

# Parent-Directed Consultations: The Family Perspective

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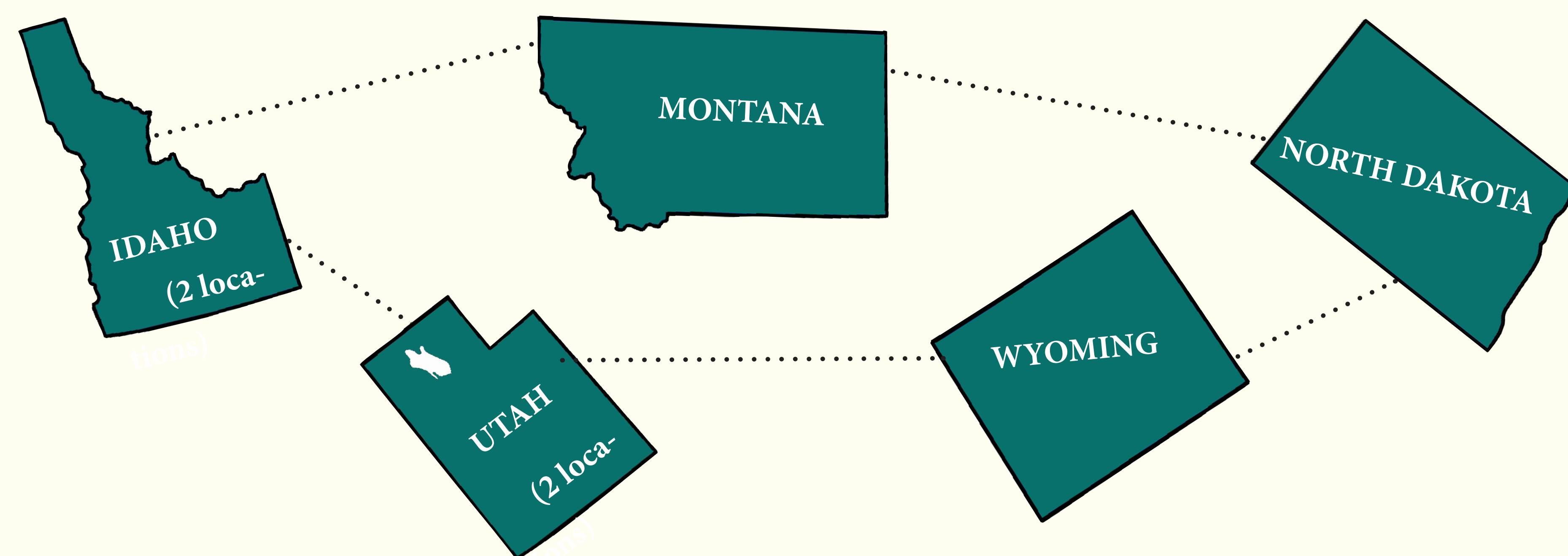


## URLEND PDC Background

Due to the rural nature of the states included in the Utah Regional LEND (Utah, Idaho, Montana, Wyoming, and North Dakota), Parent-Directed Consultations (PDCs) were created in 2005 to provide interdisciplinary training experiences using distance technology.

For the first time since the advent of the PDCs, the characteristics of the families participating in the program and outcome measures were collected for formal assessment.

## States connected via technology



## Project Goal/Objectives

- Learn more about the families who participate in the PDCs with respect to demographics, special needs of children in the family, and services the family has received.
- Assess family coping skills.
- Assess family perceptions of the extent of family-centered care received from community providers.

## Methods and Participants

- Nine parents, representing 11 children with special health care needs, participated in this project between October 2012 and March 2013.
- Three online surveys were created for this project using Survey Monkey software.
- Links to each survey (pre-PDC, immediate follow-up, and one month follow-up) were emailed to parents before and after their PDC.

## Parent Comments

Parents commented on what was most helpful to them about their PDC:

"The practical ideas received from the specialists that we could take home and work with our son."

"Amazing information all in a small amount of time. I have a lot of work to do, I am excited."

"Multiple perspectives - unbiased representation of the facts."

"Getting new perspective on our issues. It was nice to talk about the medication issues."

"All the different aspects brought together at once."



## PARENT DEMOGRAPHICS

Parent Respondent Characteristics (n = 9)	
Relationship to Child	Mother (n = 8) Father (n = 1)
Average Age	35.67 years
Marital Status	Married (n = 8) Divorced (n = 1)
Primary Language	English (n = 6) Spanish (n = 2)
Race/Ethnicity	Caucasian (n = 7) Hispanic/Latino (n = 2)
Religious Affiliation	Christian (n=2) Catholic (n=2) Latter Day Saint (n=4) Spiritual but not religious (n=1)
State of Residence	Idaho (n=1) Montana (n=3) North Dakota (n=1) Utah (n=4)

## CHILD DEMOGRAPHICS

Child Characteristics (n = 11)	
Average Age	5.11 years (Ranged from 2 to 10 years old)
Race/Ethnicity	Caucasian (n = 7) Hispanic/Latino (n = 2)
Disabilities and Chronic Conditions	9q34 duplication Autism PDD-NOS ADHD Trisomy 21/Down syndrome Chiari malformation Optic nerve drusen Auditory processing disorder Hearing loss Cognitive memory disorder Speech/language disorder Mosaic trisomy 21 syndrome Scoliosis Seizure disorder

## SERVICES RECEIVED BY CSHCN OF FAMILIES PARTICIPATING IN PDCS

Service	Number of children with history of service pre-PDC	Number of children receiving service at time of pre-PDC survey
PT	7	2
OT	6	5
SLP	8	7
Audiology	5	4
Nutrition	2	0
Special Education	7	7
Genetics	4	2
Psychology or Psychiatry	4	2
Early Intervention	8	4
Social Work	1	1

## FAMILY COPING SKILLS (CONFIDENCE) RESPONSES

Note: 0 = not applicable;  
1= not confident;  
2 = somewhat confident;  
3 = very confident

Question	Pre-PDC Mean	One Month Mean
How confident family able to provide home-based medical care for CSHCN?	2.67	2.50
How confident family able to provide access to professional medical care for CSHCN?	2.33	2.89
How confident family able to provide adequate nutrition for CSHCN?	2.67	2.67
How confident family able to gain access to emotional or psych care for CSHCN?	2.33	2.56
How confident family able to provide access to education for CSHCN?	2.44	2.67
How confident family able to provide environmental adaptations for CSHCN?	2.44	2.56

## FAMILY COPING SKILLS (SUPPORT) RESPONSES

Note: 1=no support;  
2 = limited support;  
3 = moderate support;  
4 = above average support;  
5 = complete support

Question	Pre-PDC Mean	One Month Mean
How much support do you have from family members...?	2.89	2.89
How much support do you have from friends...?	2.89	2.67
How much support do you have from the community...?	2.67	2.78

## FCS COMPOSITE

Family	Pre-PDC FCC score	1 month post-PDC FCC score	Change
1	32	31	-1
2	28	34	6
3	26	36	10
4	26	28	2
5	26	24	-2
6	27	27	0
7	31	35	4
8	26	36	10
9	23	22	-1
Mean (SD)	27.22 (2.6)	30.03 (5)	3.1 (4.4)

FCS composite scores were created by assigning a point value to each of nine FCS questions. Two point scales were used. Point values for the confidence scale were: "not confident" = 0; "somewhat confident" = 1; "very confident" = 2. Point values for the support scale were: "no support" = 0; "limited support" = 1; "moderate support" = 2; "above average support" = 3; and "complete support" = 4. With a total of six confidence questions and three support questions, the maximum score was 24 points. Again, higher FCS composite scores indicated a higher level of family coping skills.

## FAMILY-CENTERED CARE

Note. 1 = rarely; 2 = sometimes; 3 = half the time;  
4 = most of the time; 5 = always

Question	Pre-PDC Mean	One Month Mean
How often are you an active participant in developing the treatment or care plan for your child with special health care needs?	4.44	4.44
How often does your provider honor your cultural and spiritual beliefs when developing treatment or care plans for your CSHCN?	4.43	4.22
How often does your provider consider your family's insurance status and economic situation when making treatment plans for your CSHCN?	3.56	4.00
How often is length of appointment with provider adequate?	3.67	4.11
How often do you have the opportunity to provide feedback to your provider about the services he/she provides?	2.89	3.67
How often does your provider connect you with other families with similar life situations?	1.67	1.89
How often do you feel comfortable letting your provider know if you disagree with medical advice or recommendations for the treatment and care of your CSHCN?	3.67	4.00
How often do you feel like you are part of the team making medical or treatment decisions for your CSHCN?	3.89	4.00

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4	26	28	2
5	26	24	-2
6	27	27	0
7	31	35	4
8	26	36	10
9	23	22	-1
Mean (SD)	27.22 (2.6)	30.03 (5)	3.1 (4.4)

FCC composite scores were created by assigning a point value to each of the eight FCC questions. Point values were as follows: "rarely" = 0; "sometimes" = 1; "half of the time" = 2; "most of the time" = 3; and "always" = 4, for a possible total of 32 points. Higher composite scores indicate a higher level of family-centered care.