PEACE for Parents
Providing Effective Autism Care and Education
Facilitators

- Mary Linville, LICSW, Licensed Clinical Social Worker
- Julie Wise, M.A.,CCC, SLP, Master of Arts, Certificate of Clinical Competency, Speech Language Pathologist
- Debbie Olufs, Ph.D. Special Education
Diagnostic Team

• Pediatric Specialist in development or a Geneticist
• Child Psychiatrist / Child Psychologist
• Medical-Educational Specialist
• Speech Language Pathologist
• Pediatric Social Worker
• Child Life Specialist
• Audiology
• Others as needed
Family Input

• Information was provided, but parents say they:
  – Hit a wall
  – Fell off a cliff
  – Found minimal understanding and compassion from other family members
  – Struggled with implementation of recommendations
  – Struggled with grief / isolation
  – Had limited access to services / waiver
Program Development
Action Plan

• Came from parental need secondary to lack of availability of services.
• Diagnosis done – then what?
• Weekly meetings for 2 years brainstorming what to do.
• Numerous trainings
  – Washington D.C., North Carolina, Madison, Minneapolis, Pennsylvania...
  – Hanen, RDI, ABA, Ziggurat, Floor time, TEACCH, SCERTS...
The decision was made that multi-modal, intense parent education was a key, yet missing element.
Program Description

• 12-week session includes:
  – Intake interviews with all 3 providers
  – 12 parent support / education session
  – 6 alternate weekly meetings with the speech / language pathologist
  – 6 alternate weekly meetings with the licensed clinical social worker
  – Final interviews with all 3 providers

FUNDING WAS A HUGE ISSUE

First session was covered by Gundersen Lutheran.
Now, CMN covers the speech / language pathologist sessions, the education/support group is free, and insurance is used for behavioral health appointments.
Behavioral Health Sessions
Mary Linville, LICSW

• The most individualized family sessions.
• Parents meet with Mary to discuss needs.
• Support varies according to family needs.
• Sessions could involve:
  – Case management
  – Grief counseling
  – Couples counseling
  – Sibling support
  – Referral sources
  – Respite care
  – Family assessments
  – MOST IMPORTANTLY, THIS ALLOWS PARENTS TO TALK TO EACH OTHER
Speech Language Pathologist
Julie Wise, M.A., CCC-SLP

• Small group sessions which are varied according to the level of functionality of the child.
• Content-based instruction covering: speech, motor planning, language comprehension, and language expression.
• Discussion is held on how the above differ from communication and how to provide a framework to enhance communication.
• Parents of older, higher functioning children are more likely to get information from programs such as RDI, Brenda Smith-Myles and Hanen, while parents of younger children get more of the “More than Words” approach.
• Guides and molds strategies to change parental approach to child to make child’s life easier.
• GOAL IS NOT TO FIX CHILD, BUT TO INCREASE COMMUNICATION AND INTERACTION BETWEEN PARENTS AND CHILD.
Education / Support Group
Debbie Olufs, PhD

- Parent education is dependent upon intake interviews and may involve:
  - Guest speakers
  - Resources
  - Parent handbook...
- Support group after the education portion.
PEACE for Parents: Results of 17 Survey Questions Pre and Post Program
Change in response greater than 0.5 on a Four Point Response Scale

<table>
<thead>
<tr>
<th>Question</th>
<th>Amount of Change</th>
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<tbody>
<tr>
<td>Can cope with others reaction to my child</td>
<td>0.6</td>
</tr>
<tr>
<td>Health care provider is open to health care choices</td>
<td>1</td>
</tr>
<tr>
<td>Meet own personal expectations in caring for child</td>
<td>0.8</td>
</tr>
<tr>
<td>When child is distressed understand why</td>
<td>0.8</td>
</tr>
<tr>
<td>When child is distressed know how to help</td>
<td>1</td>
</tr>
<tr>
<td>Have the tools to help child on day to day basis</td>
<td>1.6</td>
</tr>
<tr>
<td>Know how to access services</td>
<td>1.8</td>
</tr>
</tbody>
</table>
Results:

• Survey results were verified by qualitative comments from the interviews.
  – “I now have a relationship with my child.”
  – “I was feeling a sense of desperation,...been gathering information for two years but haven’t made much progress.”
  – “This program has opened my eyes and I realize that before we didn’t even have enough knowledge to understand our own kids.”
  – “Ideally this program would be in every community.”
  – “This program should be offered to all parents of children diagnosed with an Autistic Spectrum Disorder.”

• The parents asked for additional sessions and initiated a group activity for all families.
What We Learned: A Lesson in Humility

• It was humbling to realize how much we don’t know about families of children in the spectrum.
• We learned from parents more than they learned from us.
• Flexibility is critical for all 3 portions of the program.
• The importance of individualization can’t be underestimated.
• The impact on the family is greater than we had ever suspected – emotionally and financially.
• This is most effective with the involvement of both parents.
Unexpected Findings

• We still are debating whether or not to provide child care on-site. It is helpful to some families, but for others, they value the time alone together.

• We are still questioning whether or not to base the groups on the homogeneity of the children.

• The support group has evolved into a long-term group, combining the “new” families with the “old”.

• A “Friends and Families” group as a last night meeting is quite popular.

• It is difficult to provide parents with enough information on the use of visual structure (TEACCH).