1	The interaction between social determinants of health, health behaviors, and child's intellectual
2	developmental diagnosis
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15	
16	Abstract
17	
18	INTRODUCTION: Social determinants of health (SDOH) may impact caregivers' ability to
19	implement evidence-based health practices at home during early childhood, especially in families
20	with children with intellectual and developmental disabilities (IDD). Therefore, we examined the
21	influence of SDOH and children's diagnosis (typically developing [TD], Down syndrome [DS],
22	autism) on caregiver's self-report of meeting evidence-based health practices.

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24	METHODS: Caregivers (n=172) of children ages 2-6 years (TD: n=93, DS: n=40, autism:
25	n=39) completed an online survey on SDOH and health practices related to child nutrition (CN),
26	physical activity (PA), outdoor play (OP), and screen time (ST). A total SDOH score was
27	computed by assigning 1 point for each favorable SDOH metric (range 0-13). Linear regressions
28	were used to examine associations between SDOH and CN, PA, OP, ST health practices and the
29	moderating effect of IDD diagnosis.
30	
31	<b>RESULTS:</b> Most caregivers were non-Hispanic White (84.3%), female (76.7%), 18-35 years
32	old (55.2%), and married (89.5%). The DS group had the lowest SDOH score (mean = $8.4 \pm 1.0$ )
33	compared to autism (mean = $10.1\pm1.0$ ) and TD (mean = $11.0\pm0.9$ ). No family scored 100% in
34	evidence-based practices for any health practice. SDOH score was significantly associated with
35	evidence-based practices met score for CN (b = 1.94, 95% CI = 0.84, 3.04; p = 0.001) and PA (b
36	= 4.86, 95% CI = 2.92, 6.79; p < 0.0001). Moderation analysis showed no association in the DS
37	and autism groups between SDOH score and CN percent total score, or between SDOH score
38	and CN, PA, and OP for percent evidence-based practices met. SDOH score was also not
39	associated with OP percent total score for the DS group.
40	

41 CONCLUSIONS: This study highlights the differential influence of SDOH on caregivers'
 42 implementing health practices in families with children of different IDD diagnoses. Future
 43 research is needed to understand impacts of SDOH on non-typically developing children.
 44

- 45 Keywords: caregivers, social determinants of health, health behavior, outdoor play, autism,
- 46 Down syndrome
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## 50 Introduction

Note: Person-first language is not the preferred choice for all communities. To avoid confusion
for the reader, person-first language will be used to refer to children with Down syndrome as
'children with Down syndrome,' and identity-first language for children with an autism spectrum
disorder diagnosis as 'autistic children' throughout the manuscript.

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There is a growing recognition that parents, caregivers, parenting practices, and the home 56 57 environment play a critical role in shaping lifelong health behaviors such as healthy eating, physical activity (PA), and screen time during early childhood. Research shows a significant 58 association between food parenting practices, parental education level, and children's dietary 59 intake. Children with parents of high education level are more likely to eat more fruits and 60 vegetables and be physically active compared with children of parents of low education level (1, 61 2). Parents are also instrumental in helping children be more active through modeling active 62 63 behavior and creating a home environment that promotes PA and reduces screen time (3). Ultimately, the influence of parents and caregivers during early childhood lays the foundation for 64 65 lifelong health behaviors. Yet, young children struggle to meet evidence-based recommendations 66 regarding nutrition, PA, and screen time (4-9).

However, while parents and caregivers have a significant immediate and long-term impact on their child's wellbeing, it is important to recognize that social determinants of health (SDOH) such as socioeconomics, environmental context, community factors and individual children's developmental abilities significantly influence caregiver's capacity to consistently promote good health behaviors. Lower caregiver educational level, higher rates of poverty, and neighborhoods with unfavorable conditions (e.g., safety concerns, limited or no

sidewalks/walking paths) have been associated with higher rates of obesity and physical 73 74 inactivity in children (10, 11). Specifically, poverty exposure prior to age two is strongly 75 associated with childhood obesity (12) and negatively associated with children's overall health (13). Additionally, children of parents with less than a high school education are more likely to 76 reside in unsafe neighborhoods that lack essential health-promoting features like sidewalks, 77 78 parks, playgrounds, and recreation centers, and have 30-60 percent higher likelihood of 79 childhood obesity (10). Furthermore, SDOH contribute to more health inequities and challenges 80 in individuals with intellectual and developmental disabilities (IDD; e.g., Down syndrome, 81 autism) (14), who historically have been underrepresented in health behavior research, widening 82 the health disparity gap between children with and without IDD (15). Children with IDD experience difficulties in activities of daily living, motor skills, communication, and participation 83 at home, school, and in the community (10, 11), and are more susceptible to physical inactivity 84 85 and obesity (10, 11, 16-18). Caregivers of children with IDD face distinct challenges, including 86 the need for more intensive interventions, coordination among multiple healthcare providers, management of co-morbidities, and navigating the absence of standardized treatments (14). 87 88 These families often encounter significant financial burdens due to healthcare costs, medication 89 costs, not being able to work, supplemental therapies and other support services which highlights the multifaceted demands of caregiving in this population (14, 19). Understanding how these 90 91 additional challenges impact parents' and caregivers' ability to promote health behaviors are 92 essential steps toward fostering healthier environments and improving outcomes for all children, 93 especially those with IDD.

Existing studies have explored the impact of SDOH on health and parenting styles (2022), however, to our knowledge, no study has investigated the relationships between SDOH and

96	caregivers' evidence-based health practices within the home environment, particularly among
97	families with children with IDD. In the current study we leveraged data obtained from a web-
98	based family health practices survey to investigate the influence of SDOH on caregiver practices
99	related to child nutrition, PA, outdoor play, and screen time in families with typically developing
100	(TD) children, those with Down syndrome (DS), and autistic children, aged 2-6 years. This study
101	seeks to gain insights into the underlying external factors (i.e., SDOH factors) influencing health
102	behaviors within diverse family contexts, informing strategies for promoting healthier lifestyles
103	among all children.

104 Methods

### 105 Study design and participants

Our study sample comprised participants who completed a web-based cross-sectional 106 survey to explore family-level health practices around seven content areas: 1) physical activity, 107 108 2) outdoor play and learning, 3) child nutrition (2-6 years only), 4) oral health, 5) farm to home 109 (i.e., serve family local foods for meals or snacks, gardening and gardening activities with child, education about fresh and local foods), 6) screen time, and 7) breast/infant feeding (0-2 years 110 only). The survey also included questions about the types of health information resources used 111 112 and participants' trust in these resources. The researchers employed convenience sampling to recruit parents and caregivers of children aged 0-6 years old with DS, autism, or TD to complete 113 114 the online survey. Participants were recruited between November 2022 and February 2023 115 through flyers, advertisements in traditional social media platforms (LinkedIn, X [formerly 116 Twitter], Facebook, Reddit) and emails to relevant foundations and organizations. To be eligible 117 for the survey, respondents were required to be 18 years or older, live in the United States, and 118 have a child aged 0-6 years. Participants were excluded if their child required a full liquid,

119	mechanically altered, soft, pureed, and/or tube fed diet. Participants provided consent before
120	taking the survey and were eligible to receive one of thirty randomly allocated, \$50 gift cards
121	after completion. More details on the survey development and participant recruitment can be
122	found elsewhere Thompson, Clarke (23). This manuscript was written in alignment with the
123	checklist for the Strengthening the Reporting of Observational Studies in Epidemiology
124	(STROBE) Statement. The study was reviewed by the University of North Carolina at Chapel
125	Hill Institutional Review Board and was determined exempt.
126	The present study focused on four family-level health practice content areas for children
127	ages 2 to 6 years: child nutrition, PA, outdoor play and learning (hereinafter, outdoor play), and
128	screen time practices. Of the 659 primary caregivers who were eligible and consented to
129	participate, 387 completed the survey. We excluded participants whose child was aged 2 years or
130	younger ( $n = 171$ ), and those who were missing relevant data necessary for calculating SDOH
131	metric scores ( $n = 44$ ).
132	Measures
133	Demographics. Caregivers self-reported basic demographic information (age,

race/ethnicity, sex, marital status, education level, household income) in the online survey.
Education level was reported as "Less than high school", "High school graduate or GED",
"Some college or technical school", "Associate degree", "Bachelor degree", or "Graduate or
professional degree" and household income was reported as "less than \$15,000"; "\$15,000 to
\$34,999"; "\$35,000 to \$74,999"; "\$75,000 to \$149,999"; or "\$150,000 or more." Caregivers also
self-reported their child's age group (0 -12 months, 12-23 months, 2 to 6 years) and
developmental disability diagnosis (TD, DS, autism).

141	<u>SDOH</u> . All SDOH metrics and their corresponding survey items are described in Table 1.
142	Caregivers self-reported on 13 items related to SDOH, which were grouped into five broad
143	SDOH metrics, in line with the definitions provided by the Office of Disease Prevention and
144	Health Promotion's Healthy People 2030 and the World Health Organization: Economic
145	Stability, Education Access and Quality, Healthcare Access, Residential Environments, and
146	Social Context and Support (22).
147	The Economic Stability score was computed based on total household income (favorable
148	score >\$34,999) and the perception of food insecurity (favorable score = never true), resulting in
149	a construct score ranging from 0 (no favorable SDOH) to 2 (all favorable SDOH) points.
150	Education Access and Quality score was determined based on language and literacy
151	barriers (favorable score = no) and education level (favorable score = greater than a high school
152	education), with a construct score range from 0 to 2 points.
153	The Healthcare Access score was derived from satisfaction with healthcare access
154	(favorable score = at least satisfied), satisfaction with social services/programs access (favorable
155	score = at least satisfied), personal health literacy (favorable score = no difficulty),
156	organizational health literacy (favorable score = receive adequate information on at least 6 of 8
157	wellness-related topic areas), and barriers to care (favorable score = no barriers reported), with a
158	construct score range from 0 to 5 points.
159	Residential Environment score was calculated based on transportation issues (favorable
160	score = none) and perceived neighborhood safety (favorable score = at least fairly safe), resulting
161	in a construct score range from 0 to 2 points. Social Context and Support score was determined
162	based on race and ethnicity (favorable score = non-Hispanic white) and relationship status
163	(favorable score = married living together), with a construct score range from 0 to 2 points.

- 164 A total SDOH score was computed by assigning 1 point for each favorable survey metric,
- resulting in a range from 0 (no favorable SDOH) to 13 (all favorable SDOH). Each variable was
- 166 weighted equally, consistent with prior analyses (24-26).

SDOH metric	Survey Metric	Measures Used	Favorable SDOH Score = 1 point
Economic	Poverty	1 = less than \$15,000;  2 = \$15,000 to \$34,999;3 = \$35,000 to \$74,999;  4 = \$75,000 to \$149,999;5 = \$150,000 or more.	>\$34,999
Stability	Food Insecurity	Within the past 12 months, have you been worried that your food would run out before you got money to buy more:1 = Never true; 2 = Sometimes true; 3 = Often true.	Never true
Education	Language and Literacy	Language Barriers are a challenge when trying to find information or resources to help support my child's health and well-being. $1 = \text{Yes}$ ; $2 = \text{No}$ .	No
Access and Quality	High School Graduation	Highest Level of schooling completed: 1 = Less than high school; 2 = High school graduate (or GED); 3 = Some college or technical school; 4 = Associate's degree; 5 = Bachelor's degree; 6 = Graduate or professional degree.	> High school
	Satisfaction with Health Care Access	1 = Very Unsatisfied; 2 = Unsatisfied; 3 = Neutral; 4 = Satisfied; 5 = Very Satisfied.	> Neutral
	Satisfaction with Social Services/Programs Access	1 = Very Unsatisfied; 2 = Unsatisfied; 3 = Neutral; 4 = Satisfied; 5 = Very Satisfied.	> Neutral
	Personal health literacy	Difficulty understanding resources is a challenge to accessing information and resources to support health and well-being of your child.	No
Healthcare Access	Organizational health literacy	Do you feel that you receive adequate health information and resources to help support your child in 1) Developmental Milestones, 2) Nutrition/Eating Habits, 3) Physical activity and play, 4) Screen time, 5) Behavior Management, 6) Social and Emotional Development, 7) Sleep habits, 8) Oral health.	Receive adequate information on at least 6 of 8 topic areas
	Delayed Access to Care	Delayed care for your child for any of the following reasons: 1) No transportation, 2) Live in rural area and distance to provider was too far, 3) Nervous about seeing provider, 4) Could not get time off work, 5) No childcare, 6) Provide care for an adult and could not leave, 7) Could not afford copay, 8) Too high deductible, 9) Had to pay out of pocket, 10) Other, 11) None of the above.	None
Residential Environment	Transportation	In the past 12 months, has lack of transportation kept you from any of the following: 1) Medical appointments, 2) Getting medical supplies (i.e., medication), 3) Non-medical meetings, 4) Work, 5) Getting living essentials (i.e., groceries, clothes), 6) Other, please specify, 7) None of the above.	None
	Perceived Safety of Walking in Neighborhood	1 = Very unsafe; 2 = Fairly unsafe; 3 = Neither safe nor unsafe; 4 = Fairly safe; 5 = Very safe.	> Neither safe nor unsafe
Social Context	Race/Ethnicity	1 = non-Hispanic White; 2 = non-Hispanic Black; 3 = AI/Asian/NHPI; 4 = Hispanic, Latino, or Spanish origin; 5 = More than one race; 6 = Other.	non-Hispanic White
and Support	Primary Caregiver Relationship Status	1 = Never married; 2 = Married; 3 = Widowed/divorced/separated.	Married

#### Table 1. Social determinants of health (SDOH) metric definitions

Family-level health practices. Self-assessments were developed for each of the four 169 content areas using questionnaire items adapted for home use from the web-based Nutrition and 170 Physical Activity Self-Assessment for Child Care's (Go NAPSACC) family child care home 171 assessment tool (27). The Go NAPSACC family child care home self-assessment items allow 172 173 individuals who provide care for children in their homes to evaluate to what degree they are 174 meeting current evidence-based recommendations. These self-assessments were created 175 following a thorough review of regulations, performance standards, and recommendations from 176 scientific literature and governmental and professional organizations. Survey adaptation was a 177 collaborative effort among experts in early childhood health behaviors, registered dietitians, and key informants. Final items were reviewed by experts for face validity prior to dissemination. 178 Final self-assessments included 35 items for child nutrition, 14 items for PA, 10 items for 179 180 outdoor play, and 6 items for screen use.

Survey items were scored using a 4-point Likert-type scale, from 1 = "not engaging", 2 =181 "minimally engaging", 3 = "somewhat engaging", to 4 = "fully engaging" in evidence-based 182 practice recommendations. Self-assessment total percentage scores (total percentage score) were 183 calculated for each content area by summing all scored items divided by the total possible points 184 185 for all applicable items multiplied by 100, yielding a percentage score between 0 (least engaging) to 100 (most engaging). The percent of evidence-based practices met for each topic area was 186 187 calculated by summing the number of items where the evidence-based practice was fully 188 engaged (score = 4) and dividing this number by the total number of evidence-based practices  $\frac{1}{2}$ 189 multiplied by 100, yielding a percentage score between 0 (not fully engaging) to 100 (fully 190 engaging). The total percentage and evidence-based practice met percentage score helps measure 191 the full range of caregivers' engagement in evidence-based practices.

# 192 Statistical analyses

193	Data were summarized using means and standard deviations for continuous variables, and
194	frequencies and percentages for categorical variables. Separate linear regression models were
195	used to examine direct associations between SDOH and evidence-based family-level health
196	practice content areas (i.e., child nutrition, PA, outdoor play, screen time), as well as the
197	moderating effect of a child diagnosis (TD, DS, autism). All models were adjusted for primary
198	caregivers' age, sex, and the child's diagnosis. Interaction terms between child diagnosis and
199	SDOH total score were entered into the models to examine potential moderating effects.
200	Statistical significance was set at $p = 0.05$ for interpreting main effects and at $p = 0.10$ for
201	interpreting moderating effects. All analyses were conducted using SAS version 9.4 (Cary, NC).
202	
203	Results
204	Participants. The median completion time of the online survey for participants was 29
204 205	<u>Participants</u> . The median completion time of the online survey for participants was 29 minutes. Table 2 shows the participant characteristics of the 172 primary caregivers that were
205	minutes. Table 2 shows the participant characteristics of the 172 primary caregivers that were
205 206	minutes. Table 2 shows the participant characteristics of the 172 primary caregivers that were included in this analysis. Overall, caregivers were primarily non-Hispanic White (84.3%), female
205 206 207	minutes. Table 2 shows the participant characteristics of the 172 primary caregivers that were included in this analysis. Overall, caregivers were primarily non-Hispanic White (84.3%), female (76.7%), 18-35 years old (55.2%), married (89.5%), held a graduate or professional degree
205 206 207 208	minutes. Table 2 shows the participant characteristics of the 172 primary caregivers that were included in this analysis. Overall, caregivers were primarily non-Hispanic White (84.3%), female (76.7%), 18-35 years old (55.2%), married (89.5%), held a graduate or professional degree (36.6%), and had a household income of \$75,000 - \$149,999 (47.1%). Fifty-four percent of
205 206 207 208 209	minutes. Table 2 shows the participant characteristics of the 172 primary caregivers that were included in this analysis. Overall, caregivers were primarily non-Hispanic White (84.3%), female (76.7%), 18-35 years old (55.2%), married (89.5%), held a graduate or professional degree (36.6%), and had a household income of \$75,000 - \$149,999 (47.1%). Fifty-four percent of families self-reported their child was TD, 23% reported their child was diagnosed with DS, and
205 206 207 208 209 210	minutes. Table 2 shows the participant characteristics of the 172 primary caregivers that were included in this analysis. Overall, caregivers were primarily non-Hispanic White (84.3%), female (76.7%), 18-35 years old (55.2%), married (89.5%), held a graduate or professional degree (36.6%), and had a household income of \$75,000 - \$149,999 (47.1%). Fifty-four percent of families self-reported their child was TD, 23% reported their child was diagnosed with DS, and 23% reported their child was diagnosed with autism. Primary caregivers of a child with DS
205 206 207 208 209 210 211	minutes. Table 2 shows the participant characteristics of the 172 primary caregivers that were included in this analysis. Overall, caregivers were primarily non-Hispanic White (84.3%), female (76.7%), 18-35 years old (55.2%), married (89.5%), held a graduate or professional degree (36.6%), and had a household income of \$75,000 - \$149,999 (47.1%). Fifty-four percent of families self-reported their child was TD, 23% reported their child was diagnosed with DS, and 23% reported their child was diagnosed with autism. Primary caregivers of a child with DS included in this study were younger (85.0% between 18-35 years old) compared to caregivers of

74.4% of primary caregivers were married compared to 97.5% and 92.5% among caregivers of achild with DS and TD child, respectively.

217	<u>SDOH</u> . The overall SDOH mean score was 10.2 points (standard deviation $[SD] = 1.4$ ).
218	Total SDOH score was significantly lower for primary caregivers of a child with Down
219	syndrome (8.4 points, $SD = 1.0$ ) compared to autistic children (10.1 points, $SD = 1.0$ ; p < 0.001)
220	and those that are TD (11.0 points, $SD = 0.9$ , $p = 0.006$ ). Primary caregivers of children with DS
221	self-reported the highest prevalence of food insecurity ( $DS = 67.5\%$ vs. $TD = 24.7\%$ vs. autism =
222	17.9%), language barriers related to health information and resources ( $DS = 25.0\%$ vs. $TD =$
223	10.7% vs. autism = 2.6%), difficulty understanding resources (DS = 55.0% vs. TD = 10.7% vs.
224	autism = 5.1%), transportation issues (DS = $85.0\%$ vs. TD = $21.5\%$ vs. autism = $5.1\%$ ), and
225	delaying care for their child ( $DS = 87.5\%$ vs. autism = 33.3% vs. $TD = 23.6\%$ ; Table 2).
226	Primary caregivers of autistic children reported the highest prevalence of dissatisfaction with
227	access to healthcare services (autism = $41.0\%$ vs. DS = $25.0\%$ vs. TD = $15.1\%$ ), social services
228	programs (autism = $56.4\%$ vs. TD = $29.0\%$ vs. DS = $27.5\%$ ), and health-related resources
229	(autism = $48.7\%$ vs. DS = $35.0\%$ vs. TD = $24.7\%$ ; Table 2).
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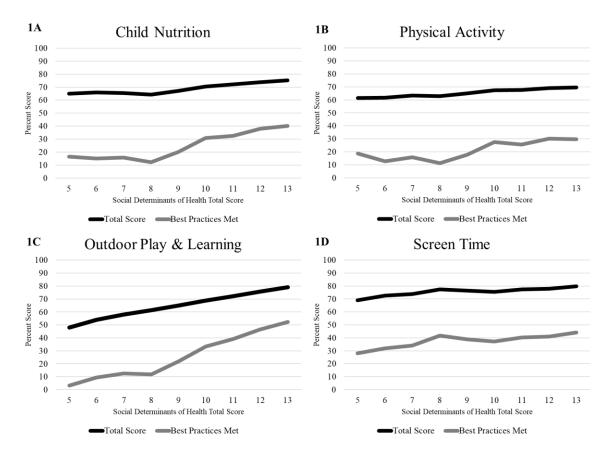
All Typically Down Autism parents Developing syndrome (n=93)(n= 172) (n=40)(n=39)Variable % % n % % n n n **CAREGIVER CHARACTERISTICS** Age (years) 18 to 35 95 55.2 49 52.7 34 85 12 30.8 77 35 to 50 44.8 44 47.3 6 15 27 69.2 **Biological sex** Female 132 76.7 77 82.8 21 52.5 34 87.2 Male 40 23.3 17.2 19 47.5 5 12.8 16 SDOH CHARACTERISTICS **Economic Stability Total household income** <\$34.999 16 9.3 7 7.5 3 7.5 6 15.4 ≥\$35,000 156 90.7 86 92.5 37 92.5 33 84.6 Household food security level 7 33.1 23 27 17.9 Sometimes or often true 57 24.767.5 Never true 115 66.9 70 75.3 13 32.5 32 82.1 **Education Access and Quality** Language barriers (no) Yes 21 12.2 10 10.7 10 25 1 2.6 151 87.8 83 89.3 30 75 38 97.4 No **Primary caregiver education** 7 4.1 3 3.2 1 3 7.7  $\leq$  High School Graduate 2.5 >High School Graduate 165 95.9 90 96.8 39 97.5 36 92.3 **Healthcare Access** Satisfaction with health care access Unsatisfied/Neutral 40 23.4 14 15.1 10 25 41 16 Satisfied 76.7 79 30 75 23 59 132 84.9 Satisfaction with social services/programs access Unsatisfied/Neutral 60 34.9 27 29 11 27.5 22 56.4 112 65.1 71 29 72.5 Satisfied 66 17 43.6 Difficulty understanding resources 19.8 10 10.7 22 55 2 Yes 34 5.1 138 80.2 89.3 18 45 94.9 No 83 37 **Receive adequate health information and** resources (Yes) Developmental Milestones 137 79.7 80 86 27 67.5 30 76.9 129 75 77 82.8 27 Nutrition/Eating Habits 67.5 25 64.1 Physical activity and play 133 77.3 77 82.8 29 72.5 27 69.2 78.5 78 83.9 26 79.5 Screen time 135 65 31 **Behavior Management** 121 70.4 67 72 33 82.5 21 53.9 Social and Emotional Development 120 69.8 72 77.4 28 70 20 51.3 76.7 76 81.7 33 82.5 23 59 Sleep habits 132 Oral health 143 83.1 81 87.1 28 70 34 87.2

Table 2. Sample characteristics and descriptive information of social determinants of health by child diagnosis.

Table 2. (Continued) Sample characteristics and descriptive information	on of social determinants of health by child
diagnosis.	

		All rents 172)	Typically Developing (n= 93)		Down syndrome (n= 40)		Autism (n= 39)	
Variable	<u>n</u>	<u>172)</u> %	(II	<u> </u>	<u>(n.</u> n	- <del>4</del> 0) %	<u></u> n	- <u>39)</u> %
SDOH CHARACTERISTICS		, 0		,,,		, 0		70
Healthcare Access (Continued) Have you delayed care for your child because (No)	-							
Did not have transportation	160	93	89	95.7	33	82.5	38	97.4
Distance to health care provider is too far	153	89	88	94.6	28	70	37	94.9
Nervous about seeing a health care provider	146	84.9	83	89.3	25	62.5	38	97.4
Could not get time off work	154	89.5	89	95.7	31	77.5	34	87.2
Could not get childcare	155	90.1	85	91.4	33	82.5	37	94.9
Provide care to an adult and could not leave them	157	91.3	89	95.7	29	72.5	39	100
Could not afford copay	167	97.1	90	96.8	38	95	39	100
Too high/or could not afford the deductible	161	93.6	89	95.7	35	87.5	37	94.9
Had to pay out of pocket for some/all of the procedure	152	88.4	86	92.5	30	75	36	92.3
Other, please specify	167	97.1	93	100	40	100	34	87.2
Residential Environment								
Lack of transportation kept you from (No)								
Medical appointments	152	88.4	89	95.7	25	62.5	38	97.4
Getting medical supplies (i.e., medication)	151	87.8	84	90.3	29	72.5	38	97.4
Non-medical meetings	152	88.4	80	86	33	82.5	39	100
Work	148	86.1	85	91.4	25	62.5	38	97.4
Getting living essentials (i.e., groceries, clothes)	153	89	87	93.6	28	70	38	97.4
Other, please specify	172	100	93	100	40	100	39	100
Perceived safety of walking in neighborhood								
Unsafe/Neutral	23	13.4	9	9.7	9	25.5	5	12.8
Safe	149	86.6	84	90.3	31	77.5	34	87.2
Social context and support Race/Ethnicity								
non-white	27	15.7	11	11.8	7	17.5	9	23.1
non-Hispanic white	145	84.3	82	88.2	33	82.5	30	76.9
Primary caregiver relationship status		-						
Never/Widowed/divorced/separated	18	10.5	7	7.5	1	2.5	10	25.6
Married	154	89.5	86	92.5	39	97.5	29	74.4

236	Association between SDOH and family-level health practices. Figure 1 shows the
237	association between child nutrition (Figure 1A), PA (Figure 1B), outdoor play (Figure 1C),
238	screen time (Figure 1D) evidence-based practices and SDOH metric score. Child nutrition total
239	percentage score ranged 56.7% to 76.4%, with percent of evidence-based practice met
240	percentage scores ranging from 0% to 45.6%. SDOH score was significantly associated with
241	both the total percentage score (b = $0.81$ , 95% CI = $0.28$ , 1.33; p = $0.003$ ) and the percent of
242	evidence-based practices met (b = 1.94, 95% CI = 0.84, 3.04, p = 0.001) with child nutrition
243	family practices.
244	Similarly, PA total percentage scores varied between 55.9% and 73.6%, with evidence-
245	based practice met percentage scores ranging from 0% to 40.3%. Here, the SDOH score was
246	significantly associated with total percentage score (b = $1.10$ , 95% CI = $0.25$ , $1.94$ ; p = $0.011$ ),
247	though not with evidence-based best practices met percentage score ( $p = 0.059$ ). Outdoor play
248	total score ranged from 43.5% to 80.2%, while evidence-based practice met percentage scores
249	varied from 0% to 53.7%. For outdoor play, the SDOH score significantly correlated with both
250	total percentage score (b = 3.62, 95% CI = 2.55, 4.70; p < 0.0001) and evidence-based practice
251	met percentage scores (b = $4.86$ , $95\%$ CI = $2.92$ , $6.79$ ; p < $0.0001$ ). Lastly, screen time total score
252	ranged from 64.7% to 84.0%, with evidence-based practice met percentage scores ranging from
253	18.8% to 55.6%. SDOH score was significantly associated with total percentage score ( $b = 1.44$ ,
254	95% CI = 0.36, 2.53; $p = 0.009$ ), but was not statistically associated with evidence-based practice
255	met percentage scores ( $p = 0.060$ ).



256

Figure 1. Association between child nutrition (Figure 1A), physical activity (Figure 1B), outdoor 257 258 play and learning (Figure 1C), screen time (Figure 1D), self-assessment total percentage score and evidence-based practice met percentage score and SDOH metrics score. Total Score is 259 260 calculated by summing all scored items divided by the total possible points for all applicable 261 items multiplied by 100, yielding a percentage score between 0 (least engaging) to 100 (most 262 engaging). Evidence-based practice met percentage score is calculated by summing the number 263 of items where the best practice was fully engaged (score = 4) and dividing this number by the 264 total number of evidence-based practice multiplied by 100, yielding a percentage score between 265 0 (not fully engaging) to 100 (fully engaging).

267	Child disability diagnosis as a moderator for associations of SDOH and family-level
268	<u>health practices</u> . For the total percentage score, there were significant interactions ( $p < 0.10$ )
269	between SDOH score and child disability diagnosis for child nutrition practices, as well as
270	outdoor play practices. Further investigation into the interaction revealed that SDOH metrics
271	were significantly associated with higher scores in children's nutrition for families with TD
272	children only (p<0.0001; Table 3). Additionally, SDOH metrics showed a significant association
273	with higher scores in outdoor play for families with TD children (p<0.0001) and autistic children
274	(p = 0.022), but no significant association was observed with families of young children with DS
275	(p=0.760; Table 3). For evidence-based practice met percentage scores, there were significant
276	interaction ( $p < 0.10$ ) between SDOH score and child disability diagnosis for child nutrition, PA,
277	and outdoor play practices. Further investigation into these interactions revealed that SDOH
278	metrics were significantly associated to higher scores for families with TD children only for
279	child nutrition (p<0.0001), PA (p=0.006), and outdoor play practices (p<0.0001; Table 3).
200	

	Self-assessment Total			Evidence-Based Practice			
	Percentage Score		Met Percentage S		e Score		
	b	95	% CI	b	95%	6 CI	
Child Nutrition							
Total SDOH Score							
Typically Developing	1.74	1.10	2.39	4.40	3.09	5.71	
Down syndrome	-0.24	-1.52	1.04	-2.39	-4.98	0.20	
Autism	-0.56	-1.47	0.34	-0.82	-2.65	1.02	
Physical Activity							
Total SDOH Score							
Typically Developing	-	-	-	2.46	0.74	4.19	
Down syndrome	-	-	-	-3.45	-12.76	5.86	
Autism	-	-	-	-0.14	-2.17	1.90	
Outdoor Play and learning							
Total SDOH Score							
Typically Developing	4.98	3.62	6.34	7.52	5.10	9.93	
Down syndrome	-1.31	-9.75	7.14	-9.71	-24.69	5.28	
Autism	1.90	0.29	3.52	1.80	-1.07	4.67	
Screen Time							
Total SDOH Score							
Typically Developing	-	-	-	-	-	-	
Down syndrome	-	-	-	-	-	-	
Autism	-	-	-	-	-	-	

Table 3. Association between child nutrition, physical activity, outdoor play and learning, screen
time evidence-based practices and SDOH by child intellectual disability diagnosis.

Note: Typically developing (n = 93), Down syndrome (n = 40), autism (n = 39)

## 282 Discussion

Although the impact of SDOH on health outcomes and health inequalities has been well 283 284 documented, no study has explored their influence on caregiver health practices in the home 285 environment among families of children with and without IDD. The current study sought to explore the influence of SDOH on child nutrition, PA, outdoor play, and screen time among a 286 sample of caregivers with 2-6 years old children in three groups, TD, DS, and autism, to help 287 inform research intervention and implementation efforts in the 2-6 years old age group. 288 The results of this study revealed three main points. First, TD children have more 289 advantageous SDOH factors than children with DS and autistic children. The most unfavorable 290 SDOH factors were seen among the DS group, specifically for food insecurity, language barriers 291

related to health information and resources, difficulty understanding resources, transportation 292 293 issues, and delaying care for the child. Second, SDOH score was significantly associated with 294 the total percentage scores (i.e., 0% is least engaging and 100% is most engaging in evidencebased practices) for all four family-level health practices (e.g., child nutrition, PA, outdoor play, 295 and screen time), and with the percent of best practices met (i.e., 0% is not fully engaging and 296 297 100% is fully engaging in evidence-based practices) for two family-level health practices (e.g., 298 child nutrition and outdoor play). Third, the child's IDD diagnosis was identified as a moderator 299 for the association between SDOH and child nutrition and outdoor play practices. In families 300 with TD children, SDOH scores were significantly associated with child nutrition, PA, and outdoor play. 301

Unfavorable SDOH factors. Families of children with IDD face many health disparities, 302 including health care utilization (i.e., preventative services), access to care (28), higher 303 304 healthcare cost (e.g., specialty services, emergency department, hospitalization) (19), poverty, 305 food insecurity, access to educational resources, healthcare access, transportation, and social support (14). The current study corroborates these health disparities when comparing families of 306 children with and without IDD. Our results show that caregivers of children with DS have more 307 308 unfavorable SDOH factors, notably in four of the five SDOH constructs, economic stability, education access and quality, healthcare access, and residential environment. Families of autistic 309 310 children have more unfavorable factors under healthcare access and social context and support. 311 Unfortunately, caregivers of children with DS and autism reported dissatisfaction and difficulty 312 with healthcare access.

Caregivers of children with DS were more likely to face food insecurity; they worriedthat the food would run out before they could buy more. Also, they experience language barrier

when trying to find information or resources to support their child's health. Although caregivers of children with DS in this study were more likely to have a high school diploma or higher education and a higher household income, which are considered favorable SDOH factors, studies have shown that children with developmental needs have higher healthcare costs, which negatively impacts the household's income (29, 30).

negatively impacts the household's income (29, 30).

320 While caregivers of children with DS may report a high educational level and household income, healthcare expenses associated with the child diagnosis reduces the household economic 321 322 condition and makes the family more prone to income related issues such as food insecurity. The 323 caregiver's educational level does not explain the reported language barriers around finding health resources for the child's wellbeing. Perhaps, these barriers are not a function of the 324 caregiver's level of education but are related to the healthcare provider's knowledge (e.g., 325 educational training), beliefs about and attitudes around children with IDD. Healthcare training 326 327 deficient in IDD and low participation in research are two key areas responsible for the gap in 328 knowledge between caregiver and healthcare provider. Many medical schools do not include disability in their training program (31); this creates a gap between what healthcare providers can 329 offer and what families of children with IDD need. Consequently, providers do not have the 330 331 necessary information or are unable to communicate it in a way that resonates with families. Thus, leaving the needs of children with IDD overlooked and unmet (32). 332

A significant percentage of physicians (82.4%) rate the quality of life of people with disability as worse, and only 43% "strongly" agree to welcoming patients with disability to their practice (33). Our results revealed that 37.5% of caregivers of children with DS delay care for their child because they were "nervous about seeing a healthcare provider." People with IDDs, such as DS, are underrepresented in research (15), and the quantity and quality of health

information needed to address their health needs is lacking. The increased participation in
research by members of the DS community and other IDD members can help fill this existing
knowledge gap. Other recommendations to address the needs of people with IDDs include
improved communication strategies (e.g., health passport), a disability coordinator to improve
patient care, invite persons with disabilities to participate in key conversations (e.g., ethics
committees, hospital policy discussion), and increased IDD education for healthcare
professionals and medical school students (34).

Children with DS have co-morbidities and need consistent and adequate access to 345 healthcare. Although 75% of their caregivers report being satisfied with healthcare access, they 346 are more likely to delay care for multiple reasons including "distance to healthcare provider" and 347 "nervous about seeing a health care provider." Moreover, lack of transportation has kept families 348 of children with DS from key appointments (e.g., medical, work, and groceries) more frequently 349 350 than families with autistic or TD children. Similarly, caregivers of autistic children report being 351 dissatisfied with healthcare access and resources. Particularly, they are the most dissatisfied with access to healthcare services, social services programs, and health-related resources. They report 352 not receiving adequate health information and resources for "behavior management," "social and 353 354 emotional development," and "sleep habits." This finding is supported by Graaf, Annis (35) who reported that parents of children with special needs who have developmental, behavioral, and 355 356 emotional concerns (e.g., autistic children) need more support services compared to those who 357 do not have those additional concerns. Additionally, caregivers' dissatisfaction with healthcare 358 access and services may be due to the complexity of the disorder. Autism or autism spectrum 359 disorder covers a spectrum of symptoms and can be a complex disorder to treat. Families need

360 coordinated care services due to the complexity of care (e.g., emotional, behavioral, medical)
361 associated with treating autistic children (36).

362 SDOH and family-level health practices. Among the four family-level health practices, there is no evidence in our sample of families fully engaging in evidence-based practices. 363 Caregivers report that their children engaged the most in outdoor play and the least in PA. 364 365 Further analysis of association revealed SDOH score is significantly associated with total percentage scores for all four family-health practices, and only for child nutrition and outdoor 366 367 play for evidence-based practice met percentage score. The higher the SDOH score (i.e., more 368 favorable factors), the higher the evidence-based practice met percentage score. These findings 369 further support the idea that SDOH affects health quality.

As previously noted, outdoor play is associated with higher PA levels (37). In a study of children and youth with special health care needs, children did not meet the daily 60 minutes PA recommendation by the American Academy of Pediatrics and parents identified some SDOH factors as barriers to PA, including finances and being unable to pay for adaptive equipment (38). Yazdani, Yee and Chung (39) reported similar barriers including perceived lack of time for PA, lack of reliable transportation, no program that can accommodate the child's disability, neighborhood safety, child's behavior, and the child's developmental delay.

377 <u>SDOH, family-level health practices, and child diagnosis</u>. Child diagnosis was found to
378 be a moderator for the association between SDOH and family-level health practices. SDOH
379 score is significantly associated with higher total percentage scores in child nutrition and outdoor
380 play for families with TD children. In contrast, there is an inverse relationship between SDOH
381 score and percentage of evidence-based practices met score for child nutrition, PA, and outdoor

play in families of children with DS. No interactions were found between total percentage scoreand PA and screen time, and evidence-based practices met percentage score and screen time.

The purpose of this study was to explore the influence of SDOH on child nutrition, PA, 385 outdoor play, and screen time practices among caregivers to children with and without 386 387 disabilities. This study highlights an important association between the SDOH and health practices among understudied populations. However, these findings are subject to three 388 389 limitations. First, the generalizability of the study results is subject to certain limitations. For 390 instance, our study sample is not representative and lacks sufficient diversity of race, ethnicity, education, income, and relationship status among participants. Also, the sample sizes of the DS 391 and autism group, although equal, were smaller than that of the TD group. So, the findings must 392 be interpreted carefully. Second, our SDOH mean score was high with a relatively small standard 393 394 deviation, which again highlights limited diversity in our study sample. Third, online surveys are 395 subject to sampling bias because certain groups of people may be overrepresented or underrepresented in the data. Future research should recruit a larger and more diverse sample for 396 397 race, ethnicity, education, income, relationship status, and IDD status.

**398 Future Research and Direction** 

384

Limitations

This research's findings have identified questions in need of further investigation, opportunities for healthcare providers, and policy implications. In this study, families of children with DS had more unfavorable SDOH factors. More research is needed to confirm these findings and understand why families of children with DS and autistic children are disproportionately affected in healthcare access and health literacy. Healthcare providers should consider the specific needs of their audience when sharing health information and clearly communicate in a

way that the patient can understand and implement it. Also, a concerted effort to educate 405 healthcare providers in all healthcare settings about IDDs and disabilities is urgently needed. 406 This education might help address difficulties families of children with IDDs experience when 407 accessing healthcare, improve their comfort level around healthcare personnel, and increase their 408 health literacy. Policies at the local, state, and national level are needed to support these efforts 409 410 and improve the quality of care all patients receive, especially those who are experiencing healthcare inequities with the current system. Equally, researchers should aim to recruit people 411 412 with IDDs in their studies so we can increase our understanding of their health behaviors, factors 413 that impact their health, and in turn help improve the health services they receive. In summary, this study shows that families are struggling to meet evidence-based 414 practices and SDOH influence primary caregivers' health-related practices around child 415 nutrition, PA, outdoor play, and screen time. Child's IDD diagnosis can help explain the 416 417 relationship between SDOH and child nutrition and outdoor play. Future research must prioritize 418 SDOH in health interventions, especially in families of children with DS and autistic children to understand their varied impacts in this context. 419

### 420 **Practical application**:

SDOH influence children's nutrition, PA, outdoor play, and screen time through the
primary caregiver's health-related practices. Researchers, educators, and healthcare providers
should consider SDOH factors that families may face when working to improve their child's
health behavior.

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