
Parental Report on Development and Coordination of Care with the Education and Medical System of Children with CdLS

Dr. Mary Beth Bruder
Dr. Cristina Mogro-Wilson
Dr. Bonnie Lynch
University of Connecticut
Center for Disabilities

Purpose

To increase the amount of knowledge on children affected by CdLS, their development, and their experience with the educational and medical system.

Background

- The CdLS-USA Foundation and the Center for Disabilities at the University of Connecticut collaborated to create a research study to increase the amount of knowledge on children affected by CdLS.
- The information gathered will inform parents and other providers about this unique population about whom little is currently known and establish a baseline of knowledge on the range of services children with CdLS are receiving, and if these services are meeting their needs.

Methodology

■ **Methods of Recruitment:**

- ❑ Used the CdLS Foundation network
- ❑ June-October 2007
- ❑ Emails (to approximately 590 families)
- ❑ Newsletter (distributed to approximately 2,000 families)
- ❑ CdLS web site

■ **Data Collection:**

- ❑ online survey through Survey Monkey
- ❑ No paper copies were requested
- ❑ Participation was voluntary, and respondents had the option of bypassing any questions they did not want to answer.
- ❑ Parents of a child age birth to 21 with CdLS were eligible to participate

■ **Final n = 224**

Survey Questionnaire

- ❑ **Survey Design:**
 - CdLS foundation board members
 - UCHC faculty
- ❑ **Topic areas:**
 - (a) Background of Child
 - (b) Child Health and Medical Care
 - (c) Child Behavior and Development
 - (d) Child Learning Style
 - (e) Child Services
 - (f) Child Educational Placement
 - (g) Quality of Life
 - (h) Additional Information
 - (i) Background Information

Sample Characteristics

- Mean age of parent
 - 40 years, sd=9.15, range=19-66
- Parent completing the survey
 - mother (88%)
 - father (7%)
 - other (adoptive parents, foster parents, and grandparents) (5%)
- Mean age of the child
 - 9 years, sd=5.68, range=2 months-20
- Gender of child
 - female (61%)
 - male (39%)
- Time of CdLS diagnosis
 - 62% birth-6months
 - 10% 7-12 months
 - 14% 1-2 years old
 - 7% 2-3 years old
 - 9% over 3 years
- Diagnosis made by
 - geneticist (76%),
 - pediatrician (13%)
 - neonatologist or neurologist (4%)
 - CdLS foundation (3%)
 - obstetrician (2%)
 - NICU Doctors (2%)

Demographics

- Parents represented 39 different states with the highest response from Texas (10%) and lived in a variety of areas:
 - urban area (40%)
 - city (34%)
 - rural area (26%)
- Race/ethnicity
 - 75% white
 - 9% Hispanic
 - 5% African American
 - 1% Asian
 - less than 1% Native American
- Religion
 - non-denominational/other or multiple religions (36%)
 - Catholic (24%)
 - Christian (21%)
 - Baptist (10%)
 - none or not applicable (9%).
- Marital Status
 - married (81%)
 - divorced or separated (9%)
 - never married (6%)
 - co-parenting relationship (3%)
- Parent filling out survey working status
 - not working (38%)
 - working full time (38%)
 - working part time (24%).
 - Most spouses were working full time (76%), a few were not working (9%), and 4% were working part time.
- Highest educational attainment.
 - 11% high school diploma
 - 36% some college
 - 40% college degree
 - 10% masters degree
 - 2% PhD, MD or JD
- Income
 - Range: less than \$19,000 to more than \$150,000

72% or 161 parents suspected that something was wrong before the diagnosis

This is what made them suspicious:

Condition	Frequency	Percent
Low birth weight	100	62%
Small stature	94	58%
Slow growth	92	57%
Poor feeding	84	52%
Small head size	84	52%
Excessive body hair	78	48%
Eyebrows	73	45%
Small hands/feet	67	42%
Long eye lashes	57	35%
Low pitched crying	57	35%
Low set ears	48	30%
Curved fingers	46	29%
Strange different behavior	46	29%
Upturned nose	45	28%
Down turned lips	38	24%
Partial joining of toes	30	19%
Developmental delays	30	19%
Visual gaze averting behaviors	26	16%
Sensitive to touch	25	16%
Lack of feeling pain	22	14%
Missing fingers	6	4%
Other (Ex: Reflux, limb deformities, prenatal issues)	59	37%

Current Health Conditions of Child

Condition	Frequency	Percent
Gastroesophageal reflux disease	140	63%
Feeding problems	96	43%
Hearing loss	93	42%
Dental problems	91	41%
Physical deformities	74	33%
Ear infections	69	31%
Heart problems/defect	65	29%
Vision problems: myopia (near sighted)	61	27%
Prescribed hearing aid	59	26%
Tube Fed	58	26%
Vision problems: Prescribed glasses	54	24%
Vision problems: general vision	47	21%
Wears hearing aid	42	19%
Vision problems: Wears glasses	36	16%
Vision problems: Blepharitis	27	12%
Cleft palate	25	11%
Seizures	24	11%
Vision problems: Light sensitive	16	7%
Vision problems: hyperopia (far sighted)	14	6%
Vision problems: Cortical/cerebral visual impairment	7	3%
Other (ex: behavioral, developmental, bladder)	85	38%

Medical Care

- There is a place parents usually contact when their child is sick (81%),
 - 11% noted that there is more than one place,
 - 6% indicated that there is no such place,
 - 1% did not know.
 - The most common place to contact when their child is sick is their pediatrician (81%),
 - followed by the hospital (14%),
 - Herbalist (2%),
 - GI doctor (2%)
 - nurse (1%).
 - Almost all parents noted that there is a personal doctor or nurse that is a health provider for their child and knows them the best (91%)
 - Most parents felt that it is not a problem to get a referral to a specialist that their child needed to see (66%), while 11% of children did not need to see a specialist in the last 12 months, and 8% of parents noted that they do not need referrals.
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Care Coordination

- Almost half of parents (45%) noted that in the past 12 months there was a time that their child needed care coordination among different health care providers and services.
- Of those who stated that care coordination was needed
 - 64% indicated that all the necessary coordination was received
 - 28% reported that they did not receive all the coordination that was needed.
- Care coordinator title
 - case manager or coordinator (34%),
 - doctor (31%),
 - the parent themselves (16%),
 - nurse (8%),
 - social worker (6%)
 - early interventionist (3%).
- Someone helps coordinate child's care among his/her different providers and services
 - never (46%),
 - sometimes (38%),
 - usually (5%),
 - always (8%),
 - 2% indicated they did not know.

Care Coordination continued

- Satisfaction with the help they have received in coordinating their child's care:
 - ❑ 32% very satisfied
 - ❑ 27% somewhat satisfied
 - ❑ 10% somewhat dissatisfied
 - ❑ 10% very dissatisfied
 - ❑ 21% did not know
- How well child's doctors and other health care providers communicate with each other
 - ❑ excellent (16%),
 - ❑ very good (20%),
 - ❑ good (23%),
 - ❑ fair (19%),
 - ❑ poor (12%),
 - ❑ not needed (9%),
 - ❑ did not know (3%).
- How well child's doctors communicate with their school, early intervention program, child care providers or vocational program:
 - ❑ excellent (11%)
 - ❑ very good (10%)
 - ❑ good (13%)
 - ❑ fair (21%)
 - ❑ poor (20%)
 - ❑ not needed (21%)
 - ❑ did not know (5%)

Child Behavior and Development

	At what age did your child first do this a lot? Mean (S.D.)
Sitting or crawling	16 months (15)
My child responds to his/her name	18 months (22)
My child understands yes/no	19 months (22)
Communicates using distinctive sounds	22 months (24)
Communicates using objects, gestures, pictures, icons, communication device	23 months (22)
Communicates using eye gaze	23 months (27)
Walking	25 months (19)
Drinks from cup by self	25 months (27)
Communicates using sign language	27 months (21)
Going up stairs	28 months (29)
Feeds self with spoon/fork	29 months (29)
Running	31 months (27)
Communicates using words	34 months (27)
Takes clothes off at appropriate times (e.g., going to bed)	41 months (41)
Puts clothes on by self	48 months (45)
Recite alphabet	50 months (37)
Write first name	50 months (43)
Communicates using complete sentences (more than 3 words)	53 months (38)

Child Learning Style

	Not At All True	A Little True	Somewhat True	Very True
When visiting a new place, my child independently explores it on his/her own.	42 23%	32 17%	47 25%	66 35%
When visiting a new place, my child remains near me or someone familiar.	45 24%	52 28%	42 23%	46 25%
My child enjoys learning new things. For example, learning the words to a new song, riding a bike, a new toy.	37 20%	43 23%	44 24%	60 33%
My child requests assistance when encountering new things, such as a toy, asking a question about a new subject in class, etc.	57 32%	47 26%	44 24%	32 18%
My child likes receiving praise. For example, when teacher says “good job” or parent says “great work” when learning a new skill.	23 12%	24 13%	25 13%	115 62%
My child tells me about their day.	109 61%	33 18%	25 14%	13 7%
When my child is explaining something, and I do not understand, he/she gets frustrated.	74 44%	32 19%	29 17%	32 19%
My child is easily upset by simple demands, such as no, stop, etc.	85 48%	45 25%	28 16%	21 12%

Services Provided

- Services provided that a child currently receives
 - special education (84%),
 - speech and language therapy (78%),
 - occupational therapy (65%)
 - physical therapy (63%)

- The most commonly provided services received in the past were
 - early intervention (70%),
 - feeding therapy (44%),
 - physical therapy (33%)
 - occupational therapy (29%),

Educational Placement: Early Intervention (n=95)

Early Intervention (Birth to 3 Years)	Not At All True	A Little True	Somewhat True	Very True
My child's Individualized Family Service Plan (IFSP) includes outcomes that are important to me	5 5%	5 5%	13 14%	72 76%
Early Intervention staff recognize/build on my child's strengths	3 3%	5 6%	17 19%	65 72%
Early Intervention staff are provided as listed on my child's Individualized Family Service Plan	3 3%	2 2%	13 14%	72 80%
Early Intervention staff are knowledgeable about CdLS	24 26%	35 38%	20 22%	14 15%
Early Intervention staff help me learn how to work with my child	9 10%	16 17%	33 35%	36 38%
School staff work closely with medical professionals treating my child	41 45%	25 27%	14 15%	12 13%

Educational Placement: Pre-school (n=63)

Preschool (3 to 5 Years)	Not At All True	A Little True	Somewhat True	Very True
Preschool staff communicate regularly with me	2 3%	3 5%	9 15%	45 76%
Preschool staff are knowledgeable about CdLS	15 25%	19 32%	18 30%	8 13%
My child's Individualized Education Plan includes goals that are important to me	2 3%	3 5%	12 20%	43 72%
My child's teacher/therapists encourage my child to do his/her best	2 3%	0 0%	11 18%	48 79%
School staff work closely with medical professionals treating my child	23 38%	17 28%	8 13%	13 21%

Educational Placement: Elementary School (n=76)

Elementary School (Grades K to 5)	Not At All True	A Little True	Somewhat True	Very True
My child has classmates that are his/her friends	8 11%	21 28%	24 32%	22 29%
School facilities are fully accessible to my child	3 4%	2 3%	17 22%	54 71%
My child's Individualized Education Plan includes goals that are important to me	1 1%	2 3%	19 25%	53 71%
My child's teacher/therapists are knowledgeable about CdLS	13 17%	29 38%	20 26%	14 18%
School staff work closely with medical professionals treating my child	31 43%	19 26%	13 18%	10 14%

Educational Placement: Middle/High School (n=64)

Middle and High School	Not At All True	A Little True	Somewhat True	Very True
My child's teachers/therapists are knowledgeable about CdLS	13 20%	17 27%	26 41%	8 13%
My child's Individualized Education Plan includes everything it should for teaching reading and writing skills	15 26%	10 17%	10 17%	23 40%
I expect my child to graduate from high school with his/her classmates	21 35%	11 18%	7 12%	21 35%
School staff work closely with medical professionals treating my child	28 47%	22 37%	6 10%	4 7%
I receive support and/or services from Vocational Rehab counselors	47 78%	6 10%	5 8%	2 3%
I receive support and/or services from other agencies and community programs	24 39%	11 18%	12 19%	15 24%

Quality of Life

	Not At All True	A Little True	Somewhat True	Very True
I am happy with how my life is going	4 2%	15 18%	86 46%	83 44%
Family meal times are stressful	82 44%	45 24%	43 23%	17 9%
Our family likes spending time together	1 .5%	9 5%	21 11%	156 83%
Some days it is hard for me to “get going”	54 29%	62 33%	52 28%	19 10%
I enjoy relaxing with other family members	4 2%	9 5%	37 20%	137 73%
Family members drive each other crazy	70 38%	71 38%	41 22%	3 2%
I let little things bother me	71 38%	85 46%	23 12%	8 4%
Our family has the best life possible	16 9%	18 10%	90 48%	63 34%

Conclusions, Next Steps & Questions

Web Site & Documents

Website contains Data Report and Presentation

<http://www.uconnucedd.org/Projects/schoolage/Cornelia.html>

Contact Information

Mary Beth Bruder
Professor & Director
860-679-1500
bruder@nso1.uchc.edu

Cristina Mogro-Wilson
Assistant Professor & Research Director
860-679-1529
cmwilson@uchc.edu

Bonnie Lynch
Professor & Associate Director
860-679-1585
blynch@uchc.edu