Guidelines for Establishing a Special Needs Parents Network

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I. Overview

Raising children is not easy. Raising children who have intellectual and developmental disabilities is even more challenging. Without the help of others it can be an over whelming step by step process from the time of the diagnosis to the challenges of raising a special needs child. Without God in the lives of parents with children who have special needs it can be an even greater challenge.

A special needs parents network offers those in your congregation and in the community some hope in an often seemingly hopeless situation. It offers hope in a very real way through God and His Word. It offers hope to those who are just starting their journey by gathering with those who have been through the journey. By making the journey along with the support, prayer, and advice of others the journey will likely be smoother. By sharing ideas and resources along with learning from others mistakes there is a sense that they are not in it alone. It will also allow those who face these challenges to grow in their faith.

II. Purpose

Carry each other's burdens, and in this way you will fulfill the law of Christ. (Galatians 6:2)

"Neither this man nor his parents sinned," said Jesus, "but this happened so that the work of God might be displayed in his life." (John 9:3)

In the same way, let your light shine before men, that they may see your good deeds and praise your Father in heaven. (Matthew 5:16)

The purpose of the network is allow for those who have children with special needs another avenue of spiritual healing through God's Word and through other Christians who are on this journey or have faced this journey or may have qualifications to help with the journey. The need for parents who have children with special needs to share their stories with others is important to help them know they are not the only ones facing such a challenge. By having experienced parents, family, friends, and others who have gone through this and who are willing to share their stories, insight, knowledge, and faith, those who are struggling will be encouraged during their journey with their child.

It will also allow the congregation to reach out to those in their community that may have children with special needs and are unchurched. According to the Christian Council on Persons with Disabilities, over 80% (of people with disablities) are unchurched. A welcoming attitude to those in the community who have children with special needs may encourage them to attend worship services at your church. A diagnosis does not alter a soul's need for God's love.

III. Structure

Where do you start? Identify those within your congregation who have children with special needs. A good way is to do a brief survey in your church bulletin or newsletter. Once you gather this information and can identify potential volunteers to help get a program started, call them and discuss the opportunity.

Determine if someone(s) can be the leader of the network. To be successful it is suggested that more than one leader who is willing be identified. These leaders should be spiritually mature and have a good knowledge of God's Word and an understanding of Christian doctrine. Consider also the need to be able to listen without judging, lead a group and give guidance (typically a parent of a child with a disability), have the time, energy and motivation to commit, have comfort and understanding of their own grief, can solve problems, believe that every child is valuable, is sensitive to cultural and ethnic differences, can offer support, can accept rejection without being offended, and show Christ's love to others without exception of receiving something in return.

Determine a day and time of the month that the network can meet. It is suggested that the network meets once a month. Most often Saturday morning is a good time to meet. Realize that many who may want to participate will have to line up caregivers for their child that will allow them to attend. Invite those you have identified. Publicize the network in your church bulletins, newsletters, and into the community via other churches, newspapers, community bulletin boards, etc.

What will the day look like? A good start time might be 9:30 a.m. A good end time might be 11:30 a.m. Ask those who attend to bring a fruit or breakfast item and that you will provide coffee and juice. It is nice to have something small to share.

Have the room set up in a comfortable way for discussion. A circular shape or square works well so that all participants can make eye contact with one another. If you have a presenter coming, then a U shaped set up is best. Make the snacks and coffee easy to get to so people can move back and forth without interruption. If you use a room with more comfortable furniture, just make sure to arrange them so good communication takes place.

Have name tags and pens available so that as they arrive they can put them on. Though you may know some names, it helps those who have not met or might not remember someone's name.

Once everyone has gathered and settled in open with devotion and prayer (see resource list). This can be led by the pastor or by someone from the network that is willing to do so. You may want to arrange to have a guest speaker with experience in the special needs field. This can often be a well informed veteran parent of a child with special needs. Take time to go around the room and introduce yourselves. Share why you are there. What is your child's diagnosis? What are your feelings? How can the group help you? How can you help the group? It would be wise at this time, especially the first time, to have a box of tissues handy. There will be tears. For some it will be easy to share, for some it will be hard. Be encouraging. Each time you gather go around the group and share the latest in regards to the special needs journey you are on. This may include times of joy or happiness or times of sadness and sorrow. Those who have experience can help, and those needing help will find it through those who have experienced it.

The purpose of the meeting is to allow for healing through God's Word and through other Christians in similar situations. It is not about sharing gripes.

Before leaving gather up all names, email addresses, phone numbers and the like to allow for communication to continue both for future gatherings. Be respectful of each others privacy and those things shared in confidence. It should be a time that allows for all to share their needs and feelings. It is a time to help each other on the journey by creating a network of friends, a time to help and support each other. Take time to reflect on who else may be able to become part of the network to help in this journey. Close with a prayer. Stay connected.

IV. Guest Speakers

Prescreen your guest presenters. Make sure that what they intend to discuss has only to do with the topic you have asked them there to discuss. It needs to fit and comply with our Christian perspective.

Ideas for guest speakers include Christian psychologists, hospital program directors, community disability advocates, special education teachers, and the like.

V. Discussion Starter Ideas

- How do you get a diagnosis for your child?
- Share something kind someone has done for you/your family recently.
- Tell a funny/endearing story about your child.
- What's your favorite Bible passage and how does it apply to you as a parent?
- Tell us about your family's morning routine.
- Tell us about your last family vacation.
- Share something that you have done that was difficult for you.
- What is your favorite thing about your child?
- Do you have a favorite restaurant? Do you take your child/children?
- What kind of school or therapy experiences has your child had?
- Share one thing you learned from your child's therapist, teacher, and doctor.
- If you had to describe your child in two minutes what would you say?
- If you had to describe yourself as a parent in two minutes what would you say?
- What part of your day is the most enjoyable?
- What part of your day is the most overwhelming?

VI. Resources

http://connect.wels.net/special-ministries WELS Special Ministries

http://mecp2gospel.blogspot.com/ Devotions written by Wendy Heyn.

www.wlcfs.org Member Assistance Program (MAP) has online support groups

http://snappin.org/ Snappin' Ministries - There are two good special needs parent network leader's guide and a one devotional book that could be used in your parent network gatherings. It should be noted that the prayer on page 9 of leader's guide volume 1 and page 8 of leader's guide volume 2 are not in keeping with our WELS doctrine and should not be used.

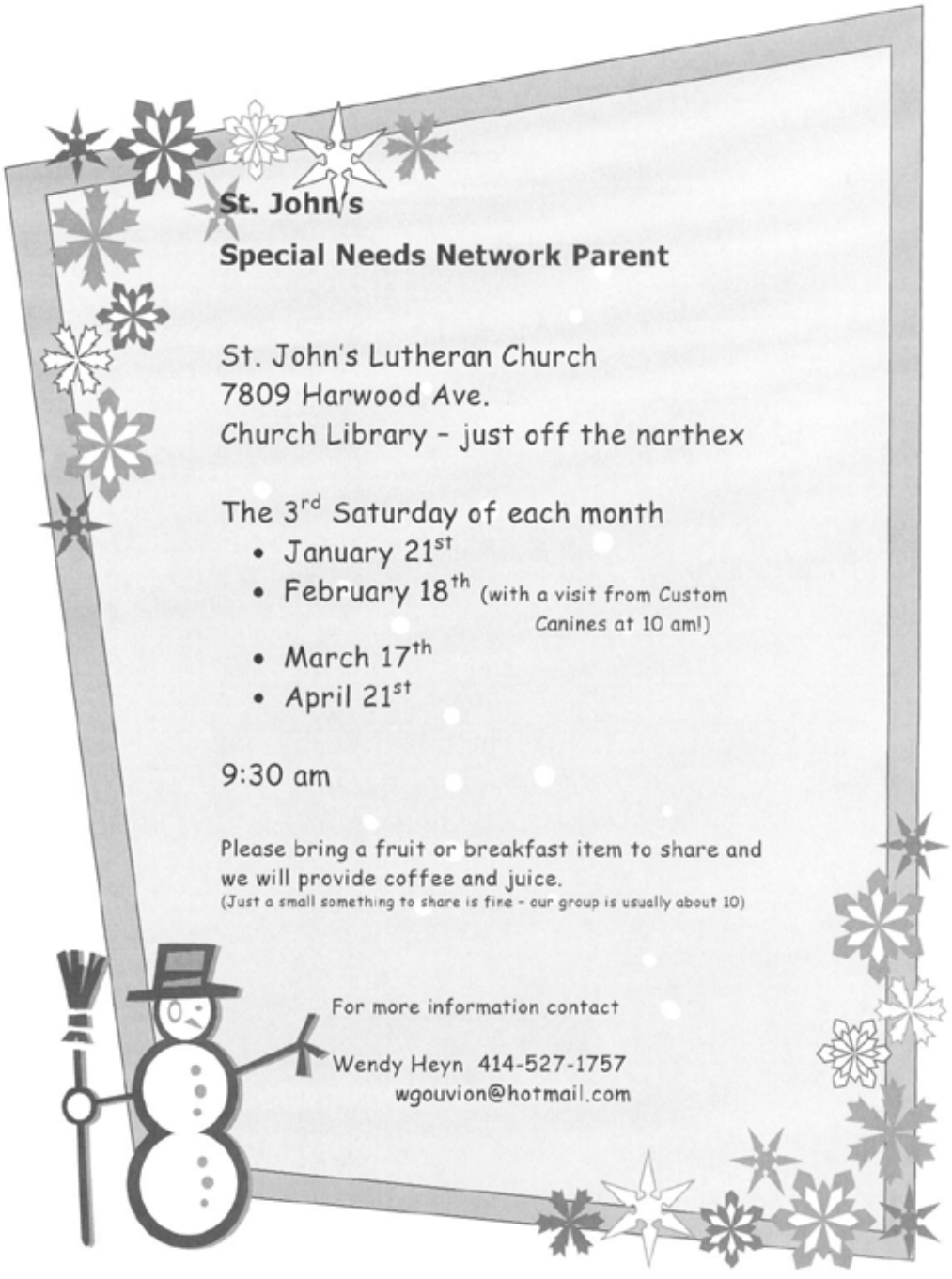
http://www.aaidd.org/ American Association on Intellectual and Developmental Disabilities

http://www.tlha.org/ The Lutheran Home Association and Jesus Cares Ministries

http://www.bethesdalutherancommunities.org/ Bethesda Lutheran Communities

http://www.ccfh.org/ Christian Church Foundation for the Handicapped.

Sample Flyer



Sample Church Survey

1. Does a member of your family have an intellectual and developmental disability? Yes ____ No ____

2. Do you have a friend or neighbor who has someone in their family with an intellectual and developmental disability? Yes ____ No ____

3. What is your family or friend's family member's special need? _____

   _____

4. Does he/she attend church regularly? Yes ____ No ____

5. If not, would he or she like to attend church regularly? Yes ____ No ____

6. Our church has started a special needs parent network support group. Would you like to become involved? Yes ____ No ____

   Name: _____

   Phone: (_____) _____

   Email: _____

7. Would you like your friend or family member to become involved? Yes ____ No ____

9. We would like to help your friend/family member. Please let us have his or her name, address, and other contact information so we can contact them.

   Friend/relative name: _____

   Phone: (_____) _____

   Email: _____

   Address: _____

Additional comments: _____

_____

Please return this completed survey to the church.

Sample Outline for When the Group Gathers

- Determine who will be the leader
- Leader does a brief introduction of who they are, any background that may help, and your child's special needs.
- Introduction to purpose of group: This group meets to provide spiritual and emotional support to parents/caregivers of children with special needs. We will use Bible lessons to help us with ideas, issues, and experiences presented or shared at each group gathering. Please note that your child's doctor and teacher will provide the best information concerning treatment, evaluation procedures, and laws concerning special education.
- Introduction and brief comment of those attending
- Prayer
- Bible Lesson or Devotion
- Discussion, Questions, Comments
- What are some of the disabilities we are dealing with? A time for greater sharing of their child's needs. What are your questions, comments and experiences? A round table discussion to help with the spiritual and emotional journey.
- Closing Prayer
- We will see you here again on this date and time. Who else can you invite to come along? God's blessings on your week.

