



Educating, Assisting, Supporting, and Informing through this newsletter...
A newsletter for and by parents with sons & daughters with disabilities and education advocates.

Families Together, Inc.

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(All toll free numbers for Kansas
parents & education advocates)
www.familiestogetherinc.org

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Scoop Essentials: Disclosing Disability, Tackling A Dickey Proposition

By Michelle Diamant



Reprinted with permission from Disability Scoop, The Premier Source for Developmental Disability News. On the Web at www.disabilityscoop.com

Whether you're out in public or in the company of family, talking about a disability and what it means to you or a family member can be tough business. But with the right approach, talking about a disability can go from stressful to meaningful, says family therapist Diane Smith, who herself has a child with a disability.

In this installment of Scoop Essentials, Smith helps you find the right words and a healthy approach to explaining a disability to family, friends or even perfect strangers.

Disability Scoop: How do you prepare yourself to tell others about a disability?

Diane Smith: There are several things to consider. What do we say to other people? Who do we say it to? What does it mean to speak aloud the diagnosis? Is it safe? How will the information be used? What about our child's privacy? What will other people think? Will there be discrimination or exclusion?

In terms of preparation, I think it's really a matter of examining all of these questions. Why am I giving this information and what is going to be done with it? I think it's important for a parent to know what the disability means to them.

Then, who do you share it with? There's a tendency for parents to not want to share the information about the diagnosis because they feel that it will prejudice people against their child. What can happen is that it can make it more difficult in some situations because people don't know how to respond appropriately to the differences that the child is exhibiting.

Parents can think that giving their child a diagnosis makes them different, but in actuality it doesn't make their child different. It just provides information about the child who already has some differences.

Disability Scoop: When is the right time to disclose a disability to others?

Diane Smith: I don't think there's a right way, a wrong way or a particular time or place. I think in circumstances where you believe it will benefit the people around the child to have that information. When we give information about our child it needs to be done in the context of educating other people about our child, while always keeping in mind what is going to be done with the information.

Oftentimes we think that if we don't talk about the disability then no one will notice it. More often than not the disability is noticed and giving it a name helps everyone to understand better.

[continued on page 2...](#)

Inside this Issue...



[From the
Director's Desk p. 2](#)

[Education Advocate
Update p. 3](#)

[Family Story p. 4](#)

[Resources..... p. 5](#)

[How to Help Your Child
with LD Have a
Happy Holiday p. 6](#)

[Como Ayudar a que su
Nino Pase unas
Felices Fiestas
Decembrinas p. 7](#)

[Calendar of
Events.....p. 8](#)

[The Kansas Youth
Leadership Forum ... p. 8](#)

**Statewide
Conference
Registration insert**

[...continued from page 1](#)

Disability Scoop: How do you broach such a discussion?

Diane Smith: My bias is always toward openness so I think sharing information about your child is very important. You can say my child has just been diagnosed and it's really overwhelming for me and this is what I'm dealing with. Personally, I might address my child's difficulties in context. For example, my child is 21. When people say, "oh what is he doing now? Has he gone off to college?" I might say, "no he's in a post-secondary program. He has special needs." And then they might say, "what does he have?" Then it becomes part of the conversation.

Another issue that comes up is what to do in a public place when a child's behavior draws a lot of attention. I think when people don't understand something, they make up in their minds what it is. One of the hardest things about having a child with a disability, especially if it affects their behavior, is that other people make assumptions about them being a bad parent. Some parents respond by saying, you know, my kid has special needs and he really can't help himself. That's a way of providing information about the child that helps other people accept who he is. I've also seen people who have cards describing autism for example, or other disabilities, to give to people and say this is what's going on with me or my child. They have a disability and this is where you can find more information about it. The risk is that you put that information out there and not everybody really responds in the way that you need.

Disability Scoop: Is there anything your can do to avoid undesirable responses?

Diane Smith: Yes, I think it comes with time. It's being able to say to people, this is what I'm going through and this is what I really need from you. My child has autism and I was just told that he's going to need therapy 30 hours a week and I'm feeling really overwhelmed. One of the things that might be helpful to me is I have some information and I would love it if you would read it. And I would love it if you would ask me questions about my child every once in a while. People don't always understand how to respond to this kind of information and it can be overwhelming.

Disability Scoop: What are the most important things to remember when telling other people about a disability?

Diane Smith: So much has to do with where you are psychologically in processing this information. It's important to say this is what is going on with my child and then tell them what you need from them and include things like I want you to continue to see my child for the amazing little person that he or she is. Ask me about my child, about any meetings that I've gone to. Follow up. Being able to put out there to other people what it is we need and want is helpful.

Disability Scoop: What should you expect from others when you tell them?

Diane Smith: What I think we all would love to expect is to be supported. We don't want people to minimize it, like oh, I bet you he'll be fine in a year or two or comparing that child

[continued on page 3...](#)

A Note From the Director's Desk...



Dear Parents and Education Advocates:

Greetings to all of you from the Families Together staff for a wonderful holiday season! Enjoy the break from the routine and gather your strength for a great second half of the school year.

During this season, we are so thankful for the opportunity to offer services to all of you. We are also very thankful for the donors who make our services possible. In addition to our agency partners, many of you have become regular contributors to our organization. We appreciate your confidence in our services!

This fall, there were two **Step-by-Step** walks to raise funds for Families Together. On November 12, the Wichita Center hosted Thanks for Giving, an event to thank the walk teams, and other contributors. The event included an Open House and a presentation of awards. The Britney Bunch, a walk team in Hutchinson, took home the award for the highest fund raising team. Visit our website to see pictures of the **Step-by-Step** walks and the Thanks for Giving celebration. (www.familiestogetherinc.org)

As we end 2009, please consider a gift to Families Together, Inc. to reflect the value of the services that your family has received.

The Statewide Conference in Wichita provided a great training and networking opportunity for parents in early December. But your opportunities are not over yet: we have another one scheduled in Topeka on February 27. Plan to attend!! The brochure is included with information and registration form.

Merry Christmas and Happy New Year,

Connie

..continued from page 2

to another child that you know. What we'd all like to expect is for somebody to just listen and know that they can support you in this difficult time that you're having without giving advice.

Of course people might say these things and we just need to be able to say, you know that's just not very helpful to me right now. I know you want to fix it, but you can't fix it. I just need a friend or I just need to be able to say it out loud.

Disability Scoop: You've talked a lot about the idea of saying it out loud. What role does that play?

Diane Smith: I think it's the idea of telling our story. One of the things that I think is important any time where we're in the grieving process is to be able to tell our story in some place where we feel it is safe. I don't mean announcing it on the radio, but just to somebody who feels really safe. Speaking about something helps to integrate it into our daily lives rather than it being that thing over there. This helps us learn to, if not accept it, then at least learn to live alongside it.

Disability Scoop: Is it different to discuss a disability that's obvious versus hidden?

Diane Smith: That's a really tough one. Our kids are listening to us all the time. We don't want them to get the impression that we're whispering something about them. I think it requires some discretion.

There's no formula for it. There's no handbook. Sometimes we may say too much. Sometimes we may not say enough. There are certain circumstances where information given to a teacher or a scout leader or a soccer coach helps them understand our child. But here's the thing, I think when we talk about our child's disability we have to provide more than a diagnosis. We have to talk about the child in terms of who they are. I have a child and this is what he's good at and this is what he struggles with. So there's less of a focus on shining a light on their disability and more of a focus on what other people can do to help this person.

Disability Scoop: If you're a parent or caregiver, how should you tell your child with a disability or their siblings about the disability?

Diane Smith: There are a lot of people who have different feelings about this. My bias is toward openness. If parents have a level of acceptance and they are able to see their child's disabilities as just part of who the child is, then we can start to talk to our kids about how everybody has some differences. The things that are going on with you, they actually have a name for it. This is what scientists call it. This way it doesn't become their identity, but they have a way of explaining why some things may be more difficult than others.

My bias is toward a matter-of-factness about the information that we give our child and then help them to find the words to explain to other people why they might have some difficulties. I think that it's the same with siblings. All of this has to be done meeting the appropriate

developmental age of the child, not just the chronological age, but meeting their ability to understand.

There comes a point where it almost seems unfair for a child not to have the information that everybody else around them has, especially when a child comes into adolescence. Once they have a sense of what particular difficulties they have, they can begin to advocate for themselves and say what they need. For example, a child can say I really have a hard time concentrating. I have attention deficit disorder so what I need to do is to sit in this particular place in the classroom and here's what I need help with. Not that it's an excuse, but it becomes a way of asking for what you need.

Education Advocate Update

Submitted by [Darla Nelson-Metzger](#),
Education Advocate Co-Coordinator



- Q: I've been asked to sign a release of educational records. I'm the person to do this and if so, should I sign?
- A: Birth and adoptive parents, legal guardians, persons acting as parents and education advocates are the only persons who have the authority to sign for the release of special education records.

You should sign for the release of these records if you believe it is in the student's best interest to do so. If you do not know who the records will be going to, ask. If the answer you get seems to legitimate, go ahead and sign. If not or if the release seems too vague, you don't have to sign or you can limit the release to certain agencies or persons by name.

Opening in the Kansas City Center

- ✓ 30 hours per week
- ✓ Some travel and minimal evening/weekend work

The successful candidate should have

- a basic knowledge services to children and youth with special health care needs,
- an interest in helping others learn about health care options and educational rights, and
- strong organizational and people skills.

Parents of children with disabilities encouraged to apply

Please send resume to Deedee at the Kansas City Center
Fax **913-287-1972**

Email: deedee@familiesotogetherinc.org



FAMILY STORY

DESTINY'S JOURNEY

By Johnni Ramsey

I received the phone call that no parent wants to hear... "Mom, I'm pregnant and they (her father and his family) are going to make me have an abortion.

I got that phone call in the fall of 2001. My new husband, Bob, and I had only been married for a few months. Both of us had led single lives for many years and when we met, were both close to having the empty nest syndrome. LOL

We tossed and turned for several sleepless nights and then Bob said, "We can't allow this to happen, no matter what else happens." The "what else" he was referring to, was the fact that my daughter, Nichole, has many issues and we knew that she would never be able to raise a child. He was so correct on the "what else".

On a rainy day in March of 2002, Destiny entered a world that was full of fear, doubts and concerns, yet also a few sighs of relief that she was OK. More tears were shed over the worries that would come rather than the celebration of life that she deserved.

We thought that everything was going well with her until, at about 5 weeks of age, Destiny began having what is called, "Benign Neonatal Familial Convulsions". What this meant was that she had some weakness in the brain and that she would outgrow the "seizure" type convulsions that she was having. After almost a week in NICU, we went home for the second time with even more fears.

At the age of about 5 months, I had to put Destiny into daycare because my daughter was not able to take proper care of her while I worked.

I will never forget taking Destiny to get her Pre-School Screening when she was about three. I was appalled when they tried to tell me that she failed all five areas of the testing. I could not believe what they were saying to me. I went home and talked to our family doctor, whom I just happened to work for. He assured me that she would come around, and that I had nothing to worry about.

In the fall, I got a phone call asking me to bring Destiny back in to be retested. I had already taken her to see an optometrist, and an ENT and had many long conversations with our family doctor. I almost didn't go back, but I had to see if she could do any better. Once again and not any easier to hear, she failed all five areas.

I went back to our family doctor, and after a long and sometimes deeply heated conversation, we were going to Kansas City. Nine months later, we got the diagnosis of autism. I have learned a lot and I continue to learn new things everyday. I have so many people to thank for this. One group of people is Families Together. They have given me the information so that I know what I need to ask for on an IEP, what I can ask for on an IEP and who to call to ask for help - not just for me, but for other families that I have met along the way.

Families Together is not just a name, but the people that work with you become your FAMILY. I have attended several conferences over our journey and I have learned more, felt more at ease and more welcomed to ask questions and get answers than I have with Families Together than any other organization. I encourage everyone I meet, that has a child with an IEP or IFSP, to contact Families Together as soon as possible.

I have discovered my voice in this world, and with the help of Families Together, I am using it! I am out there talking to families, groups, school districts, even people I don't know. I have been approached by people who have a grandchild, child, niece, nephew, cousin or a friend with a child who want to know who to call or how to handle something. If I don't have the answer, I pass them on to Families Together. I only hope that they are making the calls. I know they will get answers from them.

I would never tell a family, "I told you so", but what I will tell them and have told them is, "I am glad that you finally found Families Together!"

RESOURCES



FAMILIES TOGETHER TOLL FREE NUMBERS:

Wichita	1-888-815-6364
Topeka	1-800-264-6343
Kansas City	1-877-499-5369
Garden City	1-888-820-6364
Spanish line	1-800-499-9443

www.familiestogetherinc.org

MAKE A DIFFERENCE INFORMATION NETWORK

1-800-332-6262

An information service for children and adults with disabilities, their families, and their service providers.

www.makeadifferenceks.org

KPIRC

Kansas Parent Information Resource Center
(A resource for parents of any child)
3500 SW 10th Room 011E • Topeka, Kansas 66604
785-783-2975 • e-mail: jgroff@kpirc.org
website: www.kpirc.org

NICHY

*National Information Center for
Children and Youth with Disabilities*

NICHY Website

www.nichcy.org

- ★ All text-only publications have been reformatted to a new easy-to-read layout
- ★ A side-bar menu makes navigation easy
- ★ The ALL-NEW resource library featuring the Technical Assistance & Dissemination (TA&D) Network makes finding information a breeze

Call us or visit
our website!

1-800-695-0285
www.nichcy.org

CHECK OUT THESE WEBSITES!



Autism Speaks Unveils 100 Day Kit, A Unique Resource for Parents of Children Newly Diagnosed with Autism

From: CEC SmartBrief

Autism Speaks, the nation's largest autism advocacy organization, today announced the launch of its 100 Day Kit, a personalized resource to assist families in getting through the critical time following an autism diagnosis. In addition to receiving the contents of the kit, which includes information about services and service providers in a family's community, those who register will also be connected with a regional Autism Speaks Autism Response Team member who can provide further insight and guidance. http://www.autismspeaks.org/press/100_day_kit.php

Imaginative Play May Help Solve Some Behavioral Problems

Researchers say unstructured play helps children learn to control their own emotions and behavior -- abilities that are a better predictor of a child's academic success than IQ. The regulated play many modern children experience doesn't foster such skills because the control has shifted to adults, which is something several researchers suspect may be behind the rising number of ADHD diagnoses. "I think a lot of kids get diagnosed with ADHD now, not all but many just because they never learned how to exercise ... the executive functions early," neuroscientist Adele Diamond says. National Public Radio (text and audio) (2/28) <http://www.npr.org/templates/story/story.php?storyId=76838288>



Happy Holidays!

How to Help Your Child Have a Happy Holiday

By: Dale S. Brown (2008)

The holiday season is a time for family togetherness, community, and friendship when we enjoy parties and fun celebrations. Unfortunately, children who struggle with social and behavioral problems can feel lonely and excluded during this happy time. There are many ways, however, that you can make things easier for your child throughout the season, by helping him enjoy the holidays and feel beloved. This article provides a dozen ideas designed to help your child with learning disabilities have a happy holiday and lessen stress on your family. Read these ideas and choose the ones that you think are the best fit for your child.

Prepare your child for events such as holiday parties

Tell children the schedule and what you expect him to do. Tell him details such as these:

Guests will arrive between 2 and 3. I will greet them at the door. I need you to stay in the family room. The children will join you there and play.

Most of the grown-ups will be in the living room, and most of the children will be in the family room. I will visit you occasionally and see how things are going. Come and get me if you need me.

The meal will start about 6. I need you to help me in the kitchen around 5:30. We will get everything ready and ask people to come to the table and eat.

Teach your child the names of guests ahead of time if possible

Consider showing your child pictures of guests before the party, or reminding him of people he has met before. Teach him how people are related to each other (brother, sister, wife, husband, cousin, etc.).

Role-play scenarios with your child

You might want to teach your child to receive a gift graciously, look happy when she opens it, and thank the giver by name. Or you might want to practice greeting guests at the door.

Prepare relatives and guests for the possibility of unusual behavior by your child or actions that might be misinterpreted

If any of these things apply to your child, you might tell guests that he:

- Sometimes doesn't get jokes
- Won't understand a sarcastic tone of voice
- Will tend to take things very literally
- May talk without pause and not notice that someone wants to take a turn to speak
- Interrupts other people because he cannot tell when his conversational partner has finished speaking
- Dislikes being hugged, touched, or stroked
- Is clumsy and doesn't like being teased about it

If you feel comfortable doing so, give your guests some suggestions on how they might respond to these behaviors.

Plan to handle overstimulation

The crowds, loud noise, hustle, bustle, and confusion of holiday parties can cause some children to get overloaded with sensation. They can explode, "melt down" or "shut down." Make a plan with your child. Tell him that he can ask you for time to leave the party and be alone in an empty room in the house or go outside. You and other family members may decide to keep an eye on your child and take him on a walk or sit quietly with him if he seems to be overwhelmed.

Give your child a role that helps her to shine

You might ask him to:

- Cook something for the meal
- Put one of her projects in the living room, such as a mechanical train set he put together or an interesting science fair project
- Put together toys and games after the gift is opened
- Organize a group for a game
- Make a table centerpiece or decorations for a room
- Hand out gifts or other items to each guest

Thank the adults that guide your child

The holidays are a good time to express gratitude. Give your child's teachers a note thanking them specifically for how they help your child. If a neighbor, babysitter, youth club leader, or other professional has taken a particular interest in your child, let them know how important they are to your child's self-esteem and future growth. Help your child write a letter, give a gift, or make a special token of appreciation.

Ask your child to do good deeds and contribute to your community

The holiday season is a good time to ask your child to do service projects that help others. Your whole family could volunteer. Or you and another family member could try a new activity the first time and figure out the best way for your child to participate. Encourage children to follow up on their ideas that might help those who are less fortunate. These activities will help your child prepare for future careers and develop his self-esteem. Even more importantly, your child will learn that children with learning disabilities can make their communities better by sharing their unique abilities.

This article was found at the following website in both Spanish and English: www.colorincolorado.org

Cómo ayudar a que su niño pase unas felices fiestas decembrinas

Por: Dale S. Brown (2008)

La temporada de las fiestas decembrinas es la época de la unión familiar, la comunidad y la amistad en la que gozamos de divertidas fiestas y celebraciones. Desafortunadamente, los niños que padecen de problemas sociales y de comportamiento pueden sentirse solos y excluidos durante esta época de felicidad.

No obstante, hay muchas maneras en que usted puede facilitarles las cosas a su niño durante esta temporada, ayudándole a que disfrute de las fiestas y a sentirse querido. En este artículo se presenta una docena de ideas sobre cómo ayudar a que su niño con discapacidades pase unas felices fiestas decembrinas y a disminuir la tensión en el seno de su familia. Entérese de estas ideas y elija las que le parezcan que mejor se adaptan a su niño:

Prepare a su niño para los eventos tales como una fiesta

Comuníquese a su niño el horario y lo que usted espera que él haga. Infórmele de los detalles tales como éstos:

- Los invitados llegarán entre las 2 y las 3. Yo los recibiré en la puerta. Necesito que tú te quedes en la sala de estar familiar. Los niños se reunirán y jugarán allí contigo.
- La mayoría de los adultos se quedará en la sala formal, y la mayoría de los niños estarán en la sala de estar familiar. Vendré a visitarte de vez en cuando para ver cómo van las cosas. Ven a buscarme si me necesitas.
- La comida se servirá cerca de las 6. Por ahí de las 5:30 necesitaré que me ayudes en la cocina. Tendremos todo listo e invitaremos a los invitados a pasar a la mesa a cenar.

Para obtener más información sobre la manera de preparar a su niño para una fiesta y otros eventos de la temporada, lea [Cómo mejorar el comportamiento de su niño en situaciones públicas](#) (en inglés), de Rick Lavoie.

Si es posible, déle a conocer a su niño los nombres de los invitados por anticipado

Considere la posibilidad de mostrarle al niño fotografías de los invitados o de recordarle a la gente que ya ha conocido con anterioridad. Enséñele cómo se relacionan las personas entre sí (hermano, hermana, esposa, marido, primo, etc.).

Juegue a representar situaciones hipotéticas con su niño

Quizás podría enseñarle a su niño cómo recibir cortésmente un regalo, cómo mostrarse feliz cuando lo abra y cómo darle las gracias a la persona que se lo obsequia refiriéndose a ésta con su nombre. O tal vez podrían practicar cómo recibir a los invitados en la puerta.

Prevenga a los parientes e invitados sobre la posibilidad de que presencien un comportamiento inusual de su niño o acciones que pudieran ser malinterpretadas

Si alguna de estas situaciones se aplica a su niño, usted podría informar a sus invitados de que el niño:

- A veces no entiende las bromas
- No entiende un tono de voz sarcástico
- Tiende a tomarse las cosas literalmente
- Puede hablar sin parar y no notar que alguien desea tomar la palabra
- Interrumpe a las personas porque no puede distinguir cuando su colocutor ha terminado de hablar
- No le gusta que lo abracen, toquen o acaricien
- Es torpe y no le gusta que se burlen de él

Si a usted no le incomoda, déle a sus invitados algunas sugerencias sobre cómo podrían responder ante cualquiera de estos comportamientos.

Plan para manejar el exceso de estimulación

Las multitudes, el elevado ruido, la prisa, el alboroto y la confusión de las celebraciones de las fiestas decembrinas pueden provocar que algunos niños se saturen de sensaciones. Ellos pueden explotar, "descomponerse" o "ensimismarse". Establezca un plan junto con su niño. Dígale que él puede solicitarle unos momentos para ausentarse de la fiesta y quedarse solo en un cuarto vacío de la casa o salir al exterior. Usted y otros miembros de la familia pueden optar por vigilar a su niño y, si les parece que está abrumado, llevarlo a dar un paseo o sentarse discretamente junto a él.

Asigne a su niño una función que le ayude a sobresalir

Usted podría pedirle que:

- Cocine algo para la comida
- Coloque uno de sus proyectos en la sala, tal como el tren mecánico que armó o un proyecto interesante de la feria de ciencias
- Armen juntos los juguetes y juegos después de abrir los regalos
- Organice a un grupo para que realicen un juego
- Haga un centro de mesa o algunas decoraciones para un cuarto
- Entregue los regalos u otros artículos a cada invitado

Agradezca a los adultos que orientan a su niño

La temporada decembrina es un buen momento para expresar gratitud. Entregue a los profesores de su niño una nota para agradecerles específicamente la manera en que ayudan a su niño. Si el vecino, la niñera, el líder del club de jóvenes u otro profesional han mostrado un interés particular en su niño, hágale saber lo importante que es para la autoestima de su niño y su crecimiento futuro. Ayude a su niño a escribir una carta, a entregar un regalo o a hacer un obsequio especial como muestra de su aprecio.

Pida a su niño que realice buenas obras y contribuya a su comunidad

La temporada de fiestas es un buen momento para pedirle a su niño que realice proyectos de servicio de ayuda a los demás. Su familia entera podría ofrecer sus servicios en calidad de voluntarios. O bien, usted y algún otro miembro de la familia podrían primero probar una nueva actividad y averiguar cual sería la mejor manera de que su niño participe. Anime a los niños a que lleven a cabo sus ideas sobre cómo podrían ayudar a los menos afortunados. Estas actividades ayudarán a su niño a prepararse para realizar carreras futuras y a fomentar su autoestima. Pero más importante, su niño aprenderá que los niños con discapacidades pueden contribuir a mejorar sus comunidades al compartir sus capacidades especiales.

This article was found at the following website in both Spanish and English: www.colorincolorado.org

Winter Calendar of Events



Date	Event	Contact
Dec 12, 2009	Families Together KC Holiday Party for Parents	877-499-5369
Feb 6, 2010	Families Together Real People Real Life Dreams Transition Conference, Kansas City	877-499-5369
Feb 20-21, 2010	Families Together Family Enrichment Weekend, Garden City	888-820-6364
Feb 27, 2010	Families Together Statewide Conference, Topeka	800-264-6343
Mar 19-20, 2010	Families Together Parent Networking Conference, Hays	888-820-6364
Mar 26-27, 2010	Families Together Family Enrichment Weekend, Wichita	888-815-6364
Apr 9-10, 2010	Families Together Parent Networking Conference, Kansas City	877-499-5369
Apr 23-24, 2010	Families Together Family Enrichment Weekend, Manhattan	800-264-6343

The Kansas Youth Leadership Forum

The Kansas Youth Empowerment Academy has announced the 2010 Kansas Youth Leadership forum and is recruiting delegates and volunteers. The forum is June 8-12, 2010 at Washburn University in Topeka, Kansas. Delegates must be high school juniors or seniors with disabilities who have show some leadership in their school or outside activities. Deadline for applications is December 15. Call Carrie Greenwood at 1-866-577-5932 for an application today!

Volunteers are also needed for the forum. Because this forum is for youth with disabilities, the volunteers need to be adults with disabilities. Call Carrie Greenwood at 1-866-577-5932 for an application and more information.

Return Service Requested

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