



Autism: A Photo Analysis of Family Occupation and Health

WFOT 2018

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Disclosure

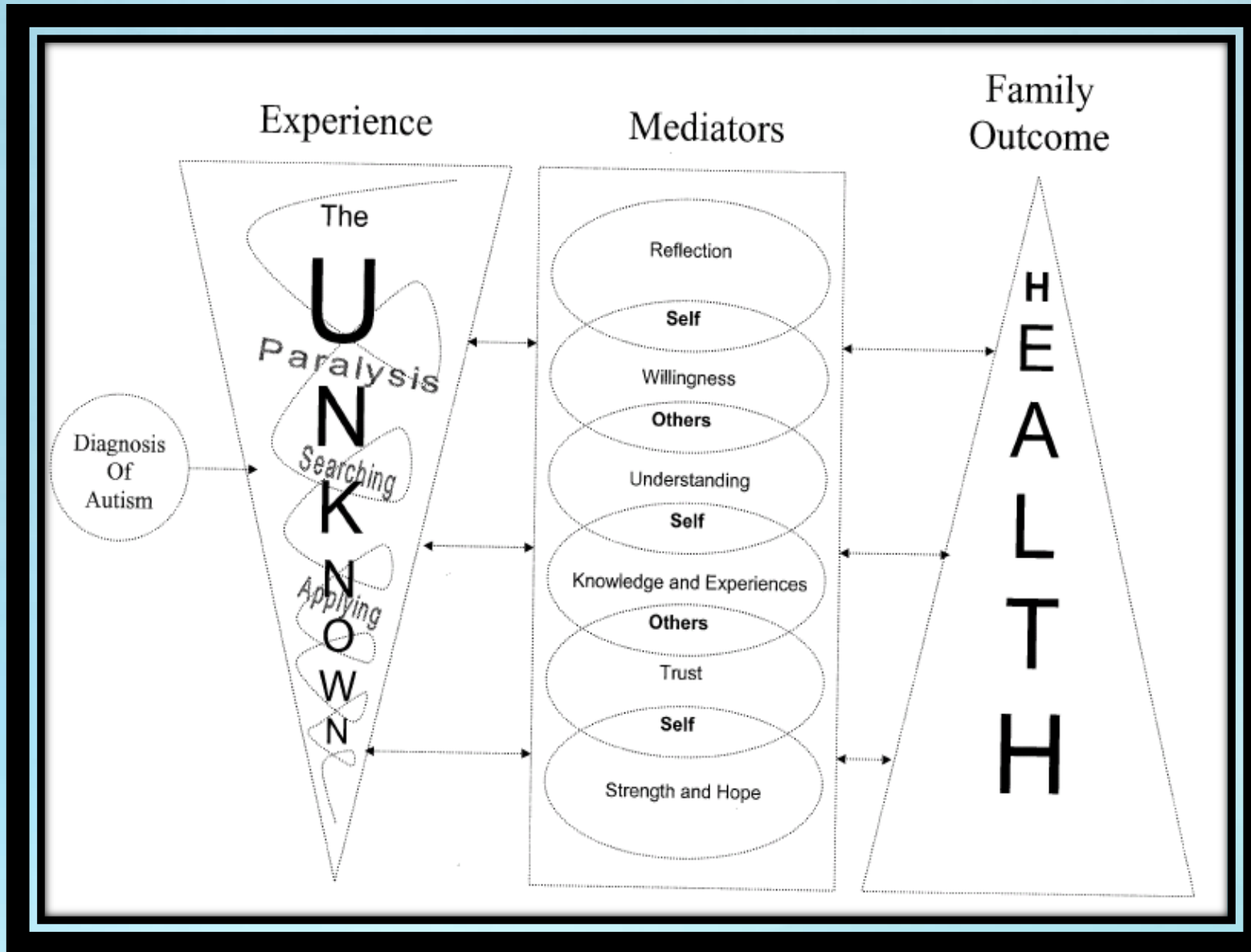
- I have no financial disclosures or conflict of interest.

Acknowledgements

- Families for their participation in the studies I am discussing today
- Research Assistants and Colleagues
- Funding provided by the College of Allied Health and Oklahoma Family Center for Autism.
- Thank you for the opportunity to speak today

Objectives

- Introduction to Family Experiences of Occupation and Health Model
- Present findings from a phenomenological approach to photo capture to reveal experiences and contextual findings of family health



DeGrace, BW, Hoffman, C., Hutson, T. L. & Kolobe, T. K. (2014). Family Experiences and Health Following the Diagnosis of Autism, *Journal of Occupational Science*, 21(3), 309-321

Model Testing

- Concepts, particularly family health, needed to be clarified
- Phenomenological approach to photo capture
 - Responsive to the nature of experience and reveal characteristics related to the experience of family health
 - Allows complex patterns and the influence of time and environment to emerge, factors easily overlooked by quantitative analyses

Procedures

- 12 Families recruited through email, Facebook, flyers and support groups
- Consent was obtained
- Completed demographic survey,
- Families provided with a digital camera and journal
- Family interviews were audio recorded, transcribed verbatim, and de-identified to protect family privacy

Families with Children with Autism: An Exploration of Family Health



Are you raising a child with autism?

Are you willing to share your family's experiences?

If so, please contact us at:
405 271-2131 ext. 47127

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University of Oklahoma is an equal opportunity institution.

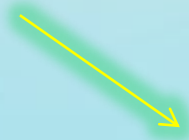
IRB# 16091

Overall processes in the study

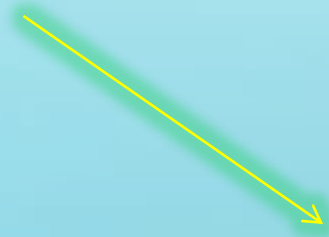
1. Family Training (journals, photographs)



2. Family Interview 1 (2 researchers present)



3. Collecting information about family health via photographs and journaling (1 month) and contact via team



4. Family Interview 2 (2 researchers present)

Initial Interview Questions

- What is a healthy family? When you think of a healthy family, what do you think of?
- How would you describe your family's health?
- On a scale of 1-5, how would you rate your family's health?

1	2	3	4	5
Most undesirable state of family health			Most desirable state of family health	

- Can you share a time with me when you feel like your family acted in a way consistent with your (thoughts or feelings) on family health?
- Do you have anything you would like to add?

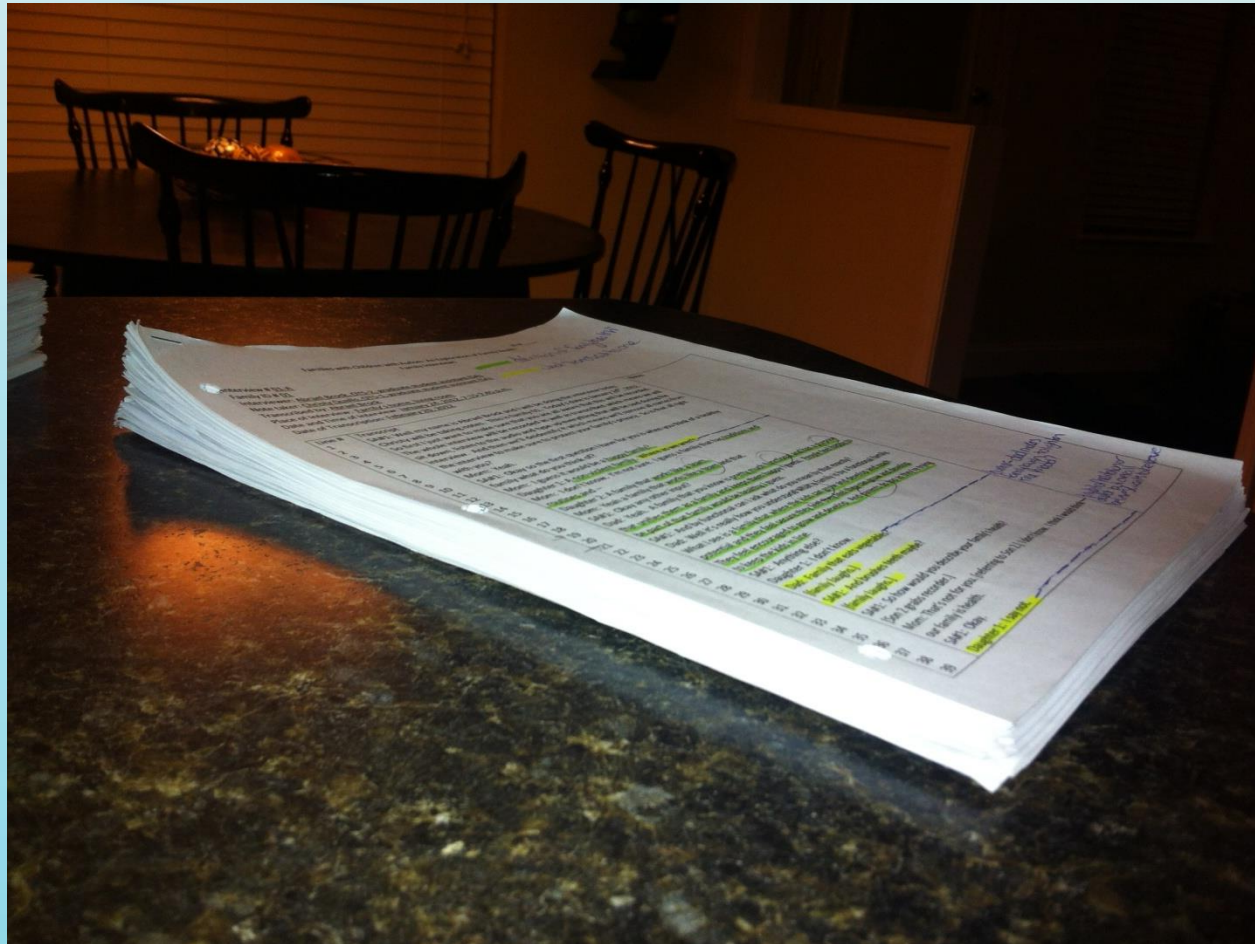
Demographic Data

N= 12				
Gender (of person filing out paperwork)	91.6% Female	8.4% Male		
Race	50% Caucasian	25% Hispanic	18.75% Native American	6.2% Other
Age (of person filing out paperwork)	16.6% 20-29	50% 30-39	25% 30-39	8.3% 50-59
Employment Status (of person filing out paperwork)	78.5% Employed	14.2% Unemployed	7.1% Other	
Number of Children in household	25% 1 child	41.6% 2 children	25% 3 children	8.3% 4 child

Demographic Data

N = 12				
Number of Adults in household	91.6% 2 adults	8.3% 3 adults		
Highest Level of Education (7.1% GED/ high school)	35.7% Some College	21.4% Associate's Degree	21.4% Bachelor's Degree	14.2% Graduate Degree
Annual Total Household Income	36.3% \$25,000-44,999	63.6% > \$65,000		
Diagnosis	53.8% Autism	30.7% Asperger's	15.3% PDD-NOS	
100% of households: two-parent families, married				

Initial Interview Transcriptions



Initial Interview Themes

- “We’re all in it together”
- “Learning to deal”
- “We don’t”
- “So it’s just constant nonstop”

“We’re all in it together”

Well we’re all in it together. You know we are one— All for one and one for all type... So we’re a very I would say we’re a very cohesive family unit. That’s our thing is we’re together more than we’re apart.

We spend time together... Support one another and just do what we can as a family to stay together.

“Learning to deal”

...obviously there's differences and conflict is a natural part of the family. Learning to deal and resolve it is part of part a functional family.

We still go and do everything everybody else does. Maybe not in the same way but... We have to prepare for it better... Your expectations are a lot different. At least we can try and you know so it may not be worth going back but so... But we try.

“We don’t”

... we don't do that many things together... We can't do things like we can't go out to eat, we don't take vacations... We don't eat dinner together... We don't do anything together at all... We don't go to the fair. We don't go to a mall. We don't go. We don't go.

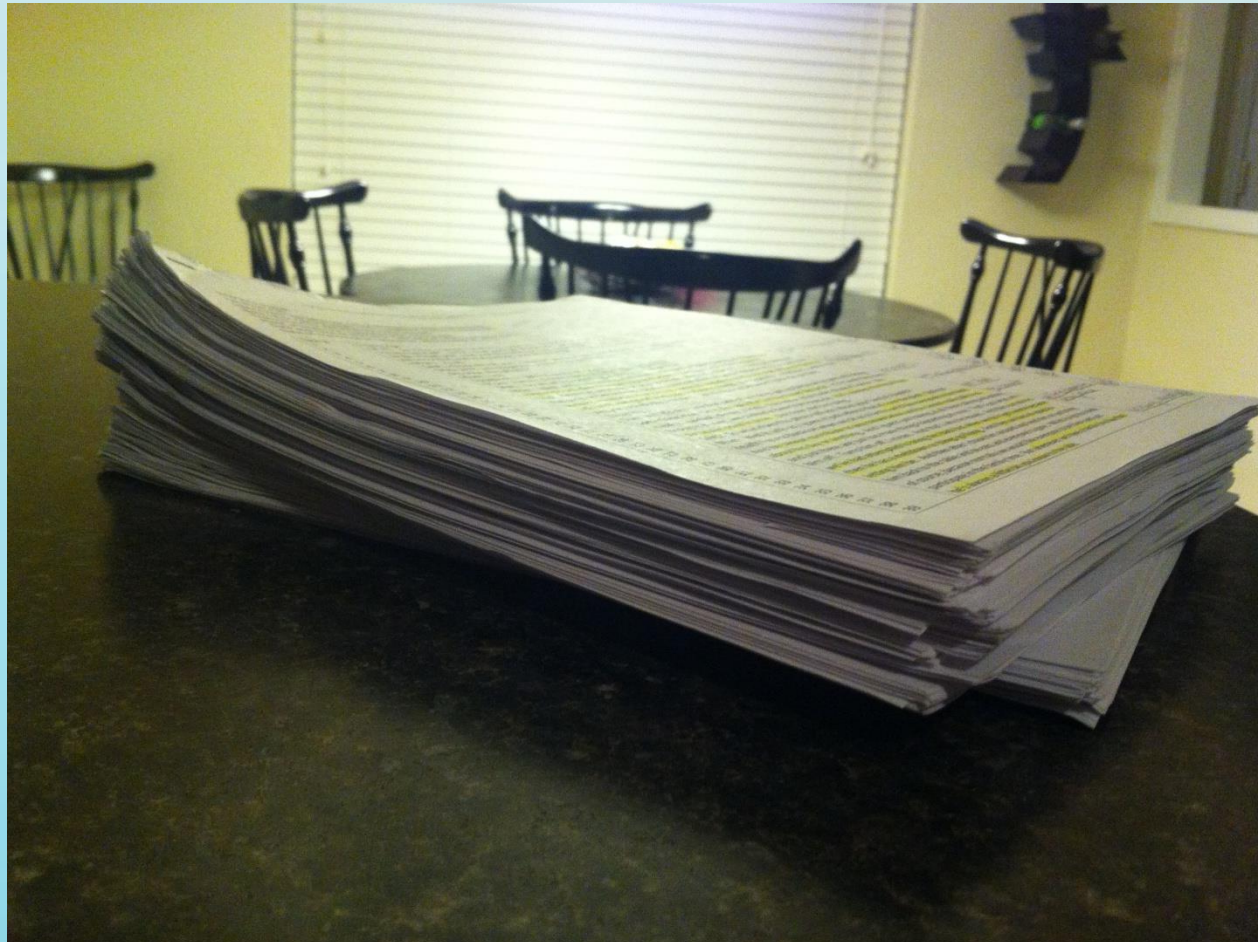
... it's just we've found ways of just not going because it's a whole lot easier than getting him out.

“So it’s just constant nonstop”

*... he wants what he wants when he wants it. But then, because he’s so amped up, it’s just he can get **violent** and he will **pull my hair** or **bite me** or **scratch me**... he can **hurt** me and just be **loud**. **It’s constant** trying to redirect or trying to come up with something that will make him happy, at least right now, to get him past whatever he’s upset with right now. **So it’s just constant nonstop.***

*... it’s like we make it over one mountain and we’re given a higher one and we’re just like ‘ahh’... we’re both **stressed to the max**... **exhausted**... and it’s not like you can find a babysitter fro him or anything cause **nobody** wants to babysit a kid who’s, in their mind, often **uncontrollable**...*

Final Interview Transcriptions



Final Interview Themes

- “Even though autism”
- “Then there’s these moments”
- “That’s just emotionally draining”
- “We keep trying”

“Even though autism”

- SA#1: *Why did you take this picture?*
- Mom: *... they were playing so well together and it was perfect.*
- Daughter#2: *It was cute*
- Mom: *It was success, yes*
- Daughter #2: *It just showed that he can still do normal stuff **even though he has autism.***



“Even though autism”

- Mom: *It shows that brothers can be brothers **even if autism** is in the picture. They love each other and we know they love each other... Like our older son still rooms with his autistic brother, like they don't go to sleep without each other. So they bicker all day but yet they are brothers. So in their hearts, brothers are brothers **regardless** if you have autism.*



“Even though autism”



“Then there’s these moments”

- Mom: *And I came over there to take a picture and he was with these two little girls and they were goofing around and smiling and laughing at each other and it’s like ‘**This is awesome**’. [laughing.]...*
- Dad: *And it was a night of I would say **pure joy** for us because he truly showed himself to be capable of socializing which we always knew he was obviously he’s in a regular school but he also stood out as an individual.*
- Mom: *.... You know you work through the hard times and **then there’s these moments of spiked joys**...*



“Then there’s these moments”



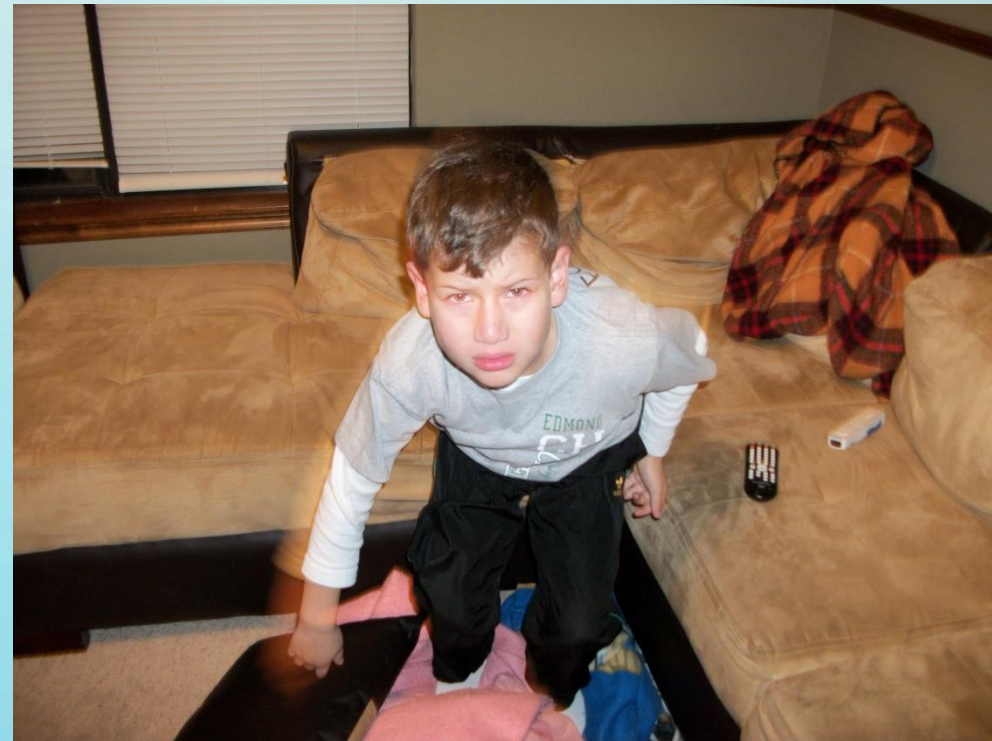
“That’s just emotionally draining”



- That’s at **4:00 in the morning** and she’s **awake**. That’s a 1.
- ED: What is she doing?
- Mom: She’s up for **hours**. She just goes we have to use Melatonin sometimes to help her sleep at night but then that will get to where it **doesn’t work** and then you know—
- ED: You have to take her off, yea.
- Mom: And she’s off of it right now but she’s slept the last 6 nights in a row without getting out of bed once. That’s a **big deal**. So she has this chart and then—
- ED: So what does she do? She gets out of bed and she comes—
- Mom: to get me. **Wakes me up. She wakes T. up** sometimes so **that’s bad** because he’s in school and he’ll she’ll first go into his room actually and he’ll say ‘go get mommy’ just to get her out of there. And then she comes and gets me up

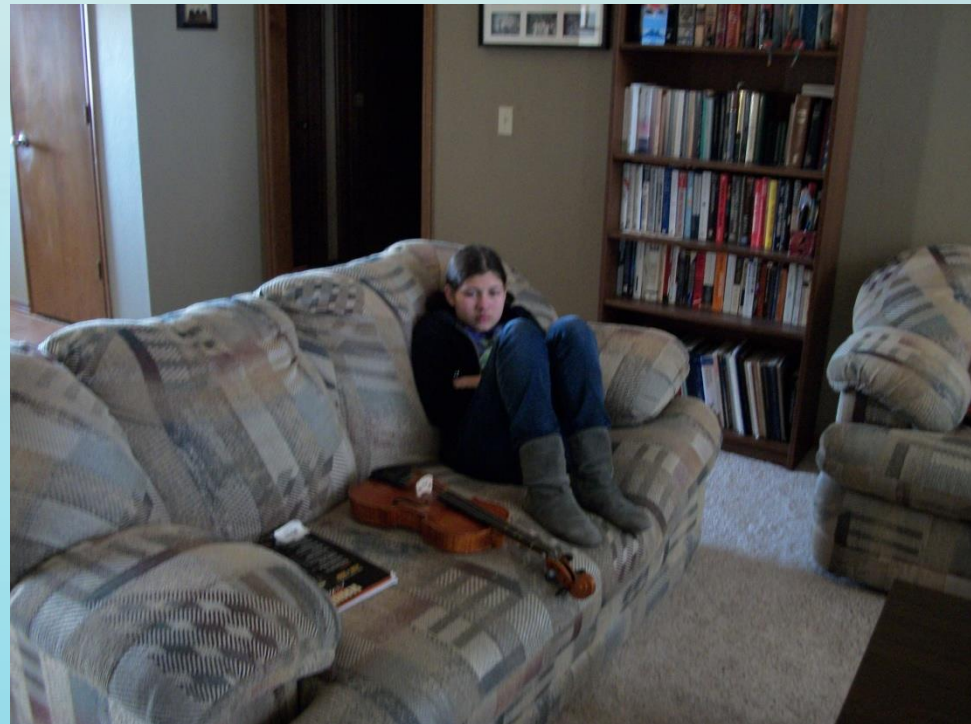
“That’s just emotionally draining”

- Mom: *I know that a little thing will **set him off**... for example, when he eats his cereal in the morning first is the cereal, then honey, then the milk. For him even not getting the all the things in the right order **sets him off**. So those little things are **hard** for him. And then if one little thing sets him off then **I know** it’s going to set him off and then the rest and **that’s just emotionally draining** for me and physically too.*

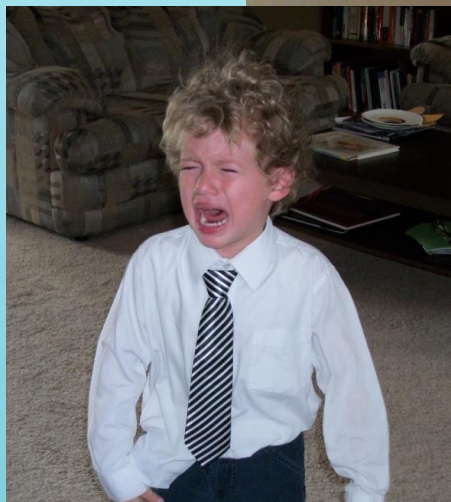
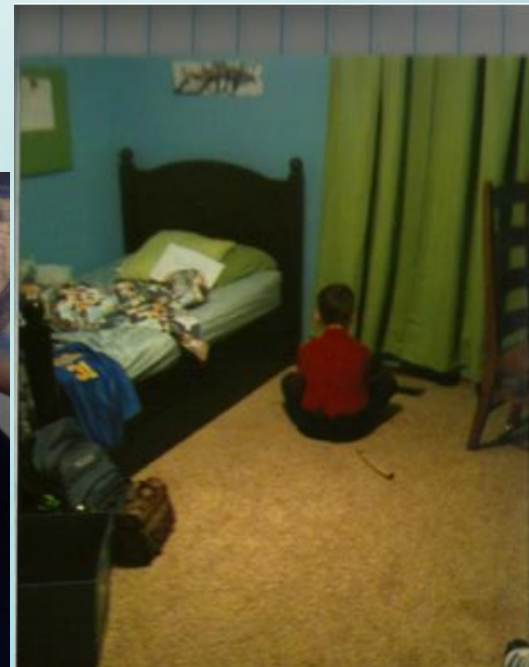
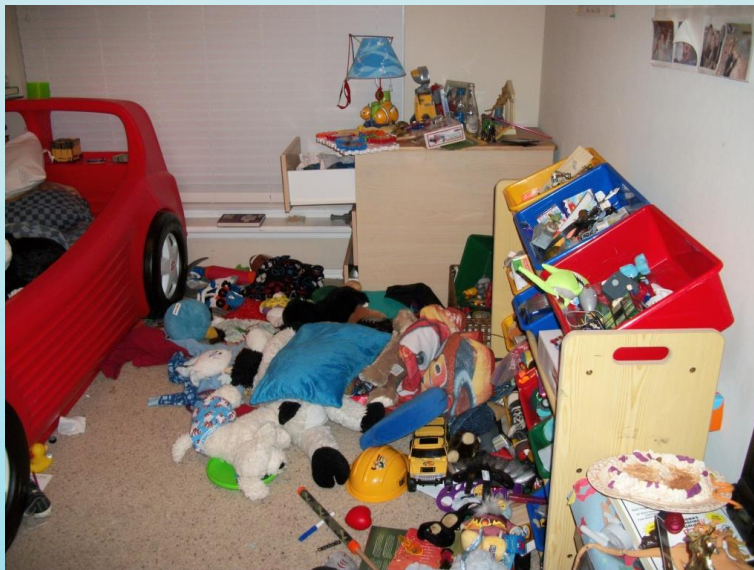


“That’s just emotionally draining”

- Mom: *She [sibling] tries to tell me something and **I can't listen** to her because (as it is often the case) I'm holding him [son with autism] in my arms and he is **screaming** in my ear. **She tells me she hates her life, her siblings and me.***



“That’s just emotionally draining”



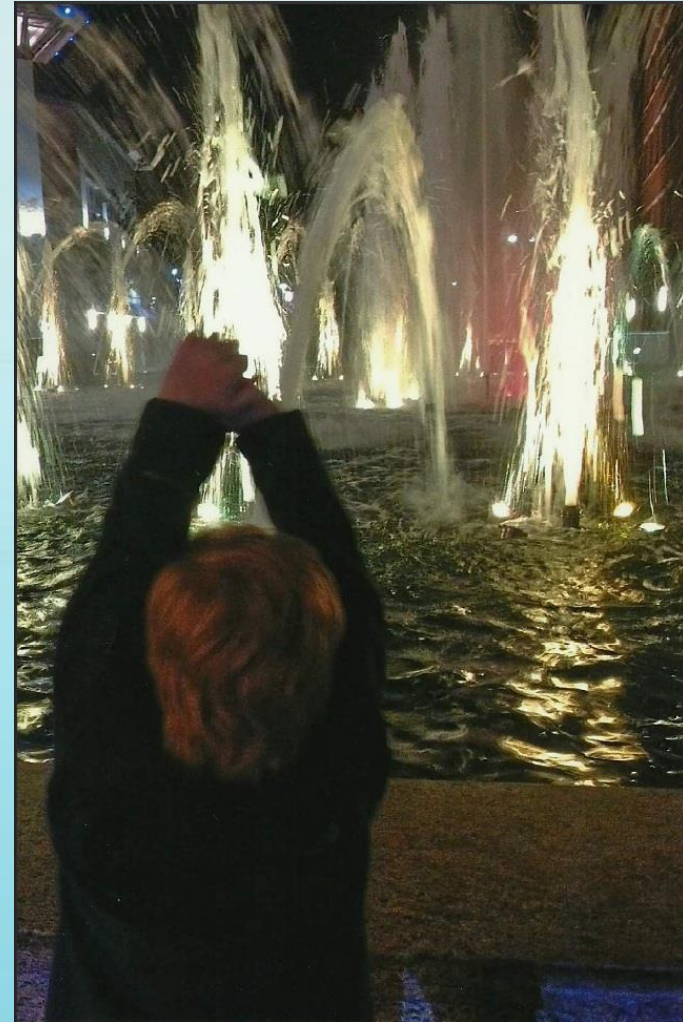
“We keep trying”

- SA#1: *Why did you take this picture?*
- Mom: *Oh well I guess we took it because it shows how **we try** to have a normal you know family time together **even though it's challenging...** and we **work through it, try** to teach him how to do it*
- SA#1: *So what does this picture tell you about your family's health?*
- Daughter #2: **We're trying.** *I mean he has autism but we don't let that get in the way of us having **trying** to have a normal happy family.*



“We keep trying”

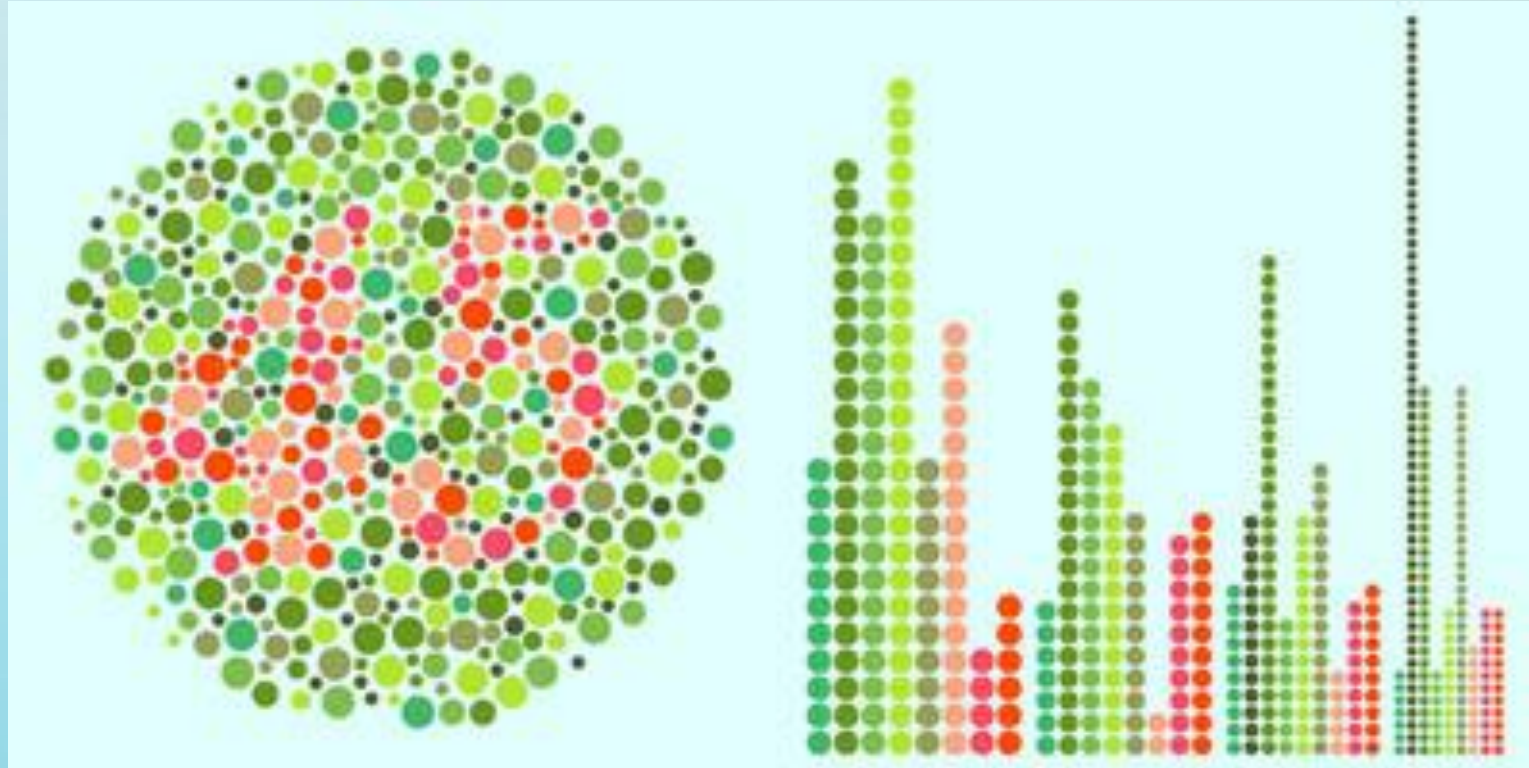
- SA#1: Ok and then on this photo can you say what it would provide to other families what kind of information?
- Mom: I don't know maybe that just to do something fun even though it's hard
- Dad: Yeah I mean I guess yeah when you think there might be you realize –
- Mom: **Try things**
- *Dad: Yeah it might not end the greatest but **go ahead and try it** and come up with different plans what happens when this happens next time*



“We keep trying”



Next Phase – Visual Analyses



FAMILY HEALTH ICONOGRAPHIC REVIEW

Iconographic Chest Sheet:

1	3
2	4

Take time to look at the picture in quadrants and then the whole

Person:

Interests:

We are looking at the objective aspects of occupation.

Area of family occupation: refer to pp. 631-633 of framework (label the chart with a, b, c, d, e, f, or g), if we see people doing separate occupations include each of them (e.g. A/F)

- A. ADL
- B. IADLS
- C. Education
- D. Work
- E. Play
- F. Leisure
- G. Social Participation
- H. sleep

Explanation: Explain rationale for why that area

Impression: Label with A, B, C, D, E

- A. Connected (being engaged with each other, hugs, eye contact, consoling)
- B. Collective (more than one, together experience)
- C. Mutual meaning/enjoyment
- D. Purpose (planned, purposeful, outcome focused)
- E. No family occupation noted

Looking for word patterns:

- Cultural: Comment on custom, belief, habit? For a typical family in the US in Oklahoma.
- Temporal: Comment on activities related to age?
- Physical: Comment on environment – tools, devices, animals, plants, furniture, room
- Social: Comment on who is available and relationships
- Person: Describe what you see in terms of emotion, behavior
- Tasks: What is going on and what is available for tasks
- Impression of why a family chose this to represent family health:
- Rating of family health 1-3 one being worst 3 being best

FAMILY HEALTH ICONOGRAPHIC REVIEW

Iconographic Chest Sheet:

1	3
2	4

Take time to look at the picture in quadrants and then the whole

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Explanation: Explain rationale for why that area

Impression: Label with A, B, C, D, E

- A. Connected (being engaged with each other, hugs, eye contact, consoling)
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- Tasks: What is going on and what is available for tasks
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- Rating of family health 1-3 one being worst 3 being best

Overview of photo production analyses process

- 4 raters
- Independently rated each photo
- Discussed at meetings
- Consensus
- Total of 179 photographs

Example of ratings



- Area of FO: A, B

- A. ADL
- B. IADLS
- C. Education
- D. Work
- E. Play
- F. Leisure
- G. Social Participation
- H. sleep

- Impression of FO: A,B,D

- A. Connected (being engaged with each other, hugs, eye contact, consoling)
- B. Collective (more than one, together experience)
- C. Mutual meaning/enjoyment
- D. Purpose (planned, purposeful, outcome focused)

- Autism

Example



- Area of occupation G

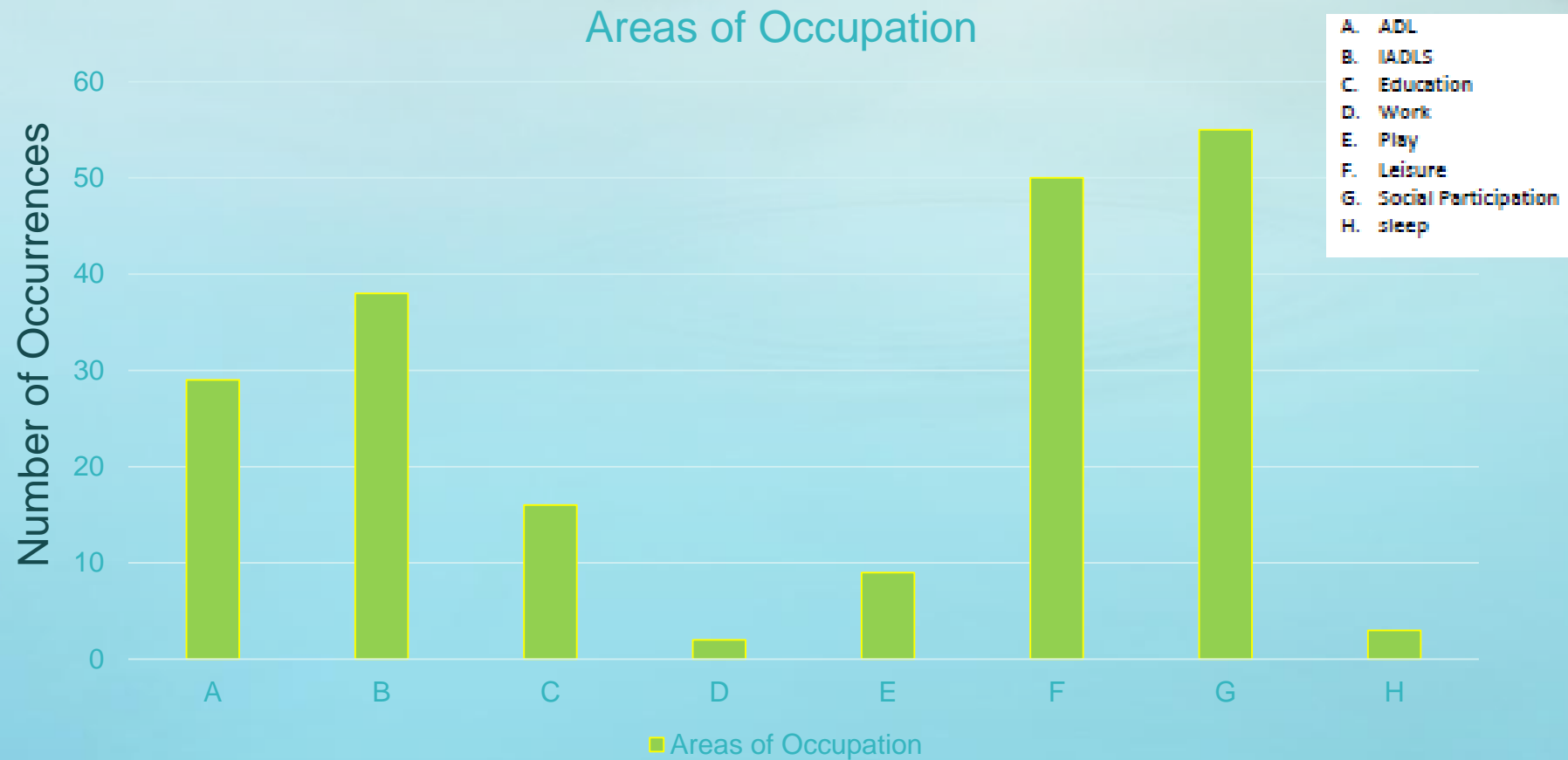
- A. ADL
- B. IADLS
- C. Education
- D. Work
- E. Play
- F. Leisure
- G. Social Participation
- H. sleep

- A,B,C,D

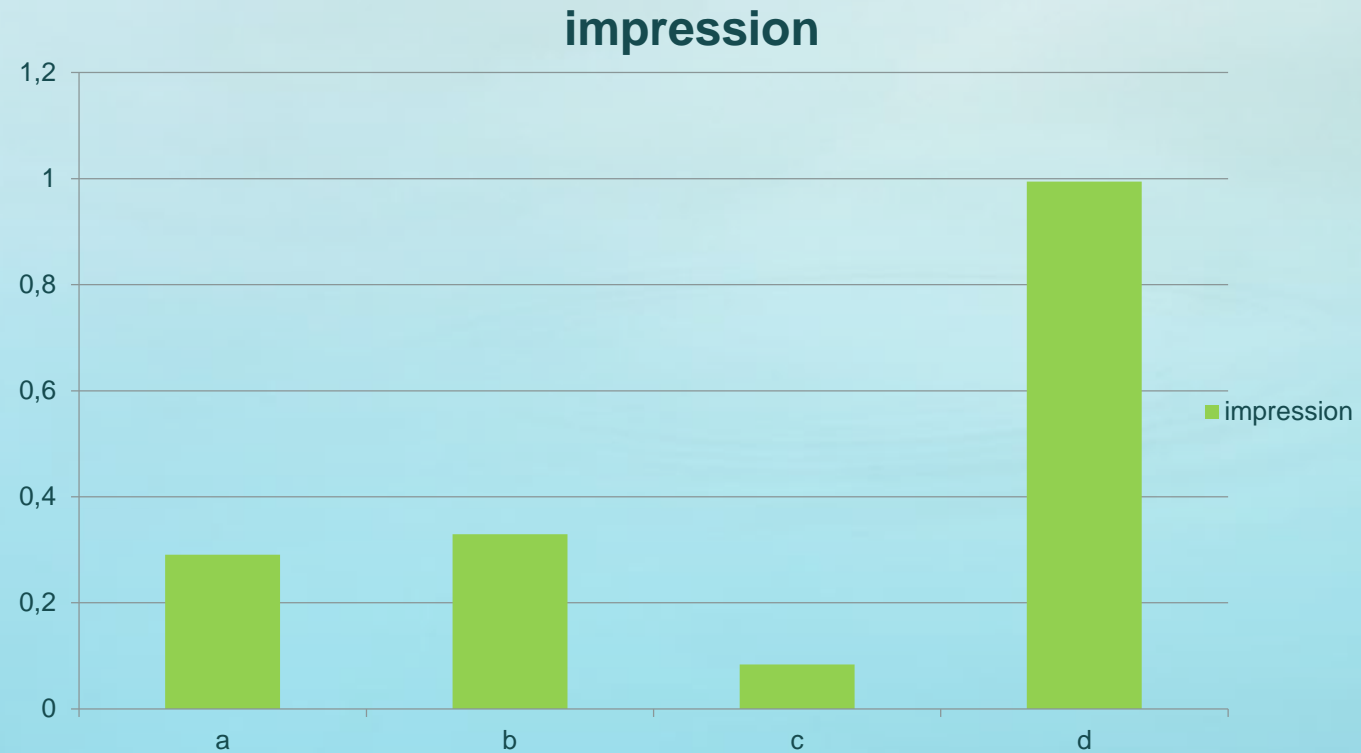
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- B. Collective (more than one, together experience)
- C. Mutual meaning/enjoyment
- D. Purpose (planned, purposeful, outcome focused)

- Autism

Profile of Family Occupation



Impression of Family Occupation



- A. Connected (being engaged with each other, hugs, eye contact, consoling)
- B. Collective (more than one, together experience)
- C. Mutual meaning/enjoyment
- D. Purpose (planned, purposeful, outcome focused)

Percentage of Autism

	autism	%
Y	149	0.83
N	30	0.17
Total	179	

Findings

- Patterns: adl, iadl, play and social participation predominately related to family health
- Older children higher leisure and social participation
- Younger children higher IADL and play
- Meaning of family occupation was minimal across families
- Majority of photographs were related to autism

FAMILY HEALTH: ANALYSIS OF THE CONTEXT

Culture:

Behavior/Norms

- a) Expected behavior (age appropriate; looks typical)
- b) Unexpected behavior (doing something that they shouldn't be doing; weird thoughts)
- c) Unsure

Practices

- a) Structured (rules)
- b) Unstructured
- c) Semi structured
- d) Not sure

Customs

- a) Daily rituals (meal, dressing, bathing, etc...)
- b) Parties/celebrations
- c) Holidays
- d) Birth
- e) Funerals
- f) Weddings
- g) Graduation
- h) Not obvious
- i) Other _____
- j) Posed/family photos
- k) Religious

Temporal

Stages of life

- a) Infants and toddlers
- b) Children
- c) Adolescents and teens
- d) Adults
- e) Older adults and seniors
- f) Not obvious

Physical:

Where

- a) home
- b) church
- c) restaurant
- d) park/playground (kids go for fun)
- e) therapy/medical
- f) school
- g) outdoors
- h) other

Where at home:

- a) living room
- b) bathroom
- c) kitchen
- d) office
- e) garage
- f) backyard
- g) bedroom
- h) playroom
- i) car
- j) dining room
- k) laundry room
- l) not at home
- m) no idea where
- n) entry way
- o) porch

Terrain:

- a) Messy/chaotic
- b) Tidy/neat

Sensory Qualities Light

- a) Dim
- b) Bright light
- c) Dark
- d) Average

Animals

- a) dog
- b) cat
- c) horse
- d) hermit crab
- e) fish
- f) guinea pig
- g) hamster
- h) rabbit
- i) other
- k) none

Environment (what is surrounding the child/child is using)

- a) Part of the structure of the building/home (fireplace, countertops/ floor)
- b) Furniture (desks)
- c) Tools – (utensils, bottle, cups)
- d) Devices – computer, cell phone, laptop
- e) Home appliances
- f) Sidewalk
- g) Toys/games/books/art supplies
- h) Food/drink
- i) Signs
- j) Visuals
- k) Holding animal
- l) Comfort object (a toy, blanket, etc...)
- m) Laying/sitting/standing on the floor
- n) Other
- o) Child not pictured (only choice if child other than child with autism is pictured. Code if object)

Natural

- a) Typical environment
- b) Therapeutic environment

Social

Significant Individuals (completely in picture)

- a) Spouse
- b) Friends
- c) Parents
- d) Siblings
- e) Caregivers
- f) Therapists
- g) Alone
- h) Teachers
- i) None
- j) Other

Number of people (includes child with autism)

- a) 1-2
- b) 3-4
- c) 5-6
- d) >6
- e) None

Relationships

- a) Individual
- b) Individuals (2-3)
- c) Group
- d) Organization (church, school, boy scouts, etc...)
- e) None

Rationale for not looking at time of day/year because not evident in majority of photographs, not obvious for virtual too.

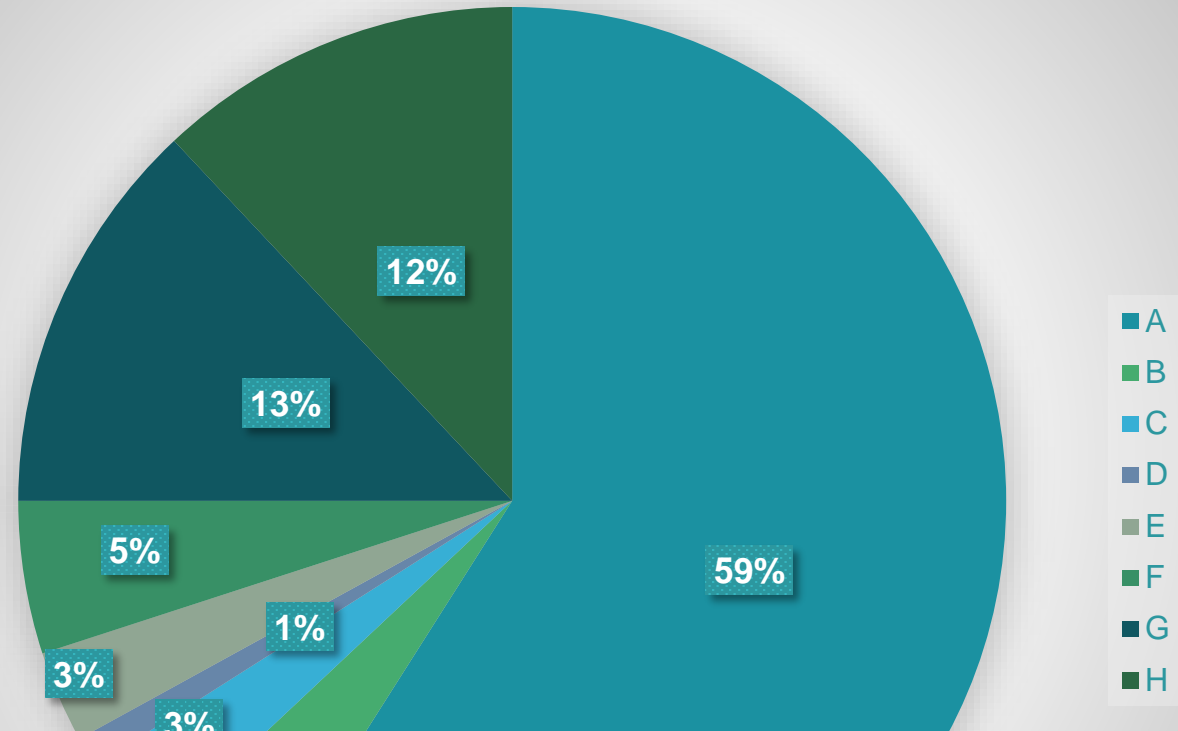
Context Key

Family Number	1
Photo No.	100-0003
Culture: Behavior/Norms	a
Culture: Practices	b
Culture: Customs	h
Temporal: Stages of Life	b
Physical: Where	a
Physical: Where at home	a
Physical: Terrain	b
Physical: Sensory qualities Lighting	d
Physical: Animals	a
Physical: Built Environment	b
Physical: Nautral	a
Social: Significant Individuals	g
Social: Number of People (includes child)	a
Social: Relation-ships	a



Physical: Where

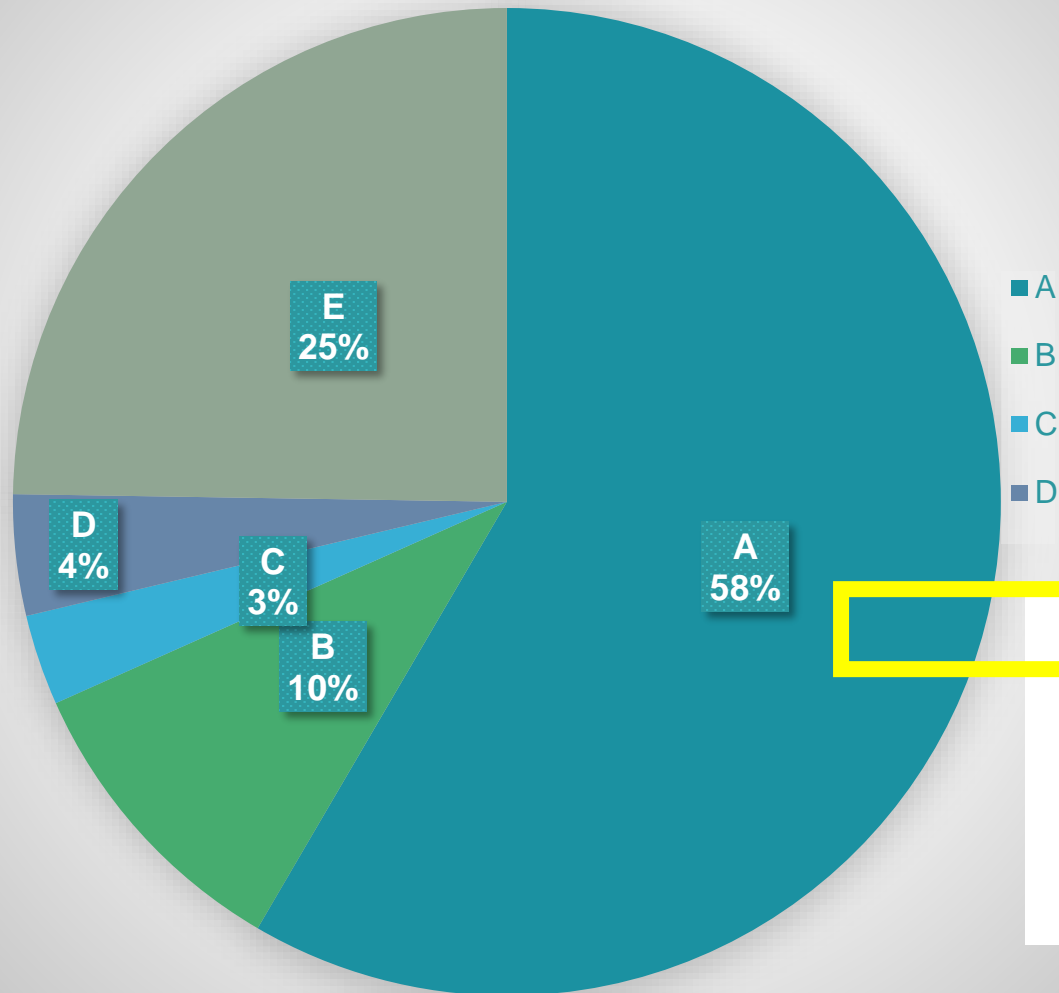
Percentage



- Where
- a) home
 - b) ...
 - c) restaurant
 - d) park/playground (kids go for fun)
 - e) therapy/medical
 - f) school
 - g) outdoors
 - h) other

Social: Number of People

Percentage



- a) 1-2
- b) 3-4
- c) 5-6
- d) >6
- e) None

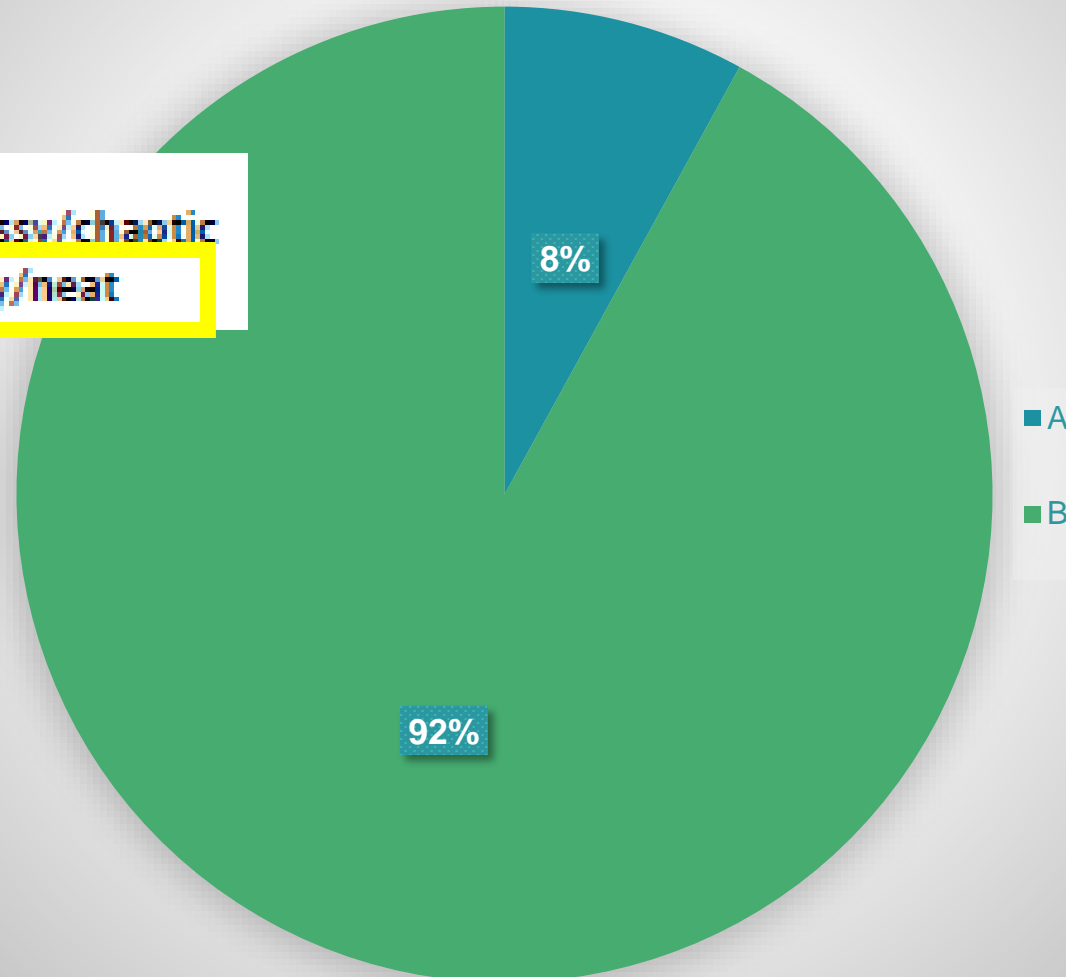
Physical: Terrain

Percentage

Terrain:

a) Messy/chaotic

b) Tidy/neat



Context Findings

- Most families thought expected behavior represented family health.
- Majority of families were in unstructured activities.
- Customs were not obvious. Daily rituals were captured in 15% of the photographs, suggesting that engagement in these activities are not prominent factors contributing to family health.

Findings Continued

- Most photographs were taken at home and in a neat, tidy living room.
- Average lighting was noted in 84% of the photographs.
- Despite literature supporting the use of animals with children with autism, 94% of the pictures did not include an animal.
- Grouped data suggest that 21% of the group photographs the child was on furniture. 12% of the photographs the child was playing, sitting or standing on the floor. 15% of the photographs were not of the child. Only 4% of the pictures had the child with a comforting object, which is a surprising finding as children with autism commonly use external strategies for self-consoling.

Findings continued

- 97% of the photographs were taken in typical, everyday environments
- Children were alone in 32% of the pictures. There were no children in 22% of the pictures and parent and siblings were most frequently (33%) the significant individual pictured with the children
- Children were alone in 32% of the pictures. There were no children in 22% of the pictures and parent and siblings were most frequently (33%) the significant individual pictured with the children

Discussion

- Overall findings are consistent with what we know about families raising children with autism.
 - Minimal social participation
 - Life revolves around child with autism
 - Routines prevail over rituals
- Study sheds light into what contributes to family health in families raising children with autism.
- Further study is needed to elucidate the concept and instigators for positive change in family health.
- Current study: Family cohesion and family rituals.

Findings

- *Our initial findings* regarding family health suggested that family health included a sense of togetherness, learning to deal yet families often don't challenge themselves to new experiences or experiences previously failed.
- Families found the “typical” everyday family experiences (e.g. going grocery shopping, eating out) overwhelming and unable to master.
- Often they “couldn't” even attempt to participate in these experiences.
- It (AUTISM) is hard and the family is learning to deal with the constant nonstop of “autism”.

Findings cont.

- Following a month of picture taking and journal writing, the families presented a slightly different perspective of family health.
- While not intended to be a therapeutic intervention, but rather a deliberate and critical family review of what contributes to family health, the research team repeatedly heard that **reflecting** on the photos and journaling experiences was a **defining moment for change and trying**.

Findings cont.

- The final themes included “even though autism”, “then there’s these moments”, “that’s just emotionally draining” and “we keep trying” seem to imply a reframing of the influence of “autism” on family life.
- The picture of family health the families are conveying is one of appreciating the little things in life, that even though he has autism we “can” engage in family experiences, and while days can be emotionally draining the family (WE) come together to keep trying.
- Examples of being, doing and becoming.

Final Thoughts

- We recognized autism poses a threat to family occupation and family health as families talked about the cost of autism to the family
- Interactions and interventions can recognize the health of the family is at risk and interventions can target family health preservation
- Our research suggests that once a family has opportunity for deliberate review they can begin to create new family life trajectories with family members viewing themselves as having control over their lives and ability to influence outcomes.
- Families shared the importance of being able to do family things, which complements the research of everyday family life for children with autism and suggests that routines and rituals are key ingredients to family occupation

Final Thoughts Continued

- Interventions can focus on family variables and contextual variables (beyond physical)
- Families indirectly talked about personal skills or attributes that seemed to make everyday life easier. These findings resonated with results from types of coping strategies used by mothers of children with autism (Smith, Seltzer, Tager-Flusberg, Greenberg, & Carter, [2008](#)Smith, L. E., Seltzer, M. M., Tager-Flusberg, H., Greenberg, J. S., & Carter, A. S. (2008).
- Various other studies have described the benefits of positive reinterpretation, suppression of competing activities and active planning to maternal well-being.
- Equally as important, if not more, was the influence of others on family occupation. We proposed in our findings that family occupation was mediated by the availability of understanding and willing people (e.g. profession, familial). When families have this external social support, family occupation appeared to be remarkably better.

Thank you!

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