

# The HALI Project

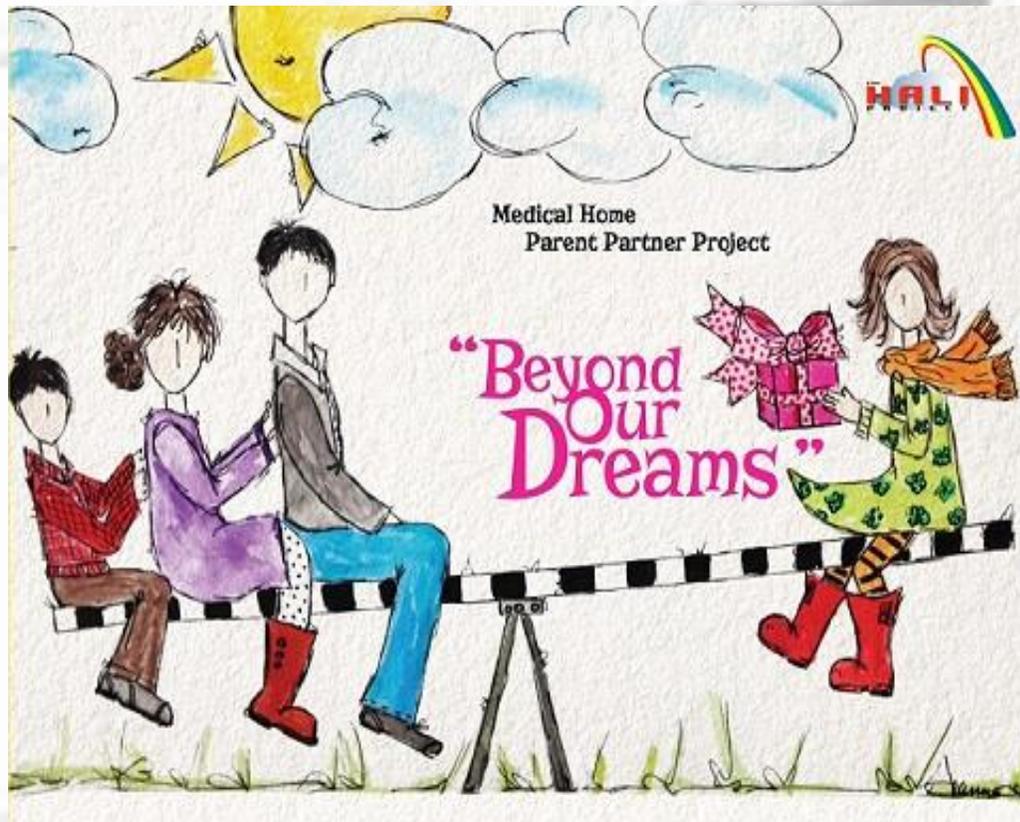


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# AAP: Innovative & Promising Practice In Pediatric Medical Home Implementation



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# Why Parent Partners?

## Introduction

1. Since the beginning of time, parents have wondered if they were “doing it right” when it comes to raising children.
2. They’ve been looking for people who’ve done it before to point them in the right direction.
3. For parents of children with special needs, finding those people to ask who have similar experience is more difficult.
4. The goal of The HALI Project/MPPP is to give every parent of a child with special healthcare needs access to a Parent Partner they can build a relationship with regardless of where they live.

# Common Elements of Successful Support

- ▶ Common components found in successful peer support efforts (Schilling, 2015):
  - ▶ **Shared experience** was seen as a necessary component of peer support by all participating groups.
  - ▶ A **safe, supportive environment** that allowed parents to speak freely without fear of judgement.
  - ▶ **Continuity** - getting to speak with the same person over time - allowed trust to be built.
  - ▶ **Training** - equipped workers with fundamental skills and taught how to set appropriate boundaries.
    - ▶ The importance of these 2 areas (along with others) is also found in a study on the Parent Engagement and Empowerment Program (Rodriguez, et al. 2011).
  - ▶ **Mutual Support of Support Givers** - having opportunity to share experiences was not only beneficial to parents, but also for those offering support to families.
  - ▶ **Ongoing Supervision** - to help offset the emotional burden of providing peer support, regular supervision to process experiences and their impact on the provider was seen as valuable in maintaining emotional well-being and preventing burnout.
  - ▶ The HALI Project/MPPP Model has had each of these components built into its training and support model since its beginning in 2005.

Rodriguez, J., Olin, S., Hoagwood, K., Shen, S., Burton, G., Radigan, M., & Jensen, P. (2011). The development and evaluation of a parent empowerment program for family peer advocates. *Journal of Child & Family Studies*, 20(4), 397-405. doi:10.1007/s10826-010-9405-4

Shilling, V. et al. (2015). Peer Support for parents of disabled children part 1: perceived outcomes of a one-to-one service, a qualitative study. *Child: Care, Health & Development*, 41 (4), 524-536. doi:10.1111/cch.12223

# Goals for the Montana Parent Partner Program

- ▶ High quality, comprehensive care that extends beyond the medical arena.
- ▶ Greater patient/caregiver satisfaction.
- ▶ Improved health outcomes and quality of life.
- ▶ Decreased caregiver stress and isolation.
- ▶ Better time efficiency for the practice.
- ▶ Higher job satisfaction for the provider.
- ▶ “Win, Win, Win”

# Who are we trying to serve?

- ▶ Any family who has a child with special healthcare needs as defined by the Maternal & Child Health Bureau.



# The Model

- ▶ The original question - “How do we improve the patient/caregiver experience while not adding more burden to the provider?”
  - ▶ What are some of those questions that families need answered but don't fit in a provider's area of expertise?
    - ▶ Local services - “where can I get help around here?”
      - ▶ Working closely with Medical Home Portal Project to make it as robust and current as possible, especially when it comes to local resources.
    - ▶ School challenges - creating IEP's that reflect our kids' potential while maintaining healthy relationships
    - ▶ Emotional challenges - “this isn't the way it's supposed to be”
    - ▶ Family issues - “they think he just needs a spanking”

# Benefits of the Parent Partner Model

- ▶ Moms will tell another mom they trust things they will never share with anyone else.
- ▶ Parents with experience in the world of special needs know who to talk to, not just what number to call.
  - ▶ This saves everyone's time.
- ▶ Parent Partners are far more available between office visits.
  - ▶ Encourages better follow-up and follow-through.
  - ▶ Can improve caregiver emotional health by decreasing the feeling of isolation.

# Benefits to Providers

- ▶ Allows you to spend more time at the top of your license.
- ▶ What are the things you do regularly that are time consuming and not reimbursable - but you try to help because your family needs it?
- ▶ How many of those things are non-medical in nature?

# Looking Forward - Lasting Relationships

- ▶ We are able to encourage caregivers to look for the best possible life.
- ▶ We can teach/model healthy communication in spite of overwhelming emotions.
- ▶ We can support families through many transitions in life, including the medical.
- ▶ We can encourage the marathon pace, not the sprint, to avoid burnout.

# What It Looks Like In Practice...

- ▶ It begins with a referral and a child or youth with a special healthcare need and their family and/or caregivers.
- ▶ Parent Partner connects with the family either while still in-clinic, via phone, virtually over a secure connection, or at another arranged time.
- ▶ Support, Encouragement and Hope are offered to families by someone with a unique understanding and experience that comes from having a similar journey.
- ▶ This support regularly continues throughout the family's journey.
- ▶ There are many access points for sources of support for our Parent Partners, our host site leaders and locations and our Program partners.

# The Montana Parent Partner Program

## Facts and Figures

- ▶ From May 2015 to June 2016, Parent Partners in Billings, Butte, Great Falls, and Missoula have served nearly 500 different patients and their families, helping them find answers for more than 2,500 separate issues/challenges. Areas addressed:
  - ▶ Emotional support - grief, acceptance, family relationships, grandparents raising grandchildren (>450)
  - ▶ Community resources - non-basic need support (>350)
  - ▶ School related issues (>200)
  - ▶ Care coordination (>150)
  - ▶ Travel/Transportation issues - (>150) - many Montana families travel to Denver, Salt Lake City, and Seattle for specialty appointments.
  - ▶ Basic Financial needs - food scarcity, clothing, utilities, housing (>100)
  - ▶ Behavior/ASD related issues (>200)
- ▶ A total of 6,000+ hours worked

# The Montana Parent Partner Program Facts and Figures

- ▶ From July 2016 to June 2017, Parent Partners in Billings, Butte, Great Falls, and Missoula have served over 400 different patients and their families, having more than 1,500 encounters and helping them find answers for more than 4,500 separate issues/challenges. Areas addressed:
  - ▶ Partnering with the Family in Their Unique Journey (>37%)
  - ▶ Resources/Referrals (>27%)
  - ▶ Family Support/Reassurance (>14%)
  - ▶ Care coordination, School support, Guardianship/Transition, Basic needs, Travel, Respite, Insurance Assistance, Misc. (>22%)

# Where We're Located in Montana

- ▶ Parent Partner Locations -
  - ▶ The Children's Clinic of Billings
  - ▶ Bozeman Health Pediatric Clinic
  - ▶ Southwest Montana Community Health Center - Butte
  - ▶ Benefis Pediatric Clinic - Great Falls
  - ▶ Missoula Valley Pediatrics
  - ▶ Shodair Children's Hospital - Genetics Clinic
  - ▶ Deaf / Hard of Hearing Population across Montana
- ▶ What if your child doesn't go to one of these places?