



Educational and Therapeutic Experiences of Children with Cornelia de Lange Syndrome and their Families

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Purpose

- To increase the amount of knowledge on children affected by CdLS; specifically their experiences with educational and therapeutic services.



Background

- The CdLS-USA Foundation and the Center for Disabilities at the University of Connecticut collaborated to create a survey to increase the amount of knowledge on children affected by CdLS.
- This survey was a follow-up to a survey conducted two years ago that focused on health and medical care, and child development and learning.
- 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

- Recruitment
 - Collaboration with CdLS-USA Foundation
 - November 2009-March 2010
 - Emails (to ~830 families)
 - Newsletter (to ~1280 families)
 - CdLS and UCONN UCEDD websites
 - Reminder emails in January and February
- Data Collection
 - Online survey through Survey Monkey
 - One paper copy was requested; not returned
 - Participation was voluntary, and respondents had the option of bypassing any questions they did not want to answer.
 - Parents of a child age birth through 21 with CdLS were eligible to participate
 - 158 people participated



Survey

- Designed collaboratively between CdLS Foundation Counsel and Committee members and researchers at the UCEDD
- Survey sections
 - Background information on child
 - Birth-Two
 - 3-5
 - 6-13
 - 14-21 (in school or not in school)
 - Demographics
- All participants completed background and demographics; completed middle section in accordance with the age of their child

Participants

- Of the 158 participants; 33 only completed six questions and were removed from the analyses (N = 125)
- 34 states and Canada represented
- 90% were the mother of a child with CdLS
- 75% married
- 41% employed full-time; 24% part-time
- Educational attainment
 - Less than high school = 2%
 - High school = 5%
 - Some college = 30%
 - 2 year degree = 14%
 - 4 year degree = 30%
 - Master's degree = 15%
 - Doctorate/Ph.D./M.D. = 5%
- Household income
 - < \$50,000 = 39%
 - \$50,000-\$100,000 = 36%
 - > \$100,000 = 25%

Child Characteristics

	%		%
Sex of child		Child's race/ethnicity	
<i>Male</i>	44.0	<i>White</i>	84.8
<i>Female</i>	56.0	<i>Latino/Hispanic</i>	10.4
Child's general health		<i>African-American</i>	4.8
<i>Excellent</i>	11.2	<i>Asian</i>	4.0
<i>Very good</i>	44.0	Age of child	
<i>Good</i>	34.4	<i>0-2 years</i>	14.4
<i>Fair</i>	8.8	<i>3-5 years</i>	20.0
<i>Poor</i>	1.6	<i>6-13 years</i>	33.6
Child's functioning		<i>14-21 years</i>	32.0
<i>Is independent</i>	12.8		
<i>Needs some assistance</i>	58.4		
<i>Needs total assistance</i>	28.8		

Therapies/Services Received

	0-2 (%)	3-5 (%)	6-13 (%)	14-21 (%)
Speech-language therapy	56	96	86	53
Occupational Therapy	78	84	74	28
Physical therapy	72	72	48	23
Special instruction	17	24	31	38
Nursing	11	8	10	18
Oral motor therapy	39	32	12	5
Service coordination	17	8	7	13
Social work	11	4	10	8

Therapies/Services Received, cont.

	0-2 (%)	3-5 (%)	6-13 (%)	14-21 (%)
Behavior management	--	12	19	20
Art therapy	--	4	2	8
Aqua therapy	--	--	--	5
Vision and mobility	--	12	5	5
Sensory integration	--	16	12	3
Hippotherapy	--	4	5	3
Pet therapy	--	--	2	3

SESSION LENGTH AND FREQUENCY

Across all therapies/services

	0-2 (%)	3-5 (%)	6-13 (%)	14-21 (%)
More than 60 minutes	6	18	15	25
31-60 minutes	68	40	40	32
30 minutes or less	26	42	45	43
Everyday	9	9	23	29
2 or 3 times a week	22	41	49	28
Once a week	19	36	20	26
2 or 3 times a month	31	7	4	10
Once a month	9	6	2	4
Every 2 to 3 months	10	--	1	3

SESSION LOCATION

Across all therapies/services

	0-2 (%)	3-5 (%)	6-13 (%)	14-21 (%)
Home	78	27	22	16
School	11			
Public preschool		50		
Other preschool		23		
Child care	--	9		
School – in classroom			56	56
School – out of classroom			41	33
Clinical setting	4	32	19	10
Community	--	--	3	8

SESSION SETTING AND PROVIDER

Across all therapies/services

	0-2 (%)	3-5 (%)	6-13 (%)	14-21 (%)
One-on-one	86	88	74	53
With one other child	12	--	2	6
Group setting	2	12	24	40
Early intervention/school	87	70	70	70
Private	9	22	23	18
Other	4	7	6	11

ROLE OF PARENT AND PROVIDER

Across all therapies/services

	0-2 (%)	3-5 (%)
When my child receives services, I am not present	8	56
I watch the provider work with my child	12	14
Provider explains what she is doing with my child to me	35	15
Provider show me how to do the interventions	29	11
Provider helps me learn how to do interventions without her help	16	4

ROLE OF PARENT AND PROVIDER

Across all therapies/services

	6-13 (%)	14-21 (%)
When my child receives services, I am not involved	4	14
I receive quarterly updates from the provider	31	18
I receive regular updates that include what is being worked on and any problems	15	29
I receive regular updates and consultation including things I can do at home	28	24
I participate in therapy sessions by observing and/or interacting with my child	22	16



Therapy/Service Provider Communication

The following results are the average percentages calculated across all four age groups

- Do your child's providers meet together and discuss your child's goals?
 - Yes = 77%
- If yes, how often are you (the caregiver) invited?
 - Never = 14%
 - Sometimes = 32%
 - All the time = 51%



Therapy/Service Provider Communication

The following results are the average percentage calculated across all age groups except 0-2 (not asked these questions)

- How often do you receive updates on your child's progress from his/her service providers?
 - Quarterly = 33%
 - Once month = 6%
 - Once a week = 11%
 - After each session = 25%
- How do you typically communicate with your child's service providers?
 - In person = 36%
 - Phone = 6%
 - Email = 12%
 - Communication notebook = 29%

EDUCATIONAL SETTING

Type of educational setting and time spent in a regular education classroom

	3-5 (%)	6-13 (%)	14-21 (%)
Public school	40	73	78
Private school	12	7	9
Child care or Head Start	12		
Other	36	20	13
All of time in regular classroom		5	6
Most of time in regular classroom		20	18
Half of time in regular classroom		25	12
A little bit of time in regular classroom		18	18
None of time in regular classroom		33	46

IFSP and Adaptations (0-2)

- Child has an IFSP
 - Yes = 82%
 - I don't know = 6%
- Adaptations in Use
 - Sign language = 56%
 - Other special equipment (adapted toys and feeding utensils) = 33%
 - Auditory amplification = 22%
 - Special equipment for sitting, standing, or walking = 22%
 - Picture communication system = 17%

Educational Programming (3-21)

- Child has IEP
 - Yes = 82%
- Child has label for eligibility
 - Yes = 47%
 - I don't know = 37%
- Educational disability
 - Developmental delay = 59%
 - Speech-language impairment = 50%
 - Intellectual disability = 41%
 - Hearing impairment = 28%
 - Multiple disabilities = 25%
 - Other health impairment = 23%
 - Orthopedic impairment = 16%
 - Visual impairment = 15%
 - Specific learning disability = 9%
 - Autism = 8%
 - Deaf-blindness = 5%
 - Emotional disturbance = 5%

EDUCATIONAL PROGRAMMING (3-21)

Adaptations and Modifications

- Communication notebook = 44%
- Modified curriculum = 42%
- Sign language = 36%
- Individual classroom aide = 35%
- Picture communication = 34%
- Special equipment for sitting, standing, etc. = 29%
- Individual programming = 24%
- Adaptive PE = 22%
- Resource room = 21%
- Behavioral intervention plan = 19%
- Other special equipment (adapted utensils) = 13%
- Computer education programs = 13%
- Visual adaptations = 9%
- Auditory amplification = 8%
- Computer assisted communication = 6%
- Tape recorder = 2%

Educational Programming (0-2)

	Not at all (%)	Somewhat (%)	As expected (%)
Assessments of my child accurately reflect his/her level of functioning	--	29	71
I am involved in deciding what my child's goals should be	--	11	89
My child's goals are objective and measurable	--	6	94
My child is making progress towards his/her goals	6	22	72
I am satisfied with the amount of progress my child is making	6	50	44
My child's behavioral challenges are being addressed (if applicable)	36	18	46
My child participates in groups/activities outside the home	53	24	24
My child participates in activities with both children with special needs and typically developing children	53	12	35
There is a transition plan in place for when my child turns 3	50	17	33
I am satisfied with the transition process (if applicable)	25	38	38

Educational Programming (3-21)

	Not at all (%)	Somewhat (%)	As expected (%)
Assessments of my child accurately reflect his/her level of functioning	9	38	52
I am involved in deciding what my child's goals should be	3	23	74
My child's goals are objective and measurable	3	35	63
My child is making progress towards his/her goals	4	40	56
I am satisfied with the amount of progress my child is making	8	44	48
My child's behavioral challenges are being addressed (if applicable)	2	39	59
My child participates in groups/activities outside the home	20	32	48
My child participates in groups/activities with both children with special needs and typically developing children	21	33	46
There is/was a transition plan in place	32	32	35

Educational Programming (3-21), cont.

	Not at all (%)	Somewhat (%)	As expected (%)
My child is/was adequately prepared for the transition	37	38	25
I am/was satisfied with the transition process	33	34	33
My child's classroom promotes social skills	8	26	65
My child's school provides activities outside of school time to develop social relationships	33	36	32
My child has a way to communicate both at home and at school	8	35	57
My child's therapies involve social interactions with peers	22	37	42
The skills my child is learning in therapy promote independence	6	32	63
My child has a 1-on-1 paraprofessional at school	48	19	32

Care Coordination (all)

- Care coordination needed
 - Yes = 56%
- Care coordination received
 - Yes = 43%
- Frequency of care coordination
 - Never = 55%
 - Sometimes = 22%
 - Usually = 5%
 - Always = 10%
- Satisfaction with care coordination
 - Very Satisfied = 27%
 - Somewhat satisfied = 25%
 - Somewhat dissatisfied = 11%
 - Very dissatisfied = 18%

Health Care Provider Communication (all)

	Communication between health care providers (%)	Communication between health care providers and educators (%)
Excellent	9	4
Very good	19	15
Good	22	10
Fair	19	13
Poor	20	27
Not needed	8	22

FRIENDSHIP

Friends invited to child's birthday party

	0-2 (%)	3-5 (%)	6-13 (%)	14-21 (%)
Total: 0 friends	36	27	32	41
Total: 1-4 friends	14	24	30	19
Total: 5-10 friends	21	29	30	22
Total: > 10 friends	29	19	8	19
0 friends with disabilities	71	72	52	46
1-4 friends with disabilities	14	22	41	33
5-10 friends with disabilities	7	6	7	13
>10 friends with disabilities	7	--	--	8
0 friends without disabilities	36	30	19	40
1-4 friends without disabilities	14	20	52	28
5-10 friends without disabilities	29	35	22	16
> 10 friends without disabilities	21	15	7	16

FRIENDSHIP

Friends who attended child's birthday party

	0-2 (%)	3-5 (%)	6-13 (%)	14-21 (%)
Total: 0 friends	36	29	32	39
Total: 1-4 friends	14	29	30	19
Total: 5-10 friends	29	29	30	23
Total: > 10 friends	21	14	8	19
0 friends with disabilities	77	78	48	50
1-4 friends with disabilities	8	22	44	29
5-10 friends with disabilities	8	--	7	13
>10 friends with disabilities	8	--	--	8
0 friends without disabilities	54	30	19	40
1-4 friends without disabilities	8	30	50	32
5-10 friends without disabilities	23	30	23	8
> 10 friends without disabilities	15	10	8	20

FRIENDSHIP

	0-2 (%)	3-5 (%)	6-13 (%)	14-21 (%)
<i>Birthday parties invited to</i>				
None	33	32	26	38
1-4	17	36	62	33
5-10	28	24	13	8
<i>Birthday parties attended</i>				
None	39	36	28	38
1-4	22	44	61	35
5-10	17	12	10	5
<i>Social gatherings attended</i>				
None				43
1-4				20
5-10				13
> 10				5



Community Participation

Children (14-21) no longer attending school (N = 7)

- All live with parents
- 2 work in the community
 - Both in special workshops doing assembly work
 - One is in small group setting (1-5) with supervisor; other in large group setting (> 5) with supervisor

Community Participation

Children (14-21) no longer attending school (N = 7)

	Not at all (%)	Somewhat (%)	As expected (%)
My child participates in groups/ activities in the community	71	14	14
My child has opportunities to participate in activities/groups with his/her peers with and without disabilities	43	57	--
There was a transition plan in place for transitioning to adult life after high school	57	14	29
Higher education and/or technical schools were discussed as options for my child during the transition process	86	14	--
I was satisfied with the transition process	17	33	50



CONCLUSIONS, NEXT STEPS, AND QUESTIONS



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This presentation as well as the complete data report for this study can be found on our website:

<http://www.uconnuceed.org/projects.html>