



ISLAND COUNTY

Parent to Parent Newsletter

SUMMER 2016

Fun in the Community: Hanging Out Special Needs Style

Do you want to see a movie? Jump on a trampoline? Visit a museum? Bounce on some inflatables? Swim during a sensory friendly session? If you have a child with complex needs, some of these trips may be very challenging. Your kid might vocalize through the entire movie. She might get jumped on while trying to bounce on some inflatables. He might get overwhelmed by hundreds of loud people at a water park or museum. Fortunately, many community locations now offer nights or mornings specifically for children with special needs. And even better, many of them are free!

MOVIES



AMC Theatres pioneered Sensory Friendly Films, a monthly event that occurs all over the country. Each month, a popular film is chosen, and the theatre is reserved for families with special needs. Lights remain on, the sound is turned down, and the environment is welcoming to children who might make noise, move around, or otherwise act like kids! While created for children with autism, the program works well for many children with special needs. For more information, www.amctheatres.com/programs/sensory-friendly-films. Cascade Mall: Burlington, WA Films are featured on the 2nd and 4th Tuesday and Saturday of each month. **Tuesday showings: 7:00pm, Saturday showings: 10:00am.** Call to Verify times, dates and films. (360)707-2727.

July Movies: 7/9 Secret Life of Pets 7/12 The BFG 7/23 Ice Age:Collision Course 7/26 GhostBusters

August Movies: 8/9 Suicide Squad 8/13&27 Pete’s Dragon 8/23 War Dogs

BOUNCING AND JUMPING



Lots of kids love to bounce and jump, but they may have trouble participating due to the chaos that tends to exist at trampoline and inflatable franchises. Many of these companies now offer a special needs night that is much calmer and safer for children with medical needs. **Pump it Up Sensory Jump Time (Inflatables)** is scheduled the **2nd Tuesday of the month at their Lynnwood office, 6:15-7:30pm.** (425)774-2297.

Elevated Sportz (trampoline) Uplift! Special Needs offers special needs jumps monthly at its Bothell location, is the **2nd Tuesday of the month, 6-8:30pm** (425)949-4488 Both places offer these dates for the summer. **(July 12th • Aug 9th • Sept 13th)** Please call and verify dates and times.

MUSEUMS & PACIFIC SCIENCE CENTER

Many children’s museums offer a special needs or sensory time each month, usually in the morning before the museum opens, or in the evening after it closes. These events work really well for families who need a little extra time to navigate the museum, or who need a calmer atmosphere. Seattle Children’s Museum offers a Sensory Sensitive Event on July 2nd, 8:30-10am. Tickets must be pre-purchased. (206)441-1768. Imagine Children’s Museum in Everett offers a **Free Admission Night FREE Admission the 3rd Friday of every month 5:30 – 9pm June 17 • July 15 • August 19 • September 16** (425)258-1006xt1000.

continued on page 7.....

INSIDE THIS ISSUE:

- Air Travel 2
- Fly Day 3
- Female Puberty 4
- Medical Equip Tips 5
- Support Groups 6-7
- Upcoming Events 8

Options for Air Travel for Children with Severe Physical Disabilities



*“Difficult Roads
often lead to
Beautiful
Destinations !”*

We want to show our children the world, despite their physical disabilities. But current Federal Aviation Administration (FAA) rules make this challenging. At this time, children are not allowed to ride in positioning wheelchairs--or any wheelchairs for that matter--on an aircraft. While we surely hope this policy will be reconsidered in the near future, we have to make do until it is resolved.

In this article, I will discuss a variety of options that may make it possible to fly with a child who is unable to sit up by him or herself.

Option 1: Use a Car Seat

For US-based flights, children may ride on the plane in an FAA-approved car seat. This includes FAA-approved special needs car seats. Note that many car seats are NOT FAA approved, though most major-brand seats are. Make sure that the seat itself is labeled as certified for use on an aircraft.

The airplane seat must remain in an upright position for takeoff and landing, which may make using a reclining car seat of limited use for some families. However, seats can be installed on an aircraft in a rear-facing (and thus reclined) position as long as the seat is designed to be used in that manner for your child's weight/height.

The FAA also approves some models of special needs car seats. These include certain models of the Special Tomato MPS car seat, the Convoid Carrot, the Tumble Forms Carrie Seat, the Columbia TheraPedic Seat, and the Thomashifen Recaro Performance Sport Reha. Always verify that your model is FAA-approved before traveling. Once again, these seats must be placed in a fully upright position for takeoff and landing.

It may be possible to borrow or rent one of these car seats for a trip. Some facilities, such as Shriners Hospitals, Easter Seals, or UCP, may have them available on a loaner basis.

Note that most non-FAA approved orthopedic seating devices can be used while in the air, as the restrictions on specialized seating are only in effect during takeoff and landing, when the seats must be in the upright position. If your child can make it through takeoff and landing without an orthopedic seating device, you can transfer him or her to the positioning device for the remainder of the flight.

Option 2: Fly with Your Child on Your Lap

While not ideal from a safety standpoint, sometimes holding your child is the best possible option. Most airlines allow you to hold a child on your lap during the flight, including takeoff and landing, as long as the child is under two years old.

Option 3: Use the CARES Harness or Other Approved Devices

The FAA has approved a belt system for children over age one who weigh between 22 and 44 pounds called the CARES harness. This device is currently the only FAA approved option that can be used on US flights. It is also used widely in Europe.

This harness can be carried onto the flight easily and is simply attached to the seat. It turns the seat into a chair with a five-point harness, which may work for children with some head control but limited upper body control.

CARES also makes a larger version of the harness for children and adults with special needs. Note that in order to use this device, a child must get pre-approval from the FAA, a process that typically takes six to eight weeks. Approval is only required the first time you plan to use the device, and is not required on subsequent flights. The harness can only be used in certain seats on the plane, typically the last row of seats. Detailed instructions on obtaining preapproval are available on the CARES website.

In Europe there are many more approved options for use on aircraft. In fact, many European airlines provide child travel seats, support cushions, or harnesses for individuals with disabilities. See, for example, this page from Virgin Airlines. A UK-initiative, Try B4UFLY, allows for trial and rental of approved devices in that country. Hopefully we will begin to see these types of devices and accommodations available in the United States within the next few years.

Option 4: Make Your Own Modifications

Certain positioning items may be used at all times on an aircraft, including during takeoff and landing, and these may be enough to help your child sit up. Travel head and neck pillows are allowed, and simple head collars designed for children with disabilities, such as the Hensinger head collar, are also allowed in most circumstances. Some of the commercially available travel pillows, especially the inflatable styles and neck rests/collars, provide remarkable support, though they may be too large for small children. Nonslip seating pads that prevent your child from sliding off the seat are extremely useful. Inflatable lumbar supports and cushions are also allowed. A small wedge cushion used backwards to slightly recline a child is also permitted in most cases. Note that anything filled with gel will likely not be permitted on the plane.

Option 5: Take a Medical Flight

Some airlines and specialty organizations offer medical air flights either for free or for very discounted rates (as compared to renting a plane yourself!). On these flights, your child may be able to ride on a stretcher or a similar device. This type of flight is particularly useful for children who require frequent procedures or have extensive medical technology.

Current options include the following: National Patient

Travel Center, Air Charity Network, Air Care Alliance, Angel Flight, Corporate Angel Network, Miracle Flights for Kids

There are, however, restrictions on these flights. Most can only be used to go to medical appointments or conferences. Many restrict children with a history of certain bacterial infections. Some restrict flights to individuals who are ambulatory, thus entirely defeating the purpose for children with physical disabilities who struggle to fly.

There are numerous other Air Ambulance services that may provide non-emergency flights, though these can be quite costly.

Option 6: Stretcher Service

While rarely available in the United States and usually very expensive, it is permitted for a child to ride on a stretcher on a commercial airline. In most cases, this requires removal of a row of seats, and the cost of all removed seats is charged to the individual flying. This option is more widely available in Europe and Asia.

We hope one of these options works for your child!



Seattle/Everett Fly Day – Saturday, July 23, 2016



Please join us on Saturday, July 23 at Paine Field Airport Historic Flight Museum for a Fly Day! Pilots, Volunteers, Families, and Agencies all need to register here on this website. We look forward to seeing you there!

Challenge Air was created to change the perception of children with special needs through the gift flight. Since 1993, we have been committed to making a difference in the lives of children with special needs. With a network of 3,500 volunteers nationwide, we continue to grow through events called Fly Days.

By eliminating the belief that they are limited, the children can grow to their full potential. They are given the opportunity to find courage within themselves and build in areas where they lack self-esteem.

Challenge Air provides an unforgettable growing experience that opens the door to possibilities while allowing the children to see if they can fly a plane they can do anything.

Mission:

Challenge Air for Kids & Friends, Inc., exists to build confidence and self-esteem in children and youth with special needs through the gift of flight.

Program Goals:

- 1) To improve the quality of life for children/youth and families with special needs
- 2) Arouse children/youth with special needs to be excited about learning and inspired about their future
- 3) Educate children/youth about the aviation industry and encourage them to consider occupational roles other than the customary ones to which they are generally directed
- 4) Involve and promote civic and community engagement
- 5) Create an environment for peer interaction for children/youth with special needs.
- 6) Promote local organizational resources to families with special needs.

To Register: <http://www.challengeair.com/air-events1/>

Please join us on Saturday, July 23 at Paine Field Airport Historic Flight Museum for a Fly Day! Pilots, Volunteers, Families, and Agencies all need to register here on this website. We look forward to seeing you there!

Date/Time

Date(s) - July 23, 2016 ; 9:00 am - 4:00 pm

Location: Seattle/Everett, WA - Paine Field Airport

Contact Phone Number: (214)3512-3353

HURRY, SPACE IS LIMITED.

Doctors Urged To Address Needs Of Females With Disabilities

by Shaun Heasley | June 22, 2016

Birth control pills are among the most common menstrual management tools used by teenagers who have developmental disabilities, according to new guidance from the American Academy of Pediatrics. The group is encouraging pediatricians to be proactive in helping adolescents with disabilities manage their changing bodies.

Pediatricians are being encouraged to take a more active role in helping families prepare for and adapt to the changes that come with puberty for girls with disabilities.

In a clinical report that will be published in the July issue of the journal *Pediatrics*, the **American Academy of Pediatrics** says that doctors should be ready to address the unique needs of adolescents with physical and intellectual disabilities surrounding puberty and menstruation.

“Even before the onset of menses, the pediatrician could be asked to assist with anticipatory guidance and options for the menstrual cycle because of parental fear of menstrual periods or hormonal mood changes as well as the complex issues of sexuality, vulnerability and fertility in the context of the disability,” according to the guidance crafted by the pediatrics group’s committee on adolescence together with the North American Society for Pediatric and Adolescent Gynecology.

The issues surrounding puberty for girls with disabilities are complex, the report acknowledges, transcending health as well as practical, legal and moral considerations.

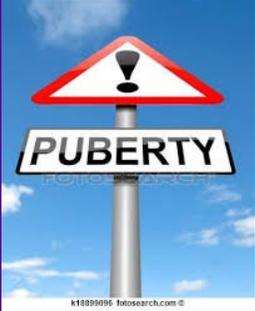
The presence of some developmental disabilities may affect the timing of sexual development while medications and self-care abilities can complicate the experience for girls and their families, the guidance indicates.

Pediatricians are urged to be prepared to discuss menstrual management options like birth control as well as surgical options like hysterectomy.

However, the pediatrics group warns that all of these considerations should be weighed in the context of legal and ethical obligations, particularly in cases where patients have intellectual disabilities and may not be able to give consent. And, the guidance recommends that physicians investigate further if families are pushing for some form of menstrual suppression solely due to concerns about being able to provide care or worries about abuse or pregnancy.

In addition to working with girls and their families, doctors are advised to step in if adolescents with disabilities need help obtaining hygiene assistance at school.

“The pediatrician plays a pivotal role during the sometimes difficult pubertal transition for patients with physical and intellectual disabilities,” according to the report.



Puberty is tough on everyone. Add special needs to the mix, and things can get complicated. Talk to your doctor, your friends, find resources.



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10 Tips for Getting Out of the House with a Ton of Medical Equipment



by Susan Agrawal

Forget about traveling--sometimes just getting out of the house for an hour seems impossible! But it IS possible, even for kids with a lot of medical devices, with just a few hacks. The most important thing to know is that the more you do it, the easier it gets.

Here are a few tried and true tips for getting out of the house:

1. Make a master list. If you are trying to simply remember what you need to bring, you are likely to forget something. It is best to make a master list of everything you need when you leave home. In fact, you may want to make more than one list--one for short trips out, and one for longer day trips. If the list is unlikely to change much, you may want to laminate it. Another option is to put it in a plastic protective sleeve. In either case, you can typically use a dry erase marker to check off items as you go along.

2. Have a pre-packed Go Bag. If you want to simplify the process, keep a pre-packed bag with all of your child's basic supplies and emergency supplies all ready to go. Keep a list of what should be in the bag, and when you get home, make sure to immediately replace anything you used. A backpack, large carry bag, or small rolling suitcase may work well as a Go Bag.

3. Pack by system or medical device. If your child has multiple medical technologies, such as a feeding tube and a tracheostomy, or your child has multiple medical conditions, such as feeding and bladder problems, you may want to consider packing by system or condition. For example, everything related to the feeding tube can be in one box or bag, while everything related to cathing or trach care can be in another. Some parents use large pencil cases or travel packing cubes to separate items. Then you can simply grab the relevant case or cube when you need to do a procedure or feeding!

4. Make sure you have portable

equipment. There are portable versions of almost every device out there, but that doesn't always mean you will get them automatically. Your DME or home health supplier may not know what is the best option, and sometimes companies or insurers automatically go with the cheapest option instead of the best one. Are you struggling with an old feeding pump that weighs a ton, or the massive old dinosaur CoughAssist device? There are now tiny feeding and IV pumps, portable CoughAssist devices and ventilators, small pulse-oximeters, and portable suction pumps. Make sure you have the very latest equipment, in the smallest sizes that meet your child's needs.



5. Don't forget power! Most medical devices either require battery power or electrical charging. In either case, don't forget the power! Power cables and

chargers are the most common items to be forgotten. Bring along an extra set of batteries for devices that run on regular batteries. For those items that run on specialized batteries, see if it is possible to get a backup battery to carry along for security. For example, both the Trilogy ventilator and CoughAssist device can run on the same small, replaceable battery. If your child requires a lot of power, consider bringing along an inverter to charge in the car, or a portable battery, such as a marine battery, to power all the equipment in an emergency.

6. Set up your backup equipment as travel equipment. In many cases, insurers and DMEs will allow you to have a backup device if your child's life is dependent on a particular item. For example, most children who use a ventilator for most or all of the day will be able to receive a backup ventilator. The same is true for IV pumps and suction machines. Many families choose to keep their backup equipment set up and ready to go for travel. They can simply transition from their home equipment to their travel equipment and be on the way immediately!

7. Prepare how you will carry the equipment. If your child has a wheelchair or medical stroller, you may be able to attach most of the equipment to the chair. Your DME and

wheelchair provider should be able to help you attach a carrying case for a ventilator or an IV pole for a feeding or IV pump. Many wheelchairs can also be adapted with a tray beneath the chair for other equipment. Additional equipment, including feeding and IV pumps, as well as some pulse oximeters, can be clamped to the chair itself using clamps from your DME. Large, sturdy carabiner clips can also be used to hook bags for carrying oxygen, feeding pump backpacks, and other items. If your child does not have a wheelchair, you can choose to use a small luggage cart (with a lot of bungee cords) or even a collapsible granny cart. This will allow you to pull items instead of carry them.

8. Bring extras and be prepared for emergencies. If you always pack a bit extra, you will likely never run out, even if your child decides to soil five diapers in a row, or the extension set breaks in half twice. Make sure you think about likely emergencies and have equipment to handle them. Can you handle a trach or tube falling out? What if the vent dies? Also, bring along some handy fix-it equipment that can be used a variety of situations, such as medical tape, duct tape, and scissors.

9. Bring your emergency information. Children with complex needs should always travel with emergency information, even if they are just going around the block. At minimum, you should carry a piece of paper with your child's name, primary diagnoses, and contact information for all parents/guardians and your child's main physician. It can also be helpful to include a brief one or two page summary of your child's condition, including medications. A great option is the AAP/ACEP Emergency form, created by pediatric emergency doctors specifically for this purpose.

10. Practice makes perfect! The first time you try to go out, it likely will take an hour just to get ready. Each time you repeat the process, you will get faster. Keep practicing, and soon you will be out the door in no time!

- See more at: <http://articles.complexchild.com/march2016/00683.html#sthash.CMLWkSff.dpuf>

Support and Advocacy Groups

Friends Helping Friends

A support group for any and all who are raising a child with special needs

When: Third Thursday of the Month, Notice New time **6-7:30pm,**

July 21st (Yoga in the Park) August 18th September 15th



Located at Aptitude Habilitation Services in Oak Harbor. Childcare provided, please contact Stephanie at smartin@aptitudeservices.com Questions and to verify date and time, contact Jaemie Witmer at jaemie.w@tlcwhidbey.org

Parent Support Partnership

Want Support from Others who “get it”?

Are you concerned about your child’s physical, intellectual or emotional development? Are you worried about behaviors, mood swings, school success, social interactions or safety? Do you care for a child with special needs?

Please Join Us! **FREE Childcare and Dinner with RSVP**

Where: South Whidbey Elementary Campus in the Family Resource Center

When: Second Tuesday Every Month: July 12th, August 9th, September 13th @6:00pm

Who: All Parents and Caregivers Call (360)221-6808xt 4321 to RSVP or ask questions



PAMI Padres Apoyando Motivando Informando

(Grupo de apoyo para familias de niños con necesidades especiales)

Día: Primer Martes de cada Mes **Hora:** 7:00-8:30 pm

Lugar: Oficina de Aptitude Habilitation Services

31955 SR 20, Suite #3, Oak Harbor WA



Aqui encontrarás información importante sobre, *Ayudas y recursos en la isla *Ideas y Actividades del mes *Apoyo y Motivación para seguir Adelante,

Se provee cuidado de niños. Si tiene alguna pregunta, por favor comuníquese con: Laiza Ramos (787)529-6788 or pamiespanol@gmail.com

For support, resources, events and local networking opportunities, find us on Facebook.

www.facebook.com/islandcountyparent2parent

Tiffany Wheeler-Thompson, Island County Parent to Parent Coordinator

(360)678-7978 t.wheeler-thompson@co.island.wa.us



People First of Washington



The purpose of People First of Washington is "to assist people to realize and appreciate that we are "people first" and our disabilities are secondary.

We are equal citizens in our communities.

People First is for adults with Disabilities that want to meet others in their community.

When: 1st Thursday of the month.

For Location, call Mike Etzell (360)678-7883



Whidbey Functioning Autism Support Group

We are an informal group that provides support, information, and social fun for individuals in the Asperger's or High Functioning Autism end of the spectrum and their families of all ages.

For dates and times: contact Todd Brehmer fineart@whidbey.net

Continued from Page 1 **Hanging Out Special Needs Style**



Pacific Science Center offers Sensory Friendly free morning visit from **8-10 a.m.** Before we open to the public. Experience our exhibits without heavy crowds when we have softened general lighting and decreased the noise level and visual stimulation on interactive exhibits wherever possible. 2016 Events: **July 9 • Aug 13 • Sept 10 • Oct 8 • Nov 12 • Dec 10**

SWIMMING

These days, all swimming pools are required to have disability access, so swimming is now a possibility for many more children. Zero depth entry pools are becoming commonplace, meaning even the most physically disabled children can get into the water. Even better, some pools are now hosting special needs swims, when the pool is a bit quieter and calmer. **Oak Harbor Pool** offers Special Swim for Special Needs on the **2nd Saturday of the Month from 4:30-6pm. July 9 • Aug 13 • Sept 10th • Oct 8th • Nov 12**



NATIONAL & STATE PARKS

Did you know that anyone with a permanent disability can get an Access Pass that allows free access to all national parks and other federally-operated recreational locations? The pass is available for free at any federal recreation site, or can be obtained through the mail for \$10. Your entire family is allowed in for free with the Access Pass. See http://store.usgs.gov/pass/access_pass_application.pdf for more details. You can also access a Discover Pass for Washington State Parks. The Dept of Licensing issues Washington state disability permits and license plates, and holders of these are exempt from needing the Discover Pass on State Parks lands. Holders of these permits and plates will need the Discover Pass to access lands managed by WDFW and DNR. **Free WA State Park Days are: Aug 25 • Sept 24 • Nov 11.**

HAVE SOME FUN! Author: Susan Agrawal • Date: 11/25/2013

Please call ahead of time to verify dates, times and events.



**Island County Parent to Parent
Tiffany Wheeler-Thompson**

Human Services
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Coupeville, WA 98239

Phone: (360)678-7978
email: t.wheeler-thompson@co.island.wa.us



facebook.com/islandcountyparent2parent

BUILD 5 ★

**BUILDING THE 5
COMPONENTS OF
GOOD HEALTH**

CARDIO RESPIRATORY HEALTH
MUSCULAR STRENGTH
MUSCULAR ENDURANCE
COORDINATION
FLEXIBILITY

**A FITNESS FUN PROGRAM
SPECIALLY DESIGNED
FOR OUR
YOUTH WITH SOME EXTRA
NEEDS!
(ALL CAPABILITIES WELCOME)**

**PATTY MADDUX, BA CPT TES OES
14485 SR 525 LANGLEY WA
(NEXT TO THE GOOSE GROCERY STORE)
425-299-4832 (TEXT)**

**DATE:
TUESDAY @2:30 TO 3:30 AGES: 6-9
THURSDAY @ 2:30 TO 3:30 AGES: 10+**

**COST:
\$45.00 (TAX INCLUDED) FOR 10 CLASSES**

EQUIPPED4LIFE FITNESS



Upcoming Events * Mark Your Calendar**

Transition Resource Fair

October 4th, 2016 Coupeville High School 4~6:00pm

If you have a child age 14 and up, this is where you need to be!

Providers, Vendors, Resources, Supports

Presentations by many Island County Providers

More information to be announced.

Planning For The Future Series

Special Needs Trusts

Wills & Estate Planning

Guardianship & Alternatives to Guardianship

Dates will be announced soon



Workshops for siblings of children with special needs

This Winter we will begin Sibshop Events. These events are geared towards siblings of children with special needs. A fun time for siblings with others that understand and "Get It". Support, Networking and a good time for all. More details to come out this fall. If you are an adult sibling, I would love your help.