctor's recommendations.

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2020 NDSC Awards Nominations are Open!

Each year awards are presented at the convention to recognize individuals and organizations for outstanding achievement and contribution within the Down syndrome community.

Nominations are now being accepted for all award categories. If you know of an individual or organization that you feel is deserving of consideration for one of the 2020 NDSC awards, please nominate them through our online nomination form.

Nominations may be submitted by any person or organization wishing to direct the attention of the NDSC Board of Directors to outstanding achievement. In its selection, the Board of Directors will not necessarily be restricted to those programs or individuals, but may consider reports of outstanding achievement from other sources and may, on its own initiative, select award recipients.

Nomination forms and supporting materials should be submitted by mail, e-mail or fax to the NDSC Center by January 3, 2020. Selections are made in the Spring. All awards will be presented at the NDSC Annual Convention.

Award Categories

Exceptional Meritorious Service Award

This award recognizes an individual whose service and contributions to people with Down syndrome and their families have had local, state and national significance.

Employer of the Year Award

This award recognizes an employer for efforts in creating employment opportunities for people with Down syndrome.

Christian Pueschel Memorial Citizen Award

This award recognizes an individual with Down syndrome whose achievements, service and contributions have enhanced the value and dignity of people with Down syndrome and their families.

Sig Pueschel NDSC Service Award

This award recognizes an individual or organization for outstanding contributions to the NDSC.

National Parent Group Award

This award recognizes an affiliate parent group of the NDSC, which has performed outstanding service on behalf of people with Down syndrome and their families. Parent groups will be judged on advocacy services, relationship to the NDSC, support to families, fundraising activities and local and regional programs and services.

Pueschel/Tjossem Memorial Research Award

This award recognizes research, which has contributed to greater knowledge and understanding of Down syndrome and has improved the lives of people with Down syndrome or their families.

AWARD GUIDELINES

- Does the program, publication, or individual promote a positive image of people with Down syndrome?
- Does it accentuate abilities, not disability?
- Does it focus on people, not on the condition of Down syndrome?
- Does it celebrate diversity?
- Does it use people-first language?
- Does it enhance the dignity of people with Down syndrome?
- Does it avoid stereotyping?
- Does it present accurate information?
- Does it recognize the value of the person with Down syndrome?

National Media Award

This award honors outstanding national media efforts, which create better understanding of Down syndrome and people with Down syndrome. The award recognizes programs on television, documentaries, feature films, national publications, serials, syndicated columns and social media. National Media Awards may be presented for the categories of film, print and online. The media efforts must have been broadcast or published within the last calendar year.

Education Award

This award recognizes outstanding performance on behalf of students with Down syndrome. Nominees will be judged by their demonstrated leadership and innovation in creating or advancing best educational practices for students with Down syndrome.



Habilidades comunicativas en adultos con síndrome de Down

Por Libby Kumin, Ph.D., CCC-SLP

Traducción al español dentro del proyecto PerMundo para la traducción gratuita de páginas web y documentos para ONG y asociaciones sin ánimo de lucro. Proyecto dirigido por Mondo Agit. Traductora: María Loaisa Gomez. Revisor: Alan Jean François.

No hay mucha información publicada acerca de las habilidades comunicativas en adultos con síndrome de Down ni de cómo están relacionadas estas habilidades con las actividades de la vida diaria y el trabajo. Se piensa que los adultos dominan todas las habilidades del lenguaje, el habla y la comunicación social (pragmática), y que no hay posibilidad de que crezcan y se desarrollen más. Esto no es verdad. Las habilidades comunicativas no tienen límites. Los adultos con síndrome de Down pueden experimentar un mayor aprendizaje y dominio de estas habilidades. Como sucede con todas las personas; las experiencias, las relaciones, los viajes, la lectura, los nuevos entornos y los trabajos producen un mayor crecimiento y desarrollo en la edad adulta.

Dentro del ámbito escolar, los logopedas trabajan con niños con síndrome de Down, pero rara vez continúan trabajando con ellos cuando ingresan en la middle y high school (en España comprendería los cursos 6º de primaria – 2º de bachillerato). A los padres se les comunica que el nivel de lenguaje del niño es proporcional a su coeficiente intelectual (CI), por lo que el logopeda ya no podrá trabajar con el niño. La mayoría de las pruebas de CI están basadas en el idioma, por lo que tendría sentido que existiera una alta correlación entre el nivel del idioma y la puntuación del CI. Cuando le digan eso, pida que su hijo se someta a una prueba de coeficiente intelectual no verbal para que se puedan evaluar por separado las habilidades cognitivas y del lenguaje.

El logopeda desempeña un papel importante con la persona en la middle school, high school y más adelante. Puede analizar las necesidades individuales y proporcionar información a las familias, a los compañeros de trabajo, a los empresarios y a los asesores laborales sobre el habla, el lenguaje y las habilidades comunicativas. Esta información es necesaria para planificar un empleo apropiado y exitoso. Es muy importante incluir una evaluación y un tratamiento en el plan de adaptación escrito a los 14 años, implementado a los 16 años y abordado hasta los 21 años. Por ejemplo, sabemos que las personas con síndrome de Down tienen facilidades a la hora de aprender algo visualmente, pero tienen dificultades a la hora de seguir instrucciones verbales. El logopeda puede hacer una prueba para determinar si es el caso de su hijo. Si es así, las adaptaciones de la ley sobre estadounidenses con discapacidades proporcionarían apoyos visuales personalizados para el trabajo y el hogar con repeticiones y recordatorios tales como normas publicadas, por ejemplo, registrarse, completar tareas, seguir el horario.

¿Qué sabemos de la investigación? A los adultos con síndrome de Down les puede resultar complicado recordar qué les pasó cuando se lo preguntaste. Ese tipo de comunicación se conoce como narrativas complejas. En la terapia del habla, podemos enseñar un modelo para recordar y expresar información compleja. Esto puede ser útil tanto en la vida diaria como en la vida laboral. La investigación pide a los adultos con síndrome de Down que cuenten una historia después de ver un cuento ilustrado que no contiene palabras «Frog Where are You». Se descubrió que los adultos expresaban más argumentos, contenidos y detalles

Pragmática

- habilidades para la conversación
- habilidades sociales en el trabajo
- habilidades sociales ADL (Advanced Distributed Learning, ADL, por sus siglas en inglés)
- habilidades de razonamiento social
- habilidades narrativas discursivas
 - volver a contar una historia
 - contar lo que pasó durante el día
- fallos y correcciones durante la comunicación
 - se da cuenta cuando otra persona no está entendiendo su mensaje
 - pide aclaraciones cuando no está entendiendo las indicaciones
- introducción, nudo y desenlace del tema
- capaz de tener una conversación más larga
- saber qué actividades y requisitos incluyen opciones y cuáles no son negociables
- lenguaje interactivo que incluye habilidades tanto verbales como no verbales
- uso de gestos y de un lenguaje corporal apropiados
- uso de la proxémica adecuada
- decodificar el lenguaje corporal en otros
- elogio/crítica apropiada
- toma de conciencia

Lenguaje receptivo

- mantener un contacto visual apropiado
- entender y seguir indicaciones verbales sencillas
- entender y seguir indicaciones verbales complicadas
- comprensión verbal
- memoria auditiva
- habilidades de escucha
- comprensión lectora
- entender los conceptos de tiempo
- entender el humor

Lenguaje expresivo

- organización de pensamientos para la codificación del lenguaje
- formulación de un mensaje
- vocabulario

- morfosintaxis (estructura y gramática del lenguaje)
- formulación de preguntas para obtener información
- formulación de preguntas para aclarar
- puede proporcionar razones o excusas
- puede expresar sentimientos
- puede usar guiones
- puede expresar humor
- puede describir objetos, personas o eventos

Forma de hablar

- inteligibilidad de la palabra/claridad
- pronunciación
- voz
- resonancia
- fluidez

Comunicación y habilidades relacionadas con el empleo

- escribir el currículum
- cómo encontrar un trabajo
- técnicas para la entrevista
- puede usar diferentes registros - jefe, compañeros de trabajo
- uso de destrezas sociales apropiadas, reglas, saludos, despedidas
- capta la atención apropiadamente, gracias, y disculpas
- proxémica apropiada
- secuencia de las actividades de la vida diaria
- habilidades de funcionamiento ejecutivo
- cociente de comunicación electrónica/tecnología
- administración del tiempo
- administración del dinero
- habilidades de comunicación requeridas en el lugar de trabajo
- hacer preguntas para entender las tareas requeridas en el trabajo
- comprender la razón y el valor de dicha tarea en el trabajo
- ser capaz de visualizar las tareas y utilizar soportes visuales
- poder recordar y seguir instrucciones secuenciales
- necesidad de adaptaciones de la ley para personas con discapacidades (ADA por sus siglas en inglés) - modelos y direcciones visuales y señales

al describir las aventuras de la rana que los controles de TD, que coincidían con la duración media de la expresión (Mean Length of Utterance, MLU, por sus siglas en inglés) y la edad mental. La investigación ha documentado que los adultos con síndrome de Down tienen conversaciones más cortas e intervienen menos en ellas. Basado en mi experiencia clínica, los adultos con muchos contactos sociales, a menudo a través de las Olimpiadas Especiales, Best Buddies y otras actividades de grupo, tienen mejores habilidades comunicativas. El funcionamiento ejecutivo, incluyendo la planificación, la organización y la memoria, puede ser complicado. La memoria auditiva, así como seguir instrucciones habladas, puede ser difícil, especialmente si son largas o complicadas. El vocabulario es más avanzado que la gramática y la estructura de las oraciones. La sociabilidad es fuerte, pero el adulto puede necesitar ayuda para mejorar sus capacidades de interacción social. La investigación demuestra que muchos adultos tienen buenas habilidades de razonamiento social, y podrían identificar el comportamiento social inapropiado en otros, y describir por qué los comportamientos fueron así. Hay una amplia gama de habilidades en la inteligibilidad del habla: algunos adultos son fáciles de entender para los oyentes y otros, por el contrario, son más difíciles.

¿Cuáles son los ejemplos de habilidades comunicativas en adultos? Las familias pueden emplear la siguiente lista de diversas maneras. Se puede usar como una lista de verificación para evaluar las habilidades que domina su hijo adulto y en las que necesita trabajar. El logopeda puede utilizarla para evaluar las habilidades y desarrollar planes de tratamiento o para la adaptación a la edad adulta. Si su hijo adulto se comunica bien, podrá usar la lista para documentarse acerca de las habilidades comunicativas para el trabajo y la vida independiente. Esta es una lista que he creado en base a los resultados de la investigación y a mi experiencia clínica. Usted puede agregar datos a la lista para su hijo. Si observa otras habilidades relacionadas, por favor envíeme las sugerencias, y lo añadiremos a la lista para que pueda ser aún más útil.

La Dra. Libby Kumin es profesora de Ciencias del Habla, Lenguaje y Audición en la Universidad de Loyola, Maryland. Participa activamente en presentaciones ante grupos locales y regionales de apoyo a las familias, y habla con frecuencia en el National Down Syndrome Congress.



Quiéreme Como Soy

Nuestro compañero Mateo Fernández, Director de Programas Multiculturales tuvo el placer de asistir al el evento “Quiere Como Soy” en Santiago, República Dominicana. Este fue un gran evento con muchos miembros de la comunidad para promover la inclusión. ¡Tenemos que promover la inclusión!



48ª Convención Anual del NDSC 25 de junio al 28 de junio de 2020 Nueva Orleans, LA!

Cada año, miles de personas de todo el mundo asisten a la Convención anual de síndrome de Down. La mayoría van para escuchar la información más reciente de expertos de renombre mundial. Para otros, son unas increíbles vacaciones. Sin embargo, para casi todos, es la sensación única de la gran reunión familiar del NDSC que contagia el fin de semana de la convención. Pero entendemos que cuando planifica un viaje puede ser estresante, así que utilice esta guía para planificar el viaje perfecto a una Convención NDSC. Si está interesado, envíe un correo electrónico a Mateo Fernández a matthew@ndscenter.org



48ª CONVENCION ANUAL DEL NDSC

Lagniappe: /lan'yap/ el sustantivo: algo extra

Down Syndrome News

is a benefit of your annual membership in the NDSC.

To renew or join, visit ndscenter.org.

To update your contact information, call 800-232-6372 or email info@ndscenter.org.

When we **empower** individuals and families from all demographic backgrounds, we **reshape** the way people understand and experience Down syndrome.



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Mission

The mission of the NDSC is to provide information, advocacy, and support concerning all aspects of life for individuals with Down syndrome.

Vision

The vision of the NDSC is a world with equal rights and opportunities for people with Down syndrome.

Statement of Policy and Disclaimer.

This newsletter reports items of interest relating to Down syndrome and provides a forum for others. The NDSC does not promote or recommend any therapy, treatment, etc. NDSC will not espouse any particular political or religious view. Individuals or organizations referred to are not necessarily endorsed by this publication or its editor. The National Down Syndrome Congress works to educate, advocate and empower. We are the leading national resource of support and information for people seeking to learn about Down syndrome.

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