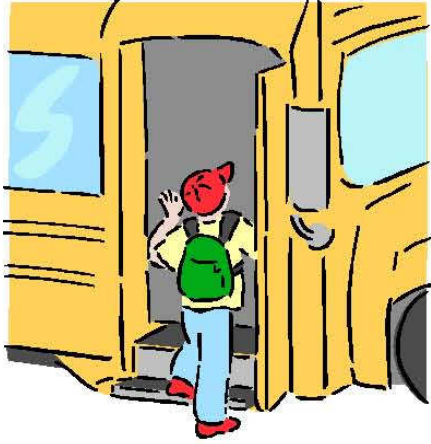


# All About Me!



*Uniting Unique People in a Unique World*

PO Box 1052~Franklin, TX 77856~USA  
979-828-4177~1-888-MDS-LINK~www.imdsa.org



# My Parent's Dreams For Me

When our child was diagnosed with MDS we worried about:

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Our hopes for this year are:

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Our lifetime goals for our child are:

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Here are some ways we think you can help our child be successful:

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# Here is My Family



My name is: \_\_\_\_\_

My Mom's name is: \_\_\_\_\_

My Dad's name is: \_\_\_\_\_

I have \_\_\_\_\_ Brother(s) Their names are: \_\_\_\_\_

I have \_\_\_\_\_ Sister(s) Their names are: \_\_\_\_\_

We have a pet: \_\_\_\_\_ My pet's name is: \_\_\_\_\_

Other family or friends that I want you to know about are:

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# Interesting Facts About Me!

My favorite activity is: \_\_\_\_\_

My favorite color is: \_\_\_\_\_

When I go outside, I like to: \_\_\_\_\_

My favorite hobby and other activities are:

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Three things that really motivate me are:

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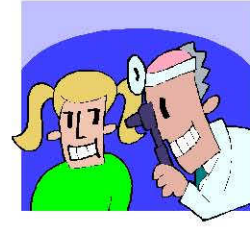
When I grow up I want to:

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# Health Considerations



Here are some things you may need to know about my health:

Surgeries:

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Current Medication (s):

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I wear glasses:    Yes      No                      I wear hearing aides:    Yes      No

When I am not feeling well I might:

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Other things you need to know about my health:

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# My Feelings

Things that make me feel happy:

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Things that might upset me:

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It's hard for me to:

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Things I may be afraid of:

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# Places I Like To Go

Here are some places that I like to go to with my family:

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My favorite vacation was when my family went to:

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My favorite places to go in my neighborhood are:

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# Communication

Here are some things you may need to know about how I communicate:

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My parents would prefer that you communicate with them by:

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If I am frustrated I might:

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# Look What I Can Do!



Here are some things I do to help around the house:

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Here is a list of things I do in the community on a regular basis:

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Here are some things I can do if someone helps me:

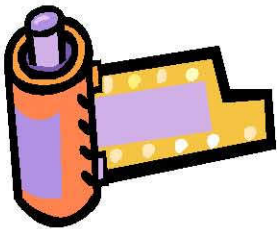
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# Pictures of Me!



# Myths & Truths

## About mosaic Down syndrome

### **What is mosaic Down syndrome?**

Truth: Mosaic Down syndrome is a rare form of Down syndrome affecting 2-4% of the Down syndrome community. \* When a person has mosaic Down syndrome a percentage of cells in the blood and/or skin has the extra chromosome that causes Down syndrome and the remaining cells are unaffected.

### **How many people have mosaic Down syndrome?**

Truth: According to research\* approximately 100-200 babies are born each year in America with mosaic Down syndrome. Due to lack of extensive international research, we are unable to confirm numbers for other countries but can assume that these numbers are similar in each country.

### **Myth: If a person with MDS does not 'look' like they have Down syndrome, they don't have developmental delays.**

Truth: Many people with MDS do not show all the physical characteristics of Down syndrome. This just means the affected cells are not in the part of the body that causes the physical characteristics of Down syndrome.

### **Myth: People with mosaic Down syndrome have less developmental delays.**

Truth: Most people with mosaic Down syndrome have developmental delays that are mild to moderate. The outcome depends upon where the cells are located in the body. IQ is not an adequate measure of the functional status of people with mosaic Down syndrome. People with mosaic Down syndrome have great potential if given opportunities.

### **Myth: Behavior problems and depression are just part of having mosaic Down syndrome**

Truth: Often, medical or mental health problems go untreated due to the assumption that it is typical of having this genetic condition. Complete examinations by appropriate health care professionals should always be pursued.

### **Myth: Children with mosaic Down syndrome are placed in segregated special education programs.**

Truth: Children with mosaic Down syndrome can be included in regular academic classrooms. Students may be integrated into specific courses or fully included in the regular classroom for all subjects.

### **Myth: People with mosaic Down syndrome need to be treated special compared to those without mosaic Down syndrome.**

Truth: People with mosaic Down syndrome have the same needs and feelings as anyone else. With acceptance, they can accomplish their goals and dreams and live a fulfilling life like everyone else.

\*Many people are misdiagnosed with Trisomy 21 Down syndrome, or they go undiagnosed due to the lack of physical characteristics and cognitive delays. Due to the lack of proper diagnosis, this number may be much higher than research suggests.

# **Mosaic Down syndrome is 'what' I have. Not 'who' I am.**

## **I am just a kid like everyone else.**

Mosaic Down syndrome is 'what' I have, but not 'who' I am. Please do not refer to me as "the mosaic Down syndrome kid" or say "he/she 'is' mosaic Down syndrome." I am not mosaic Down syndrome. I am a child who happens to have a rare genetic disorder. I can do all the same things that my peers do even if I do them in a slightly different way. I want to be included. And, with your help, I will be able to grow up to be a successful adult. My self-esteem is very important and with your help, I will be able to soar!

## **I can learn.**

Teach me all the things my peers are learning and I will learn them too. I may not learn them in the same way as my peers, but I will learn them! So, give me a chance and not only will you teach me new and wonderful things, I just might teach you a few things too!

## **I can have fun.**

I want to do the same things my peers do. I want to play. I want to have fun. I want to have friends. I want to be included just like everyone else wants to be included. Sometimes, I might need help understanding what is expected of me, but if you help me, I will learn how to make friends. I will learn how to play with them. And when I grow up, I will know how to interact with my adult peers.

## **I can be happy and I can be sad.**

I feel all the same emotions that my peers feel. I might not be able to express them in the same way, but I still feel them. I can be happy and I can be sad. I can be angry or scared. Please understand that even if I express my feelings differently, I still feel the same way everyone else does.

## **Include me in everything.**

I am growing and learning. If I am included in as much as possible then I will continue to grow and learn. One day, I am going to be an adult and I want to do the things that my peers do. I want to have a job and a house and a family. With your help, I can do all these things and more! Include me in everything so that I will learn what life is all about.