

PSYCH 201: REAL LIFE ISSUES FOR PARENTS
STRATEGIES FOR LIVING WELL WITH A VISIBLE DIFFERENCE

Understanding Differences:

Differences help to make our world a richer and more interesting place. But for children, differences can sometimes lead to feelings of worry, loneliness, sadness, anger and low self-esteem. Children can feel different because of any number of characteristics including: size, shape, skin color, ethnicity, religion, gender, abilities, etc. In order to help our children to cope with their differences, we need to help them to develop respect for others as well as themselves, and to learn that everyone is different—and special—in their own way.

It is important to note that reactions amongst children regarding their differences can vary considerably. Thus, the ease with which children are able to accept differences is not necessarily proportionate to the size or degree of the difference. For some children, having an obvious visible difference does not cause much distress while for other children, having a small, not overtly obvious difference can result in significant emotional distress.

As parents and family members of a child with a visible difference, there are a number of things that we can do to help our children to cope with, accept and embrace their differences while simultaneously fostering confidence and resiliency. By helping our children to become more resilient and more accepting of differences, in both themselves and others, we are giving them gifts that they can carry with them into adulthood.

Talking About Differences:

You can start talking with your child about differences at an early age. In an age appropriate way, you can increase your child's awareness about similarities and differences including some of the ways that people can be different from one another. Discuss the importance of learning to accept and value what makes him different from other kids.

There are some excellent books for young children, such as Todd Parr's, "It's Okay to Be Different", that illustrate this message in a fun and easy to relate to way. Books, movies, music, videos and television shows can all provide great ways to get the conversation started for kids of all ages. For some specific ideas and recommendations, see *PSYCH 201: REAL LIFE ISSUES FOR PARENTS RESOURCE GUIDE*.

Using Existing Strengths to Build Confidence and Accept Differences:

Help your child to identify her own strengths and appreciate the things that make her special. When your child is aware of her unique strengths and talents, this helps her to develop feelings of competence and boosts her self-esteem--which are two of the building blocks of resiliency.

An appreciation of her strengths and talents helps her to value herself as a person and as a result, be better able to accept that which makes her different. Building upon existing strengths can help a child to face and overcome challenges. Remember that children who face challenges in one area are often gifted in other areas!

Understanding Resiliency:

The word ‘resiliency’ gets a lot of play these days, and for good reasons. Resiliency refers to the ability to positively cope with challenges and stressful experiences. According to Kenneth Ginsburg MD, an expert in promoting resiliency in youth,

“ If we want our children to experience the world as fully as possible—unfortunately with some of its pain, and thankfully with all its joy—our goal will have to be *resilience*. Resilience is the capacity to rise above difficult circumstances, the trait that allows us to move forward with optimism and confidence even in the midst of adversity.”

[\(http://www.fosteringresilience.com/\)](http://www.fosteringresilience.com/)

Challenges and adversity are an inevitable part of life. By helping our children to become more resilient, we give them the tools to face challenges and overcome adversity. To learn more about resiliency in general and Ginsburg’s work in particular, look at *PSYCH 201: REAL LIFE ISSUES FOR PARENTS RESOURCE GUIDE* under the headings ‘Books for Parents’ and ‘Websites & Social Media for Parents’.

Facing Challenges and Overcoming Adversity:

It has often been said, written and even sung about that “what doesn’t kill us makes us stronger”. Similarly, there is a school of thought that believes that for people who have accomplished great things and helped to make our world a better place, it is the challenges that they faced earlier in life that actually *helped* them to do so. Facing challenges at an early age can teach important life lessons about the powers of perseverance, kindness, patience, compassion, empathy, courage and perspective. In her moving and inspirational keynote speech at the 2012 Nevus Outreach Conference, Jodi Unsworth echoed this sentiment when she told the audience, “*It is because of my CMN and not in spite of it that I’m who I am and able to do this work.*”

Talk with your child about people—those who you know in real life or famous people—who have made the world a better place despite facing different challenges and obstacles. You can ask her if she can see any ways in which the challenges that these people faced could have helped them to accomplish what they did. This can be inspirational for both kids and adults alike. The handout *FAMOUS PEOPLE WHO HAVE OVERCOME CHALLENGES* has some ideas to get you started. You can find many more examples online and this can be a good activity to do with your child or teen.

Help your child to remember a time when something was really hard for her but she found a way to do it anyway. See if she can identify what it was that helped her to persevere. Reminding her of past successes and reviewing what helped her to overcome previous challenges can give her the courage and confidence to take on new challenges. It can also be helpful to share age-appropriate examples of times when you overcame challenges in your own life and what you learned as a result of those experiences.

Fostering Connections:

Connection is a very important factor in promoting resiliency in children and teens. Numerous studies on resilience over the years have noted the protective value that having a close relationship with at least one adult can have for a child or teen, regardless of whether or not that person is a family member.

Feeling connected to and accepted by one's family or community increases a child's sense of belonging to a group. This is especially important when someone has a visible difference as sometimes this can lead to feelings of isolation. Having relationships in which your child feels connected, loved and accepted are of considerable value. This holds true whether these relationships are with others who are the same age, older or younger than he is, family members, friends or teammates, neighbors or people who live a distance away.

Work with your child to identify places and activities where he feels a sense of connection. For some kids, this is on the baseball or soccer field; for others it is when they go horseback riding, play with their neighbors, participate in a band or attend a youth group. Do whatever you can to foster his relationships with the people, places and activities where he feels most connected, even if this sometimes means forgoing other things in order to do so.

Helping Your Child to Realize That She Is Not Alone:

Many support groups and twelve step programs are built around this very principal. Being connected to others is a source of strength and knowing that you are not the only one who is going through something is reassuring and of considerable value.

To let your child know that they are not the only person in the world who has a giant congenital nevus, it can be helpful to share age appropriate information as well as pictures of others who also have a nevus. These can be found online on the Nevus Outreach and Caring Matters Now websites (see *PSYCH 201: REAL LIFE ISSUES FOR PARENTS RESOURCE GUIDE*).

Other ways to help your child to realize that she is not alone include:

- Attending regional gatherings and national conferences for people with a nevus.
- Using social media like the Nevus Outreach Facebook Pages, Caring Matters Now Teen Forum, and Bandaides & Blackboards to connect with others.
- Reaching out to others on the Nevus Outreach Online Support Group.

Listening to, Acknowledging and Validating Your Children's Feelings:

Listening to our children, acknowledging that we understand what they are saying and then validating their feelings is important for all children. This helps them to feel that their feelings, and by extension they, are valued. When you talk with your child, make sure to really listen to what he is saying. If you are unsure whether or not you correctly understood what he was trying to say, ask him to repeat it back to you or ask, "Did I get that right?"

Make sure to validate your child's feelings, even when they are different from your own or are hard to hear. Remember that part of helping your child to live with a visible difference *does not*

mean denying that sometimes it can just be painful and hard to be different from others, especially when that difference can be readily seen. We need to acknowledge and validate our children's feelings as well as our own--and not only the good ones!

At times, parents and children may feel quite differently about having a visible difference. Sometimes, it will be the parent who is more accepting of a child's visible difference while the child himself is struggling. At other times, it might be the child himself who is more comfortable with and accepting of his difference and his parent(s) who are struggling more. Because our children will be taking their cues from us, it is important that parents who are struggling get help to cope with their child's visible difference and how it impacts their lives. Similarly, counseling can be a wonderful resource for children and teens too as it provides a place for them to share however they are feeling in a safe and non-judgmental space with someone who is trained to offer support but not part of his daily life. It is really important to remember that going to see a counselor doesn't mean that there is something 'wrong' with either you or your child!

Resisting the Urge to 'Make it All Better':

One of the hardest things of all is to see your child in pain and wish that you could take it away, knowing that you can't. But just sitting with her, providing unconditional love and support as she expresses how she is feeling, is one of the greatest gifts that you can give her. By doing this, you are letting her know that she does not have to be alone in her pain while also communicating that it is okay to feel however she is feeling, even if it doesn't feel good. You are also letting her know that as hard as certain feelings are, she is strong enough to tolerate them, and that you will stick by her no matter what!

Educating others about your child's Nevus:

When people are educated about differences, they feel more comfortable with them. By sharing some basic information about your child's nevus with caregivers and teachers, they have the necessary information to educate other students and parents if questions arise. When teachers, counselors, coaches and other parents are educated about your child's nevus, they are in a better position to answer questions like "Why does Susie's skin look different?" or "Is it contagious?" This will ultimately help your child.

Sharing books such as "It's Okay to Be Different" and "Buddy Booby's Birthmark" with your child's class or group at summer camp can be a good way to talk about differences in general and birthmarks in particular.

Handling Other People's Reactions:

It is normal for people to notice differences, especially younger children who are innately curious. It is also natural and understandable for parents and children to feel sad, anxious and/or angry about being the subject of other people's stares, questions and comments.

When our children are young, it is up to us to address other people's reactions, keeping in mind that our children will be paying attention and taking their cues from us. Different responses are called for when the questions, comments and stares are benign and when they are rude.

The Explain-Reassure-Distract Technique:

This technique, which was developed by our friends at Caring Matters Now, provides a way to:

- Help parents to feel empowered
- Address other people's curiosity
- Maintain your child's self-esteem and self-confidence
- Model for your child how to respond to such curiosity so that she can increase her own skills in meeting new people.

In essence, this technique involves **explaining** that your child has a birthmark, nevus, etc., **reassuring** others that it isn't contagious or something that hurts, and then using **distraction** to shift the conversation away from your child's nevus and onto something else.

A more thorough description of this technique with great examples of how to put it into action can be found in the support literature for parents under the *Resources* section on Caring Matters Now Website (<http://www.caringmattersnow.co.uk/research-2/cmn-support-literature/>)

Handling Rude Reactions:

As you would with other kinds of rude behavior, it is important to set limits. How you set limits will vary depending upon different situations as well as personality styles. For some people, it may feel more comfortable to simply walk away while others would prefer to say something in response.

For example, when you see someone staring for an overly long time or in a way that feels disrespectful, it can be helpful to make eye contact so that they know that you are aware of what they are doing. This often has the effect of making the person more aware of their behavior and gets them to stop. Sometimes simply making eye contact and smiling will break a stare and ease discomfort. If none of these suggestions work, I have it on good authority from kids that sometimes when someone is staring rudely that simply returning the stare in an assertive way puts a stop to it.

You can also directly address the person who is staring/making your child feel uncomfortable. One way to handle it might be to say, "It's okay to ask questions and be curious. It is not okay to whisper and point." You can also use an "I" message to let others know how their remark or behavior has made you feel and letting them know it is hurtful. "My son's face has a birthmark on it that he was born with. We don't like it when people stare. We would prefer you to say hello or ask us a question if you are curious."

Helping your child to handle other people's reactions:

Help your child to understand that it is normal for people to be curious about differences, especially when it is something like a nevus that they haven't seen before. But also make sure to validate his feelings about how hard this can be.

Work with your child to come up with strategies that can help him to cope with stares, questions and comments in different situations such as at the park, at school, at the beach, etc. It is helpful to discuss these in advance since sometimes it is hard to think on the spot, especially when we are upset or angry.

- Practice these strategies through role-playing.
- Use stuffed animals or puppets to act them out.
- Using humor can be a great strategy and source of empowerment.

It is also important to let our kids know that they can do a variety of things when others respond rudely as opposed to with benign curiosity. They can walk away and tell an adult, use an “I” message to stand up for themselves or assert themselves in one of the ways mentioned above. They can also get ideas from other participants at this conference, or in one of the online support groups mentioned in *PSYCH 201: REAL LIFE ISSUES FOR PARENTS RESOURCE GUIDE*.

“Life is not about waiting for the storm to pass, it is about learning to dance in the rain.” (Author Unknown)

2012 Nevus Outreach Conference,
Allison D. Hurwitz, LPC, LSW, MSW, MA, ATR