

## FAMILY CARE TOOLKIT CAREGIVER GUIDE

Welcome to our home. We are glad that you are able to step in and take care of our loved ones, they mean the world to us. In this Family Care Toolkit you will find information that will help you understand our children, as well as, help guide you through their daily routines. You will find the following sections:

- Welcome
- Our Family
- Daily Living
- Health and Medical
- Legal and Resources
- Emergency

Each section provides valuable information either in an emergency situation or if we are away. If this an **emergency family situation** please go directly to the section **EMERGENCY** with the **RED TAB** for more information.

Please take time to contact the family and friends listed in the toolkit if there are questions. In the resource section you will also find information on different topics or agencies that can assist you, as well as, interesting things around town. We hope that you will find it helpful and know that we created this guide with care and concern for our family.

## TRAVEL PLANS

**How to reach parents:**

Parent's Cell numbers: \_\_\_\_\_

Emergency Contact: \_\_\_\_\_

**Destination:**

\_\_\_\_\_

**Accommodations:**

\_\_\_\_\_

\_\_\_\_\_

**Dates of Travel:**

\_\_\_\_\_

**Anticipated Time of Return:**

\_\_\_\_\_

**Airline/Cruise Line/ Etc. and arrival/departure info:**

\_\_\_\_\_

\_\_\_\_\_

**Additional Information:**



In the event that there is an emergency situation please see the last tab in the Family Care Toolkit for Emergency Information.

## GUIDE TO OUR HOME

PET CARE	
PLANTS	
APPLIANCES	
HOUSE RULES	
TV(s)	
DVD/BLU RAY	
GAMING CONSOLE	

See additional information Y or N

## Family & Friends

Name	Phone #	Relationship	Notes
Ex. Adam Smith	Ex. 123-456-6789	Ex. Cousin	Ex. Can drive kids to Boy Scouts

## OUR FAMILY

Who lives in our home:

---

---

---

---

Pets:

---

---

---

---

Picture of our family:

## WHO AM I?

Name: \_\_\_\_\_

Current Age: \_\_\_\_\_

Nickname/s: \_\_\_\_\_

Likes and Interests:

---

---

---

What motivates me:

---

---

---

Favorite games, books and/or music:

---

---

---

Devices and restrictions for use:

---

---

---

Friends that are welcome in our home:

---

---

---

Neighbors that can be visited:

---

---

---

Places I enjoy going with friends:

---

---

---

Outdoor sports allowed:

---

---

---

## WHO AM I?

My Dislikes:

---

---

---

Behaviors and kinks that could get in the way:

---

---

---

Tips for handling meltdowns:

---

---

---

---

---

---

Tips for soothing frustrations, fears and/or tears:

---

---

---

Tips for picky eaters:

---

---

---

“Grooves” and Habits:

---

---

---

---

Help with dressing:	No help	Minimal help	Maximum support
Help with bathing:	No help	Minimal help	Maximum support
Help with toiletry:	No help	Minimal help	Maximum support

Any additional things to know about me:

---

---

---

---

## I'M WORKING

Name \_\_\_\_\_

Current Employer \_\_\_\_\_

Supervisor \_\_\_\_\_

Phone \_\_\_\_\_ Email \_\_\_\_\_

Job Coach \_\_\_\_\_

Phone \_\_\_\_\_ Email \_\_\_\_\_

Transportation \_\_\_\_\_ Phone \_\_\_\_\_

Work days/hours \_\_\_\_\_

Responsibilities:

What does he/she love about the job?

What does he/she have challenges with?

Any co-workers that are friends too?

Any concerns?



## Daily Schedule

	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Early AM							
Mid-morning							
Lunch							
Mid-afternoon							
Evening							

## DAILY ROUTINE

TIME	Typical Day	Employment Notes
7:00am		
7:30am		
8:00am		
8:30am		
9:00am		
9:30am		
10:00am		
10:30am		Transportation Notes
11:00am		
11:30am		
12:00pm		
12:30pm		
1:00pm		
1:30pm		
2:00pm		
2:30pm		Notes for Special Activities
3:00pm		
3:30pm		
4:00pm		
4:30pm		
5:00pm		
5:30pm		
6:00pm		
6:30pm		
7:00pm		Additional Information
7:30pm		
8:00pm		
8:30pm		
9:00pm		
9:30pm		
10:00pm		

## DAILY MEALS AND ALLERGIES

What to eat for breakfast:

---

---

Typical time for breakfast: \_\_\_\_\_

What to eat for lunch:

---

---

Typical time for eat lunch: \_\_\_\_\_

What to eat for dinner:

---

---

Typical time to eat dinner: \_\_\_\_\_

Snacks and times:

---

---

Snacks to avoid:

---

---

Known food allergies:

---

---

EpiPen: YES \_\_\_\_\_ NO \_\_\_\_\_

Location of EpiPen: \_\_\_\_\_

## Menu Ideas

	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Breakfast							
Lunch							
Dinner							

## Social Activities

Activity	Time	Contact	Phone #	Address	Place

## MY HEALTH AND MEDICAL

NAME: \_\_\_\_\_

PRIMARY PHYSICIAN \_\_\_\_\_ CONTACT INFO: \_\_\_\_\_

DENTIST: \_\_\_\_\_ CONTACT INFO: \_\_\_\_\_

MEDICINE ALLERGIES:

FOOD ALLERGIES:

---

### CHRONIC HEALTH CONDITIONS :

(Please Circle All that Apply)

Diabetes

Celiac Disease

Asthma

Sleep Apnea

Seizures

Depression

Heart Condition

Thyroid Disease

G I Issues

Hearing Impairment

Vision Impairment

Skin Conditions

Joint Problems

Atlanto-axial instability

---

Any other Conditions?

---

Diet & Exercise

## MEDICAL HISTORY

**Name:** \_\_\_\_\_

Important Medical History:

---

---

---

---

Medications (Name, Dosages & Times):

---

---

---

Allergies:

---

---

EpiPen: YES \_\_\_\_\_ NO \_\_\_\_\_

**Name:** \_\_\_\_\_

Important Medical History:

---

---

---

Medications (Name and Dosage):

---

---

---

---

Allergies:

---

---

EpiPen: YES \_\_\_\_\_ NO \_\_\_\_\_

## MEDICATION INFORMATION

**PRIMARY PHARMACY:** \_\_\_\_\_

**PHONE NUMBER:** \_\_\_\_\_

**CHILD:  
PHYSICIAN:**

**CHILD:  
PHYSICIAN:**

**Medication Name:**

**Medication Name:**

**Medication Purpose:**

**Medication Purpose:**

**Dosage:**

**Dosage:**

**Comments:**

**Comments:**

**CHILD:  
PHYSICIAN:**

**CHILD:  
PHYSICIAN:**

**Medication Name:**

**Medication Name:**

**Medication Purpose:**

**Medication Purpose:**

**Dosage:**

**Dosage:**

**Comments:**

**Comments:**

**CHILD:  
PHYSICIAN:**

**CHILD:  
PHYSICIAN:**

**Medication Name:**

**Medication Name:**

**Medication Purpose:**

**Medication Purpose:**

**Dosage:**

**Dosage:**

**Comments:**

**Comments:**



### **Psychosocial/emotional issues common to people with Down syndrome**

People with Down syndrome may exhibit odd or repetitious behaviors. These are referred to as “grooves” or “stereotypic behaviors”. Grooves can be a strength, allowing people to organize their rooms and personal items, and present themselves to the world in a neat and dignified fashion. A groove can also be a safety valve allowing people to have some outlet when they are under stress. In these instances people can get stuck in certain set patterns of behavior that may be unproductive. These become more problematic when the grooves interfere with essential life activities or unforeseen schedule changes (i.e. Friday night is pizza night *no matter what*). Often these behaviors increase when someone with Down syndrome is stressed or very tired. Related to this are stereotypic behaviors, which may not appear to be under conscious control. This could include repetitious body movements: hand-flapping, rocking, rubbing, or unusual noises.

### **Self- Talk**

People with Down syndrome often engage in self-talk by thinking out loud, processing events of the day, or planning ahead for the week or month. For many self- talk is easier to understand than their conversations. If there is a change in quality or an increase in quantity of self-talk, it could indicate stress related to the parents not being home. If concerned, contact a relative or friend that the family has listed in the contacts for additional guidance, or review the **Who Am I?** pages of the toolkit.

For additional information contact the National Down Syndrome Congress at [info@ndsccenter.org](mailto:info@ndsccenter.org) or 800-232-6372.

## Additional Contacts

Name	Title	E-mail	Phone	Responsibilities

## SUPPORT ORGANIZATIONS

AAA - Area Agency on Aging – *advocates on behalf of member agencies for services and resources for older adults and persons with disabilities. By providing a range of options that allow older adults and persons with disabilities to choose the home and community-based services and living arrangements that suit them best, AAAs make it possible for older adults to remain in their homes and communities as long as possible.* - [www.n4a.org](http://www.n4a.org) (to search for your local office)

AAIDD – American Association on Intellectual and Developmental Disabilities - *promotes progressive policies, sound research, effective practices, and universal human rights for people with intellectual and developmental disabilities.* – [www.aidd.org](http://www.aidd.org)

AIDD - Administration on Intellectual and Developmental Disabilities - *dedicated to ensuring that individuals with developmental disabilities and their families are able to fully participate in and contribute to all aspects of community life in the United States and its territories.* - [www.acl.gov/programs/AIDD](http://www.acl.gov/programs/AIDD)

APSE - Association of People Supporting EmploymentFirst - *advances employment and self-sufficiency for all people with disabilities through advocacy and education.* - [www.apse.org](http://www.apse.org)

The Arc - (formerly Association for Retarded Citizens) - *promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes. Their website offers resources for health, financial planning, residential options and more.* - [www.thearc.org](http://www.thearc.org)

AUCD - Association of University Centers on Disabilities - *a network of interdisciplinary centers advancing policy and practice for and with individuals with developmental and other disabilities, their families, and communities.* - [www.aucd.org](http://www.aucd.org)

DD Council - Developmental Disabilities Council (each state has one) - *develops and sustains inclusive communities and self-directed services and support for individuals with developmental disabilities.* - [www.nacdd.org](http://www.nacdd.org) (to search for your state office)

DSAIA – Down Syndrome Affiliates in Action - *supports the growth and service capabilities of local and regional Down syndrome organizations.* – [www.dsaia.org](http://www.dsaia.org)

EEOC - Equal Employment Opportunity Commission - *responsible for enforcing federal laws that make it illegal to discriminate against a job applicant or an employee because of the person's race, color, religion, sex (including pregnancy), national origin, age (40 or older), disability or genetic information. It is also illegal to discriminate against a person because the person complained about discrimination, filed a charge of discrimination, or participated in an employment discrimination investigation or lawsuit.* - [www.eeoc.gov](http://www.eeoc.gov)

HHS - Health and Human Services – *the principal agency for protecting the health of all Americans and providing essential human services, especially for those who are least able to help themselves. Provides millions of children, families, and seniors with access to high-quality health care, by helping people find jobs and parents find affordable child care, by keeping the food on Americans' shelves safe and infectious diseases at bay.* - [www.hhs.gov/iea/regional/index.html](http://www.hhs.gov/iea/regional/index.html) (to search for your regional or state office) or [www.aspe.hhs.gov/office\\_specific/daltcp.cfm](http://www.aspe.hhs.gov/office_specific/daltcp.cfm) (for the office of disability, aging and long-term care policy)

## SUPPORT ORGANIZATIONS

IMDSA – International Mosaic Down Syndrome Association - *supports any family or individual whose life has been affected by Mosaic Down syndrome by continuously pursuing research opportunities and increasing awareness in the medical, educational and public communities throughout the world* - [www.imdsa.org](http://www.imdsa.org)

NARIC - National Rehabilitation Information Center - *conducts comprehensive and coordinated programs of research and related activities to maximize the full inclusion, social integration, employment and independent living of individuals of all ages with disabilities.* - [www.naric.com](http://www.naric.com)

NDRN – National Disability Rights Network - *the nonprofit membership organization for the federally mandated Protection and Advocacy (P&A) Systems and Client Assistance Programs (CAP). Collectively, the P&A/CAP network is the largest provider of legally based advocacy services to people with disabilities in the United States.* – [www.ndrn.org](http://www.ndrn.org)

**NDSC** - National Down Syndrome Congress - *provides information, advocacy and support concerning all aspects of life for individuals with Down syndrome.* – [www.ndsccenter.org](http://www.ndsccenter.org)

NDSS - National Down Syndrome Society - *advocates for the value, acceptance and inclusion of people with Down syndrome.* - [www.ndss.org](http://www.ndss.org)

NIH – National Institute of Health - *the largest source of funding for medical research in the world. NIH is made up of 27 centers and institutes, including the NICHD which conducts and supports laboratory research, clinical trials, and epidemiological studies that explore health processes; examines the impact of disabilities, diseases, and variations on the lives of individuals; and sponsors training programs for scientists, health care providers, and researchers.* - [www.nih.gov](http://www.nih.gov)

ODEP – Office of Disability Employment Policy - *develops and influences policies and practices that increase the number and quality of employment opportunities for people with disabilities.* - [www.dol.gov/odep](http://www.dol.gov/odep)

SLN – Sibling Leadership Network - *provides siblings of individuals with disabilities the information, support, and tools to advocate with their brothers and sisters and to promote the issues important to them and their entire families.* – [www.siblingleadership.org](http://www.siblingleadership.org)

SSA - Social Security Administration – *pays disability benefits under two programs, SSI and SSDI* – [www.ssa.gov](http://www.ssa.gov)

TASH - *an international advocacy association of people with disabilities, their family members, other advocates, and people who work in the disability field.* – [www.tash.org](http://www.tash.org)

The State of the States in Developmental Disabilities Project - *administered by the University of Colorado and funded in part by the AIDD, it provides longitudinal data for 1977-2011. The new State Profiles each present six pages of data on I/DD spending, revenue and other program trends in each state and DC. Customized, state-by-state comparative data, also recently updated through 2011, are also available.* - <http://www.stateofthestates.org/>

## FAMILY EMERGENCY

When a family emergency occurs there is only a short period of time to grasp vital information, regroup, and help children with Down syndrome and other children in the family keep a consistent schedule. Keeping a consistent schedule will perhaps allow children to maintain a sense of calm. Please reach out to the following people for immediate help.

Emergency Contact #1:

Name: \_\_\_\_\_ Relationship: \_\_\_\_\_

Address: \_\_\_\_\_

Primary Phone #: \_\_\_\_\_ Secondary Phone #: \_\_\_\_\_

Email Address: \_\_\_\_\_

Emergency Contact #2:

Name: \_\_\_\_\_ Relationship: \_\_\_\_\_

Address: \_\_\_\_\_

Primary Phone #: \_\_\_\_\_ Secondary Phone #: \_\_\_\_\_

Email Address: \_\_\_\_\_

Faith Community Contact:

Organization Name: \_\_\_\_\_

Contact Person (s): \_\_\_\_\_

Primary Phone #: \_\_\_\_\_

Email Address: \_\_\_\_\_

Resource for additional support: National Down Syndrome Congress 800-232-6372 or  
info@ndsccenter.org

NOTES:

---

---

---

---

## EMERGENCY INFORMATION

Family Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone number: \_\_\_\_\_

### How to reach parents:

Destination and Expected return: \_\_\_\_\_

Parents Cell numbers: \_\_\_\_\_

Emergency Contact: \_\_\_\_\_

### Location of Emergency Supplies:

First aid supplies \_\_\_\_\_

Flash lights \_\_\_\_\_

Fire extinguisher \_\_\_\_\_

Key to house and car \_\_\_\_\_

### Emergency Procedures:

Fire exit locations

\_\_\_\_\_

### Rooms for storm evacuation:

\_\_\_\_\_

### Phone numbers for household troubles:

Electrical power outage report \_\_\_\_\_

Refrigerator repair \_\_\_\_\_

Furnace repair \_\_\_\_\_

Plumber \_\_\_\_\_

Electrician \_\_\_\_\_

Gas Co \_\_\_\_\_

Other Details \_\_\_\_\_

## Consent for Medical and/or Emergency Treatment

I, \_\_\_\_\_, consent to the care, including diagnostic procedures, surgical and medical treatment and blood transfusions, by medical doctors, hospitals or their authorized designees, as may in their professional judgement be necessary to provide for the medical, surgical or emergency care of our child

\_\_\_\_\_  
Full Name of Child

\_\_\_\_\_  
Relationship

I also give consent to our caregiver \_\_\_\_\_,  
Full Name

While caring for my child from \_\_\_\_\_ through \_\_\_\_\_, to arrange for routine or emergency medical and/or dental care and treatment necessary to preserve the health of my child. In the event that our child is injured or ill while under the care of the caregiver, I hereby give permission to the caregiver to provide first aid for \_\_\_\_\_ and to take the appropriate measures, including contacting 911 and arranging for transportation to the nearest emergency medical facility.

The Caregiver should attempt to contact me. However, if medical care becomes essential, I give permission to the caregiver to make such decisions regarding such treatment as deemed appropriate by the medical doctor, hospital or their authorized designee. In the case of any treatment decisions to be made by the caregiver on my behalf for the benefit of our child, I authorize the caregiver to request, obtain, review and inspect any and all information regarding our child's health and relevant to any decisions that may be made respecting treatment.

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Legal Guardian

\_\_\_\_\_  
Primary Care Doctor

\_\_\_\_\_  
Cell/Home Phone

\_\_\_\_\_  
Dependent

\_\_\_\_\_  
Home Address

\_\_\_\_\_  
Dependent DOB

\_\_\_\_\_  
Allergies

\_\_\_\_\_  
Health Insurance Carrier

\_\_\_\_\_  
Policy Holder

\_\_\_\_\_  
Health Insurance Policy #

\_\_\_\_\_  
Policy Holder DOB

\_\_\_\_\_  
Policy Group #

\_\_\_\_\_  
Pharmacy #

## EMERGENCY CONTACT INFORMATION

Parent or Guardian #1:

Name: \_\_\_\_\_ Relationship: \_\_\_\_\_

Address: \_\_\_\_\_

Primary Phone #: \_\_\_\_\_ Secondary Phone #: \_\_\_\_\_

Email Address: \_\_\_\_\_

Parent or Guardian #2:

Name: \_\_\_\_\_ Relationship: \_\_\_\_\_

Address: \_\_\_\_\_

Primary Phone #: \_\_\_\_\_ Secondary Phone #: \_\_\_\_\_

Email Address: \_\_\_\_\_

Emergency Contact #1:

Name: \_\_\_\_\_ Relationship: \_\_\_\_\_

Address: \_\_\_\_\_

Primary Phone #: \_\_\_\_\_ Secondary Phone #: \_\_\_\_\_

Email Address: \_\_\_\_\_

Emergency Contact #2:

Name: \_\_\_\_\_ Relationship: \_\_\_\_\_

Address: \_\_\_\_\_

Primary Phone #: \_\_\_\_\_ Secondary Phone #: \_\_\_\_\_

Email Address: \_\_\_\_\_

NOTES:

---

---

---

---