

**Family Resource
Center for
Disabilities &
Special Needs**

The Coalition

**Parent Training
& Resource
Center (PTRC)**

December 2015

The Story of Us And What Happens Next?

*By Bev McCarty, Executive Director
Family Resource Center for Disabilities & Special Needs*

For many of you reading this article, there has always been a Parent Training & Resource Center (PTRC) serving Berkeley, Dorchester, and Charleston Counties. Ready to help families of children with disabilities understand their rights and responsibilities, the PTRC has been the go-to agency when questions arise about school services. Over the years, the PTRC has provided direct & intensive technical assistance to nearly 2500 parents in the tri-county. This includes accompanying parents to well over **5,000** IEP, 504, or other school-based meetings. In addition, we have provided training and information to hundreds more parents and professionals through workshops, conferences, and other methods of resource distribution.

Yet many others reading this article remember a different time when there was no PTRC. Those parents, like myself, often felt alone and unprepared as they sat in IEP meetings surrounded by a table of professionals. Many of you may be aware of some of the struggles that have kept this program afloat. I'd like to take this opportunity to tell you all a little more about how things came to be.

In 1995, the Advocacy Coalition for People with Disabilities (ACPD), a Charleston based non-profit organization, collaborated with faculty at The Citadel to submit a 3 year grant proposal to the SC Developmental Disabilities Council. The grant was awarded and with the funding the ACPD developed "The FORUM" (Families Organized for Resource Use Management) which provided a lending library, sponsored an annual disabilities conference, and published *The Coalition*, a quarterly newsletter. These information

services were targeted to a population of any age and focused on increasing the availability of resources to individuals with disabilities and their families. Eventually, this small grant project would expand and become the impetus for the PTRC.

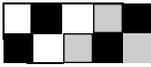
The FORUM was a success and in 1996, MUSC/ Department of Genetics and Developmental Pediatrics made space available in their Vince Mosely Clinic to house the FORUM for the next few years.

Around that same time, Congress reauthorized the Individuals with Disabilities Education Act (IDEA). The IDEA (and its subsequent revisions) is the "law of the land" regarding special education services for children with disabilities. When the law was reauthorized in 1997, Congress approved specific funding for the US Department of Education to improve parent access to information and training at the community level. This new allocation would provide funding to 30 "Community Parent Resource Centers (CPRC)" across the country through a national grant competition conducted by the Department. Many years earlier, Congress had authorized funding to assure that every state in the country would have at least one Parent Training & Information Center (PTI) to help parents throughout each state understand the special education process.

In 1999, the second year the CPRC competition was held, MUSC faculty and the ACPD collaborated on an application to create a center that would assist families of children with disabilities in Berkeley, Dorchester, & Charleston Counties. The ACPD was awarded the grant in October 1999 and the Parent Training & Resource Center was born.

Working closely with MUSC, the ACPD developed a parent-driven, family friendly center that included support from professionals dedicated to the care and well-being of children/youth with disabilities and their families. In 2001, the ACPD and PTRC stakeholders

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Preguntas Comunes de los Padres sobre la Educación Especial

Cuando los niños tienen problemas o dificultades en sus estudios, es muy importante averiguar el porqué.

Puede ser que una discapacidad esté afectando el rendimiento educativo de su hijo. Si es así, su hijo puede ser elegible para ayudas a través de la educación especial y los servicios relacionados. Para aprender más sobre la educación especial sigue leyendo. Esta publicación le va a explicar cómo usted y la escuela pueden trabajar juntos para ayudar a su hijo.

Como primer paso y antes de referir a su hijo para una evaluación para la educación especial, la escuela probablemente tendrá que probar intervenciones suficientes y modificar las prácticas de enseñanza en el aula de educación regular.

La educación especial es instrucción especialmente diseñada para cumplir con las necesidades únicas de los niños que tienen discapacidades. Esto se hace en las escuelas públicas sin ningún costo para los padres.

La educación especial puede incluir instrucción especial conducida en la sala de clases, en el hogar, en los hospitales e instituciones, o en otros ambientes. Esta definición de la educación especial viene del [Acta para la Educación de Individuos con Discapacidades](#) (IDEA, por sus siglas en inglés). Esta ley otorga a los niños elegibles con discapacidades el derecho de recibir asistencia y servicios especiales en la escuela. niños recibe instrucción especialmente diseñada:

- para cumplir con sus necesidades únicas (que resultan de tener una discapacidad); y
- para ayudar que el niño aprenda la información y destrezas que los otros niños están aprendiendo en el currículo educativo general.

Los niños con discapacidades son elegibles para recibir servicios de educación especial y servicios relacionados cuando cumplen con la definición de un “niño con una discapacidad” bajo IDEA.

Esta ley enumera 13 categorías diferentes de discapacidades bajo las cuales un niño puede ser elegible para recibir servicios de educación especial y servicios relacionados. Estas categorías son: Autismo; Discapacidad específica del aprendizaje; Discapacidad intelectual (antes conocido como re-

traso mental); Discapacidades múltiples; Impedimento auditivo; Impedimento ortopédico; Impedimento visual (incluyendo la ceguera); Lesión cerebral traumática; Otro impedimento de la salud (incluyendo Trastorno por déficit de atención/hiperactividad); Impedimento del habla o lenguaje; Sordera; Sordo-ciego; Trastorno emocional

Los estados y los distritos escolares tienen que seguir las definiciones de la ley IDEA, pero también pueden agregar detalles que les ayudarán a tomar decisiones sobre la elegibilidad de los niños. Por esta razón, es muy importante que usted conozca las políticas estatales y locales.

El primer paso es averiguar si su niño tiene una discapacidad. Para hacer ésto, llame o escríbale al Director de Educación Especial o al director de la escuela de su niño. En su carta o correo electrónico (o cuando hable con el director), describe sus preocupaciones con el rendimiento educativo de su niño y pida que la escuela realice una evaluación de su niño bajo IDEA lo antes posible.

Es posible que la escuela pública también tenga preocupaciones en cuanto al desarrollo y aprendizaje de su niño. Si la escuela también piensa que su niño podría tener una discapacidad, entonces la escuela debe evaluar a su niño sin ningún costo a usted.

La escuela tiene que pedir su permiso y recibir su consentimiento por escrito antes de poder evaluar a su niño. Una vez que usted dé su consentimiento, la evaluación debe llevarse a cabo dentro de 60 días (o dentro del plazo de tiempo que el estado ha establecido).

Sin embargo, la escuela no tiene que evaluar a su niño simplemente porque usted lo ha solicitado. Es posible que la escuela piense que su niño no tiene una discapacidad y tampoco necesita educación especial. En este caso, la escuela puede negarse a evaluar a su niño.

La escuela debe informarle acerca de su decisión por escrito, al igual que la razón por la cual se ha negado. Esto se llama darle notificación previa por escrito.

Si la escuela se niega a evaluar a su niño, hay dos cosas que usted puede hacer de inmediato:

Solicitar información del sistema escolar sobre sus políticas de educación especial, al igual que los derechos de los padres de no estar de acuerdo con las decisiones tomadas por el sistema escolar. Estos materiales deben describir los pasos que los padres pueden tomar para desafiar la decisión del sistema escolar.

Comunicarse con el PTRC – 843-266-1318.

<http://www.parentcenterhub.org/repository/lg1sp/>

The Story of Us

determined that the best future for the project would result from an organization whose mission put the PTRC in the forefront of all activities. Responding to that decision, the Family Resource Center for Disabilities and Special Needs (FRC) was established with a structure that met the funding requirements of the Department of Education. The FRC obtained non-profit status with the responsibility to keep the PTRC in operation by making application for the federal funding when available.

In this highly competitive process, the FRC has written 5 successful grant applications to secure the funding that allows the PTRC to operate. The PTRC is one of the longest running community Centers under this federal program. While we are grateful that our work has been so rewarded, it is unfortunate that the amount of the award has never been increased despite increases in the number of families served and the cost of services. In other words, we receive the same amount of money whether we attend 34 meetings (as in the 1st year) or over 600 as we have in subsequent years. We now provide information and training to hundreds more families than we did 14 years ago with the same amount of money!!

Right now you may be thinking “Good for You” & “Good for Us” - but there’s a change on the horizon. *Our current grant will expire on 9/30/2016.*

In the past, the national competition for this funding was held annually; each year 10 centers would be awarded a 3 year grant. If an application wasn’t funded that year, the agency had the opportunity to apply again the following year. This rotation method maintained the mandate of 30 operational CPRCs at all times. The 2016 competition will be different. This time, the rotation model will not be used and all 30 National Centers will be awarded at the same time with 5 year grants. The bad news is that there will not be another opportunity to compete for this award until 2021. While this is great news if the grant is funded, it can be the death blow for a small agency whose work depends on this award - an agency like the Family Resource Center/PTRC.

Recently I spoke with a parent who obtained legal counsel to accompany her to a school-based meeting at a cost to the family of over \$1000. There are other fee-for-service options available to families in the area. While no staff at the FRC/PTRC is an attorney

(although there are attorneys on our Board of Directors) our services are valuable and effective. Mentors and staff have attended over **5,000** IEP and other school-based meetings with families....at **NO COST**. The FRC believes strongly in the model it has maintained for years - to provide this free resource to families regardless of ability to pay.

Within the next couple of months, the FRC will be writing a new proposal to obtain the federal funding. As noted, there is no increase in the amount of the award and with each application the FRC has had to trim down services. This will be necessary again but we continue to be committed to the aspects of programming that provide the best outcomes - intense technical assistance (Mentoring) and training workshops for parents and professionals. To accompany the application, we need letters of support from the community. ***If you have benefited from PTRC services,*** please let us know - in writing. Call the office and we’ll tell you how to proceed.

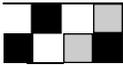
For many years the future of the PTRC has been in the hands of the FRC Board of Directors, those writing the grants, and the funding agencies. In these challenging times, faced with the possibility that the PTRC may not be around next year, we hope the community that we serve can help us help families. Whether that help takes the form of a financial contribution or volunteering time to help raise money or organize fundraisers, we know every little bit will help.

Also, the FRC is recruiting board members. We need a board comprised in majority of parents of children with disabilities (age 0-26) with the time and energy to commit to the future of the PTRC and the families who need us. We hope you will find a way to help. Please call the office if you have any ideas. If you would like to send us a donation or letter of support, please mail it to: FRC - 1575 Savannah Hwy, Ste. 6 - Charleston 29407. If you are interested in becoming a member of the board of directors, please call the office for additional information (843) 266-1318.



The contents of this newsletter were developed under a grant from the US Dept. of Education, # H328C110017. However, contents do not necessarily represent the policy of the US Department of Education, and you should not assume endorsement by the Federal Government. Project Officer, Julia Martin Eile.





IEP Fair on Transition - "Bring The IEP Night"

March 3 - 5:30-7:00 at the FRC Office (1575 Savannah Highway, CHS)

Bring your child's IEP (or 504) along with any questions regarding transition services. PTRC Mentors & Staff will be available to work one-on-one with parents. Attendees will receive a copy of the "Transition Toolkit". If warranted, arrangements can be made for free follow-up intense technical assistance provided through the PTRC's Peer Parent Mentor program.

We are asking that you register for this FREE event to assure that adequate staff/mentors are on site to help families. Please call: 843-266-1318.

Looking for a Support Group?

Trident Head Injury Support Group: meets the 1st Tuesday of each month from 7:00-8:30 PM at the HASCI Drop In Center, Westwood Plaza (intersection of Hwys 7 & 61), Suite 6, next to Hancock Fabrics. For more info: Marsha Mikell at 843-881-1214 or Colin DeResta at 843-852-5550. Follow on Facebook.

Down Syndrome Association of the Low Country: sponsors four Information Programs and four Social Events each year - in addition to Mothers Night Out. For a complete calendar of events, check their website at: www.dsalowcountry.org or follow them on Facebook. You may also call: 654-1552.

Parent & Guardian Association of the Coastal Center: This group supports those with a family member residing at the Coastal Center. General meetings are held four times a year. For more information contact Linda Bodiford at 821-5809 or Suzanne at 276-1001.

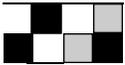
Rett's Syndrome Support: Families in need of a contact person to access support services for girls with Rett's Syndrome may call Nancy Banov at 556-4632 after 3 PM.

Trident Spinal Cord Injury Peer Support Group: This group is open to any person with a spinal cord injury or other mobility difficulties. The meetings provide a forum for the members to discuss issues and concerns and receive immediate feedback. Some members use the meetings to brainstorm possible solutions to ongoing problems. In addition, the group provides members with opportunities to develop a social network. Meetings are held on the second Tuesday evening of every month (6:00-8:00 PM) at AccessAbility, 7944 Dorchester Rd, #5, North Charleston. There are also special events throughout the year. For more information & to keep current with group activities contact Barb Delia at 843-557-4827.

Grief Support Group for Children - Bereavement group for children ages 8-12 (1 group) and 13-15 (2nd group) sponsored by Heartland Hospice, 1064 Gardner Rd, Suite 204, West Ashley, Charleston. For more information contact Kimberly at Heartland Hospice, 766-7646.

Sickle Cell Sisters (for teenage girls with sickle cell disease) is a therapeutic support group for teenage girls between the ages of 13 and 18. The group meets every other month at MUSC Children's Hospital and focuses on psychosocial aspects of living with sickle cell disease. For more information call Christine at 843-792-4152.

The National Alliance for the Mentally Ill (NAMI) of the Charleston area offers support group meetings for individuals who suffer from a brain disorder and for family members and caregivers of those who have severe and persistent mental illness. Meetings are held at various locations and times. 1st Tues of the Month: *Moncks Corner Baptist Church, 500 East Main Street, Moncks Corner, SC 29461, 6-7:15 PM, in the Fellowship Hall beside the church.* 1st Thurs. of the Month: *Seacoast Church, Mount Pleasant, 750 Long Point Road, Mt. Pleasant. Enter from Egypt Road. Meetings are held at 6 PM. Family Support Group in Trailer #21 & Connection Support Group in Trailer #22.* 2nd Mon of the Month: *Seacoast Church, West Ashley, 2049 Savannah Hwy., Charleston, Use the Main Entrance. Support: 6:00-7:15 PM, Education: 7:30-8:30 PM.* Education meetings



for consumers and family members are held together. The speakers discuss various issues related to mental health. 3rd Mon of the Month: *Bethany United Methodist Church, 118 West Third South Street, Summerville, 6:00 –7:30 PM* Every Wednesday: Support for those in recovery: 1:30 – 3:00 PM at Charleston Mental Health Clinic (West Ashley), 2100 Charlie Hall Blvd. (north wing), Charleston. For more information, call 843-871-1009 or visit <http://namisc.org/>

Summerville Autism Support - This group meets frequently, but irregularly, for a night out. Please call Jodi Hortman (870-3485) for information on the next get together.

Epilepsy Support Group for families of children with epilepsy meets on the 2nd Saturday of each month at Cathedral of Praise, Bldg. A, Room 103, 3790 Ashley Phosphate Rd., N. Charleston. Look for SAFE sign outside building. The Group meets from 11am-1pm (First hour is education/business meeting, second hour is support group) For more information contact Karen St. Marie at 843-991-7144 or at Karen@scepilepsy.org. Also check out their Facebook page under “South Carolina Advocates for Epilepsy”.

Low Country Autism Support Group sponsored by the Early Autism Project meets the 2nd Tuesday of the month at the Early Autism Project Clinic, 1123 Queensborough Dr., Mt. Pleasant, from 6:30-7:30. Speakers will be invited to each meeting and refreshments are served. Childcare is provided but you must register in advance for the free service. You do not have to be a client of the Early Autism Project to participate. Saturday respite events are being planned for every other month. For more information and to register for child care, call Anna Bullard at 912-293-5217 or visit abullard@earlyautism.com

Family Corps Support Group for parents of children with Aspergers, High Functioning Autism, Anxiety and related conditions every Tuesday from 6:30-7:30 PM at Cherokee United Methodist Church, 2105 Cherokee Ave. North Charleston. Childcare is provided free of charge. For questions call 843-747-0480.

Support Group for Spanish Speaking Families: 4th Friday of each month from 6-8 PM at the MUSC Northwoods Clinic, 2070 Northbrook Blvd., Suite A-16, N. Charleston. Call Martha at 843-876-2505.

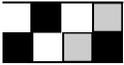
Un grupo de soporte para familias de habla Hispana se reune el cuarto Viernes de cada mes de las 6 a las 8 en la Clinica MUSC Northwoods 2070 Northbrook Blvd, Suite A-16, North Charleston. Para mayor informacion llame a Martha al (843) 876-2505.

Do You Know About Healing Farms?

Healing Farms is a local non-profit that exists to provide hope and opportunity to the special needs community. Their adult day program helps students as they transition out of high school into adult life. Healing Farms' programs utilize small, well-matched groups called PODs (People Overcoming Disability) composed of four to six young adults with disabilities, two to three volunteers and one facilitator. PODs can go anywhere and do anything that meets the needs of the individuals in the group. PODs work out of small, community based hubs, within five core domains: urban farm, technology lab, arts/movement, life skills, and community based education and recreation. To get more information on Healing Farms programs visit their website: www.healingfarms.com or call 843-971-9300

Looking for Someone to Talk with about Autism? There are two on-line ways to reach out to others in the “autism community” in South Carolina. There is an on-line support group for teachers, professionals, service providers & family members. To subscribe, send a blank email to: autismsouthcarolina-subscribe@yahoogroups.com. Also, there is a discussion group for parents & families who want to share their joys, stories, challenges, and solutions. To subscribe, send a blank email to: scautismforum-subscribe@yahoogroups.com

We try our best to keep this information current. If your group is listed here and no longer meets or if you have a group that should be listed but isn't, please call us: 843-266-1318



Family Corps Services

FamilyCorps began in 1978 as Parents Anonymous® of South Carolina a private, non-profit organization. For over 30 years the organization worked around the state to strengthen families and empower communities in the prevention of child abuse and neglect by providing training and technical assistance to individuals and agencies interested in the Parents Anonymous® model of Peer Support. In 2013, they rebranded as FamilyCorps to include more evidence-based programs to better serve families. They sponsor programs that serve parents, foster parents, kinship caregivers, fathers, and teen moms.

Their Strengthening Families Program (SFP) meets Mondays, 6:00-8:30 PM at the Cherokee United Methodist Church, 2105 Cherokee Ave. North Charleston. SFP is a skills training program for families with children age 6-11 and is designed to reduce significant behavior problems, alcohol & drug abuse, and delinquency while improving social competencies & school performance. Numerous incentives are offered to families who participate including weekly family meals, door prizes, bus passes, gas cards and more.

In addition, two specific classes are offered for a nominal fee. *Anger Management* is a 12 week comprehensive course approved for SCDSS clients & offered from 5-6:00 PM on Tues. The course attempts to teach parents better self control, the difference between anger & assertiveness, stress management, and improved communication skills. Support for parents suffering from grief and loss is included. The cost is \$36 for an individual and \$50 a couple.

Triple P- Positive Parenting Program - is an evidence based program that attempts to prevent behavioral, emotional & developmental problems in children by enhancing the knowledge, skills, & confidence of parents. Triple P classes are six weeks long and cost \$60.00 with free childcare offered.

For more information about Family Corps and their program call 843-747-0480 or visit their website: <http://family-corps.org/home>

You can help the Family Resource Center simply by shopping on Amazon.com. Register us as your favorite charity at Amazon Smiles then each time you purchase something by entering the Amazon website: <https://smile.amazon.com/> a donation will be made to the FRC. All features of Amazon are the same.

Sorrow at the Family Resource Center

The Family Resource Center shared the grief of one of our Peer Parent Mentors, Ruth Burrows Harkleroad, when her son Tommy Harkleroad passed away unexpectedly in late summer. Ruth has worked with many parents over the years who contacted us during her difficult time to let her know she was in their thoughts and prayers. In remembrance donations were made to the FRC and we greatly appreciate that. After a short break, Ruth is now back with us helping families.

Another shocking loss happened in November when one of our Peer Parent Mentors passed away suddenly after a brief illness. Mary Snyder was among the first Peer Parent Mentors who signed on with us after we were funded in 1999. She worked with us for a few years and then devoted all of her time to her daughter Faith, a child with disabilities. Sadly, Faith passed away two years ago. Shortly after, Mary came back to us for a brief time to help families. She felt giving back was a part of her grieving process. Mary was a wonderful mother and grandmother, a loving wife, a social worker who was a strong advocate for children, and a Peer Parent Mentor who believed in the educational rights of students with disabilities. She is missed by the Family Resource Center Family. Remembrance donations have been made to the FRC in her honor as well.

Let's Make a Plan for Life After High School

Start with the **TRANSITION FAIR**

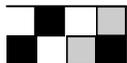
Sponsored by Charleston County School District & Charleston CAN

West Ashley High School
Feb 27, 2016 - 9-12

This event is FREE for Charleston County Families

For More information contact:

Meg Pilkington (margaret_pilkington@charleston.k12.sc.us)
or 843-937-6500



Get UNDERSTOOD

Fifteen nonprofit organizations that care deeply about helping children with learning and attention issues have come together to create a groundbreaking resource. *Understood* is a comprehensive free online resource that empowers parents through personalized support, daily access to experts and specially designed tools to help the millions of children with learning and attention issues go from simply coping to truly thriving in school and in life. *Understood* was created in recognition of the vital role that parents play in their child's success. This new, one-stop, easy-to-use resource aims to cut through the confusion and empower parents through customized support. *Understood* is designed for parents who don't know yet why their children are struggling as well as for parents whose children have a diagnosis and are receiving special services in school.

Understood covers a wide range of topics, including homework and study skills, building on strengths, partnering with teachers, self-advocacy, assistive technology, extracurricular activities and summer camp, as well as info about IEPs and 504s. It uses state-of-the-art digital technology to offer different levels of personalized content and offers free, daily chats and interactive webinars with experts. Parents are encouraged to share stories, ask for input and look for families in their local area. All content is accessible in English, Spanish and read aloud mode and also is optimized for smartphones, tablets and computers. Be sure to check out "**Your Parent Toolkit**" on *Understood*.

To access these great resources and more visit:
<https://www.understood.org>.

SC Assistive Technology Program Annual Expo

Thursday, March 3, 2016 - 9 am - 4 pm
Brookland Banquet and Conference Center
1066 Sunset Blvd. - West Columbia

Call 803-796-7525 or visit the website for information on previous Expos and to register for the event:

<http://www.sc.edu/scatp/expo/expo16.html>

South Carolina's New Parent Training & Information Center

Every state and US Territory has at least one federally funded Parent Training & Information Center (PTI) to assist families of children with disabilities throughout the state understand their rights and responsibilities, among other things. The number of these centers in each state is determined by population. SC is allocated funding for one parent center and that center is selected through a state-wide competitive grant process held every 5 years. For about the last 25 years, PRO-Parents of South Carolina was the state PTI.

This year, our state PTI was awarded to Family Connection of South Carolina effective Oct. 1. To learn more about what Family Connections has planned for their new PTI, you can contact Sherry Larson, the PTI Project Director, or other staff at 800-578-8750.

This change does not effect the services provided by the Family Resource Center or the PTRC. As noted in this newsletter, the competition for renewal of our PTRC is a national competition and is unaffected by any changes with the state PTI.

SC/DDSN Autism Division Training

The Autism Division provides a large list of training opportunities for both professionals and parents on issues surrounding Autism Spectrum Disorder (ASD). The list below is targeted for all audiences and doesn't require any prerequisite courses although other trainings do. All trainings are held at their office at the Coastal Center, 9555 Miles Jamison Rd, Summerville. Please visit their website for the training booklet with the full list of topics and registration information:

<http://ddsn.sc.gov/consumers/divisions/Documents/Autism%20Booklet%202015-2016.pdf>

Or call: 843-832-5561. Space is limited.

- 1/20/16 - Autism 101: Understanding ASD
- 2/10/16 - Teaching Toilet Training
- 3/9/16 - Early Intervention Training
- 4/13/16 - Autism 101: Understanding ASD
- 5/11/16 - Dealing with Difficult Behavior
- 6/8/16 - Visual Supports



1575 Savannah Highway - Suite 6
 Charleston, South Carolina 29407
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 www.frcdsn.org

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- Wills & other legal documents
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- Counseling on landlord/tenant issues

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 or (803) 576-3815

E-mail:
disasterinfo@scbar.org



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