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## Partnership with Parents of medically complex children : Corner stone for Family Centered Care

### Problem:

Care of children with complex and chronic medical conditions is challenging and the lack of partnership and family centered care is one of the main barriers to improve care.

### Aim:

Evaluate level of partnership with parents of medically complex after 6 month of enrolment in the Pediatric Complex Care Clinic with satisfaction target of 75%.

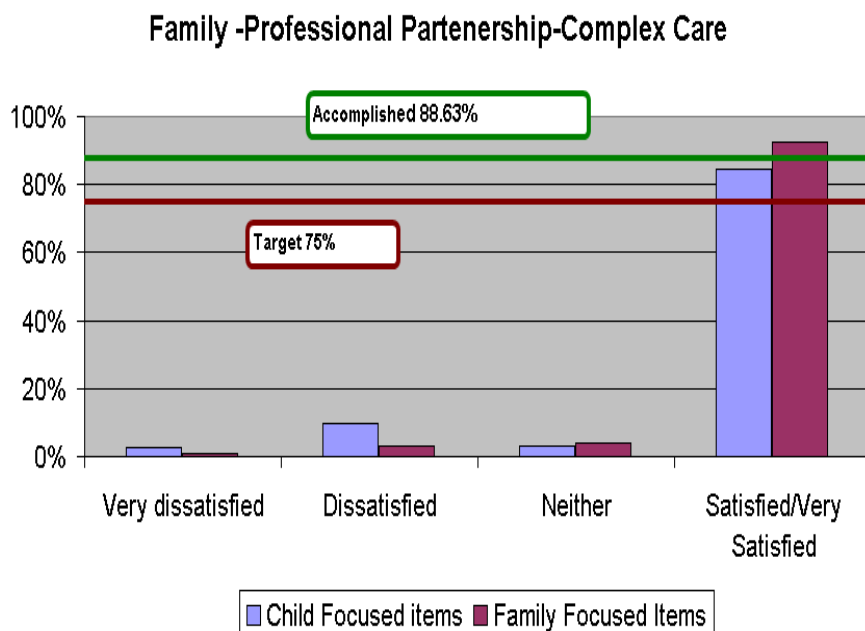
### Intervention

- Complex care clinic is an ambulatory service similar to medical home. It was started by HMC in recognition of the increasing numbers of children with complex medical conditions and their unmet care needs. The multi disciplinary team consists of physicians, nurses, RT,PT,OT,SPL, Clinical Pharmacist ,social worker and dietician who work in partnership with the families to coordinate, advocate and provide comprehensive family centered care,
- After 6month of enrollment in the clinic, 40 families were surveyed using the **Beach Center on Disability Family-Professional partnership scale** which consists of 18 items, 9 of them are child focused and 9 are family focused. The scale assesses the level of the parents satisfaction with complex care team as partners in care.

### Team:

Josephine Espinosa-Nurse  
 Fawzia Elmi-Nurse  
 Parvin Hossein-Nurse  
 Ibrahim Al Ayaseh-SPL  
 Ahmed Salah- Pharmacist  
 Ashraf El-Sheikh Ali-Pharmacist  
 Fathima Akbar-Dietician  
 Journa Liza Suyat Regala-RT  
 Honeylet Francisco-PT  
 Vince Solomon-OT  
 Aisha Ali Alnemah-SW  
**PROJECT SPONSOR:**  
 Dr. Ahmad Alhammadi  
**PROJECT COACH:**  
 Dr.Eshragh Taha

### Result :



How satisfied are you that your child's service provider....	Very Dissatisfied	Dissatisfied	Neither	Satisfied	Very Satisfied
1. Helps you gain skills or information to get what your child needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Has the skills to help your child succeed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Provides services that meet the individual needs of your child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Speaks up for your child's best interests when working with other service providers.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Lets you know about the good things your child does.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Is available when you need them.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Treats your child with dignity.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Builds on your child's strengths.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Values your opinion about your child's needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Is honest, even when there is bad news to give.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Keeps your child safe when your child is in his/her care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Uses words that you understand.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Protects your family's privacy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Shows respect for your family's values and beliefs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Listens without judging your child or family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Is a person you can depend on and trust	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Pays attention to what you have to say.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Is friendly.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### Conclusion:

Family focused items including valuing family opinion, respect, privacy and trust have achieved more than 90% score. This reflects the team concrete believe that "A child functions best with in a supportive family and a supportive community"  
[Rosenbaum et al, 1998.](#)

### Next step:

A care plan document will be shared between the complex care team and the parents of medically complex children to further enforce the partnership and communication.

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