Barriers and Facilitators to Physical Activity Engagement in Individuals with Developmental Disabilities (DD)

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INTRODUCTION

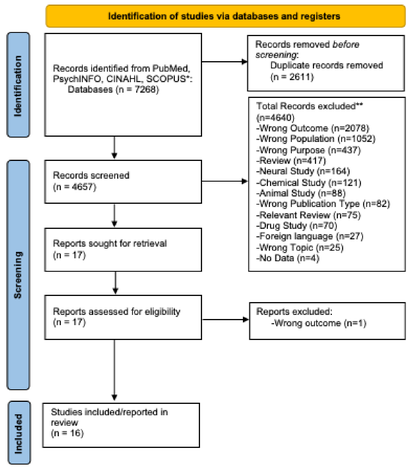
- 1 in every 6 children is diagnosed with developmental disabilities (DD).[1]
- Children with DD often display a variety of challenges that affect their social communication, cognitive, sensori-motor, and daily living skills. [2-3] Together, the diagnosis-related impairments of children with DD may become barriers to them engaging in physical activity (PA) leading to poor physical health. [4-5]
- There are also many social (caregiver/peer support) and environmental (e.g., lack of access to facilities nearby, high costs, or lack of transportation) factors which may become barriers for individuals with DD to access PA programs in the community.[4-5]
- We conducted a systematic review of the current literature, to evaluate qualitative survey and interview studies with stakeholders (including caregivers and self-advocates) reporting barriers and facilitators to PA engagement in individuals with DD including children with Autism Spectrum Disorder (ASD), Down Syndrome (DS), and Intellectual Disability (ID).
- A growing body of evidence indicates that there are many personal/individual and environmental/community-related barriers and facilitators to engaging in PA.[5]
- A systematic review conducted in 2017 focused on individuals with ID evaluated such barriers and facilitators and found that among personal factors poor health and lack of motivation to exercise were the most frequent barriers.[7] Among environmental factors, lack of financial support, limited number of PA options, and time constraints were top limiting factors to engage in PA. [5]
- In contrast, being rewarded, fun activities, and meaningful social interactions were the top facilitators to engaging in PA. [5]
- **Review Aim**: This systematic review aimed to examine the recent literature for various barriers and facilitators to engaging in PA for individuals with various DD using qualitative surveys and interviews with stakeholders (including caregivers and self-advocates).

HYPOTHESES

H1: Many personal, social, and environmental barriers and facilitators will be reported.
H2: We expect to have more reports from caregivers compared to self-advocates.

METHODS

- **Review Procedure:**
  - Abstracts were reviewed by all authors to determine eligibility for inclusion in the review and disagreements were resolved through consensus coding. Thereafter, 6 articles were coded by the first 3 authors to establish over 95% reliability on coding categories; all disagreements were resolved through discussions and consensus.
  - For risk of bias (ROB) assessment, a qualitative study review criteria of 17 points was established using the consolidated criteria for reporting qualitative research (COREQ)[6].



- **Inclusion/Exclusion Criteria**:
  - Peer-reviewed articles from 1901 to 2024. Articles whose title or abstract included words related to (i) studies examining barriers and facilitators to physical activity in populations including individuals with Autism Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD), Down Syndrome (DS), Neurodevelopmental disorders (NDD), Asperger Syndrome, Dyslexia, and Intellectual Disabilities (ID) and (ii) used qualitative methods such as surveys and interviews.
  - Data obtained per publication were tabulated in an excel sheet and converted into a tabular / color-coded format for visualization and reporting.

RESULTS

Table 1. Study Design Characteristics

Reference (Year)	Study Location	Data Collection Period	Data Collection Design	Theory/Framework	Data Analysis Method	Sampling Strategy	Inclusion/Exclusion Criteria (Y = Yes, N=No)
Summary			**SSI: 8; SQ: 2; MM: 4; FG: 2**	**SCT: 1; YPAPM: 1; DCP: 1; SEM: 1; TPB: 2; CV: 1; GT: 1; SDT: 2; PC: 1; OT: 1; EP: 1; PH: 1; PP: 2; NS:**	**DC: 6; IC: 7; TA: 5; DS: 1; QCA: 1; DA: 3; EA: 2**	**CRS: 9; CCS: 1; CVS: 8; SS: 1; PS: 4**	**Y: 12; N: 4**
Burk et al (2017)	NS	NS	SSI	SCT	DC	CRS	Y
Columna et al (2020)	NS	NS	SSI	NS	TA, DC	CCS	Y
Downs et al (2013)	Liverpool, UK	NS	SSI	YPAPM	IC, DC	CRS, CVS	Y
Folostina et al (2023)	Greece and Romania	2022	SQ	NS	DS	CVS	N
Grandisson et al (2012)	Quebec City, Canada	NS	MM	DCP	IC, QCA	CRS, CVS	Y
Hillier et al (2020)	Lowell, MA	NS	SQ	TPB	DA	CVS	N
Hudson et al (2017)	Middlesbrough, UK	NS	SSI	NS	IC, DC	CRS	Y
Colombo-Dougovito et al (2021)	US and UK	NS	SSI	CV, GT	TA, DA	CRS, CVS, SS	Y
Mitchell et al (2016)	Sweden	2018	SSI	TPB, SDT	TA, DA	CRS, CVS	N
Hansen et al (2023)	UC Irvine	NS	MM	PC	IC	CRS, CVS	N
Young et al (2016)	Scotland	NS	MM	NS	IC	CVS	Y
McDermott et al (2022)	Northern Ireland	2019-2020	FG	OT, EP	TA, DC	PS	Y
Stevens et al (2017)	Glasgow & South Lanarkshire, Scotland	NS	SSI	SDT, PH	DC	CRS, PS	Y
Taliaferro et al (2016)	West Virginia	NS	MM	SEM	TA	CRS, CVS	Y
Temple et al (2009)	Melbourne, Australia	NS	FG	PP	IC, EA	PS	Y
Temple et al (2008)	British Columbia, Canada	NS	SSI	PP	IC, EA	PS	Y

Data Collection Design: SSI = Semi-structured interview, SQ = Survey/questionnaire, MM = Mixed-methods, FG = Focus group **Theory/Framework:** SCT = Social Cognitive Theory, YPAPM = Youth Physical Activity Promotion Model, DCP = Disability Creation Process, SEM = Socioecological Model, TPB = Theory of Planned Behavior, CV = Constructivism, GT = Grounded Theory, SDT = Self Determination Theory, PC = Principal Component, OT = Ontology, EP = Epistemology, PH = Phenomenological, PP = Preceed/Proceed, NS = Not specified. **Data Analysis Method:** DC = Deductive coding, TA = Thematical analysis, IC = Inductive coding, DS = Descriptive statistics, QCA = Qualitative content analysis, DA = Descriptive analysis, EA = Editing analysis. **Sampling Strategy:** CRS = Criterion sampling, CCS = Critical case sampling, CVS = Convenience sampling, SS = Snowball sampling, PS = Purposive sampling.

Table 2: Sample Characteristics

Reference (year)	Final Sample Size	Mean age (SD); Range in years	Participant Diagnosis of	Role of Participant	Sex Distribution	Participants with Intellectual	Focus of study	Location of Data Collection	Method of Survey Distribution
Summary	8 to 125	5 to 75	ASD, DS, ID	**SA: 13, CG: 8, P:3**	**SA: 9M, 62F CG: 100M, 54F P 14M, 19F; CG > SA**	**ID: 11**	**PAH: 8 BF: 13 PAE: 8**	**F2F: 12 PH: 2 Z: 1**	**OL: 2 E: 1 M: 1**
Burk et al (2017)	18	NS(NS), 19-60	DS	SA	7M 11F	Y	PAH,BF,PAE	F2F	NA
Columna et al (2020)	9	10(2.60); 5-14	ASD	CG	9 M	NS	BF,PAE	PH	NA
Downs et al (2013)	8	16.38(5.04); 6-21	DS	SA,CG	SA: 3M 5F	NS	PAH,BF	F2F	NA
Folostina et al (2023)	NRomanian= 83, NGreek = 42	9.88(SD=3.56), 3-17 9.14(SD=2.88), 6-15	ASD	CG	CG Roman: 66M, 17F CG Greek: 34M, 8F	Y	NA	NA	NS
Grandisson et al (2012)	79	15.3(2); 12-19	ID	SA,CG,P	NS	Y	BF,PAE	F2F	NS
Hillier et al (2020)	30	22(NS); 18-27	ASD	SA	27M, 3F	NS	NA	NA	OL
Hudson et al (2017)	8	31(NS); 24-51	ID	SA	7M, 1F	Y	PAE	F2F	NA
Colombo-Dougovito et al (2021)	23	40.45(NS); 18-75	ASD	SA	12M, 11F	NS	PAH, BF,PAE	F2F, PH, Z	NA
Mitchell et al (2016)	17	NS(NS); 18-80	ID	SA	10M, 7F	Y	PAH, BF,PAE	F2F	NA
Hansen et al (2023)	12	NS(NS); 16-20	ID	SA	5M, 7F	Y	PAH,BF, PAE	F2F	NA
Young et al (2016)	13	Children: NS(NS), 0-14;	DS	CG	NS	NS	PAH,BF, PAE	F2F	F2F, OL
McDermott et al (2022)	28	NS	ID	SA,CG,P	SA: 5M, 2F; CG: 0M, 12F; P: 6M, 3F	Y	BF	F2F	NS
Stevens et al (2017)	10	17(.45); 16-18	ID	SA	7M, 3F	Y	BF, PAE, D	F2F	NS
Taliaferro and Hammond (2016)	12	SA: 23-38, CG: 40-70	ID	SA,CG	SA: 3M, 3F; CG: 0M, 6F	Y	PAH,BF	F2f, survey	E, M
Temple and Walkley (2009)	40	25(7.4); 18-41	ID	SA,CG,P	SA: 6M, 3F; CG: 1M, 6F; P: 8M, 16F	Y	BF	F2F	NS
Temple (2008)	13	34(8); 18-46	ID	SA	7M, 6F	Y	PAH,BF	NS	NS

Final Sample Size: ASD=Autism Spectrum Disorder, TD=Typically developing; **Participant Diagnosis:** ASD=Autism Spectrum Disorder, DS=Down Syndrome, ID=Intellectual Disability; **Role of Participant:** SA=Self advocate, CG=Caregiver, P=Provider/teacher **Participants of Interest with Intellectual Disability:** Y=Yes, NS=Not specified; **Focus of Study:** PAH=Physical activity habits, BF=Physical activity barriers/facilitators, PAE=Physical activity experiences/preferences, D=Dietary factors, Not applicable=NA; **Location of Data Collection:** F2F=Face to Face, PH=Phone, Z=Zoom, NA=Not applicable, NS=Not specified; **Method of Survey Distribution:** F2F: Face to Face, OL=Online link, E=Email, M=Mail, NA=Not applicable, NS=Not specified

Table 3: Methodological Rigor

Study Rigor Analysis for Qualitative Studies	Total = 17	LOC	DEF	THEO	DES	TEAM	SAMP	CRI	BIAS	PROC	SET	TIME	YR	QS.	CODE	THEM	TRI	NEG
Burk et al (2017)	14																	
Columna et al (2020)	13																	
Downs et al (2013)	13																	
Folostina et al (2023)	10																	
Grandisson et al (2012)	16																	
Hillier et al (2020)	11																	
Hudson et al (2017)	13																	
Colombo-Dougovito et al (2021)	14																	
Mitchell et al (2016)	14																	
Hansen et al (2023)	15																	
Young et al (2016)	13																	
McDermott et al (2022)	16																	
Stevens et al (2017)	12																	
Taliaferro and Hammond (2016)	15																	
Temple and Walkley (2009)	13																	
Temple (2008)	9																	

LOC=Study location specified, **DEF**=Defined research question, **THEO**=Defined qualitative research theory, **DES**=Appropriate qualitative research design, **TEAM**=Description of research team, **SAMP**=Defined total sample size, **CRI**=Defined inclusion/exclusion criteria, **BIAS**=Acknowledgement of researcher bias, **PROC**=Defined data collection process, **SET**=Defined study setting, **TIME**=Defined length of data collection sessions, **YR**=Defined data collection time frame, **QS**=Stated interview/survey questions, **CODE**=Defined coders, **THEM**=Defined theme development, **TRI**=Data triangulation, **NEG**=Defined negative/unual responses

Total score is shown as the sum of all the item. Study Transferability Rating: Low = <8, Medium = 9-12, High = >13, based on total score received for each qualitative study.

Table 4: Barriers & Facilitators to PA Engagement

(B)arriers & (F)acilitators to Physical Activity (PA)	Personal																Social										Environmental										
	IM		SE		KN		SM		SB		SA		ES		GS		TM		IND		PHY		BHV		FAM		FR		RM		PRG		PFS		JDG	
Type of factor	B	F	B	F	B	F	B	F	B	F	B	F	B	F	B	F	B	F	B	F	B	F	B	F	B	F	B	F	B	F	B	F	B	F	B	F	B	F
Studies reporting category as B/F	4	4	5	4	3	1	7	2	1	4	0	2	2	6	1	1	8	2	3	0	0	4	2	1	8	12	6	12	1	5	5	1	5	0	2	0	1	4
Total studies reporting as B/F	**8**		**9**		**4**		**9**		**5**		**2**		**8**		**2**		**10**		**3**		**4**		**3**		**20**		**18**		**6**		**6**		**5**		**2**		**5**	
Burk et al (2017)																																						
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Downs et al (2013)																																						
Folostina et al (2023)																																						
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Temple et al (2009)																																						
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(i) **Personal:** IM = Intrinsic motivation, SE = Self-efficacy, KN = Knowledge of existing PA programs, SM= Sensori-motor skills, SB = Sense of belonging, SA = Sense of achievement, ES = Enjoyment and satisfaction, GS = Goal setting, TM = Time management, PHY = Physical well-being, IND = Independence BHV = Behaviors; (ii) **Social:** FAM = Support of family/caregiver, FR = Support of friend, RM = Positive role models, PRG = Existing community programs, PFS = Professional support, JDG = Judgement from others; (iii) **Environmental:** FAC = Access to PA facilities, EQU = Access to PA equipment, CP = Access to PA programs, SAF = Safe environment for PA, WE = Weather, DIST = Proximity of PA location to home, TRS = Transportation, CO = Cost of PA

Top Barriers & Facilitators

	Personal	Social	Environmental
Main Barriers			
	Knowledge of existing PA programs	Existing Community Programs	Safe Environment for PA
	Sensori-motor / physical abilities		Weather
	Time Management		Transportation
			Cost of PA
Main Facilitators			
	Sense of Belonging	Support of Family/Caregiver	Access to PA facilities
	Sense of Achievement	Support of Friend	
	Enjoyment and satisfaction	Positive Role Models	
Other Factors (B/F)			
	Intrinsic Motivation		
	Self-Efficacy		

SUMMARY OF RESULTS

- **Study Characteristics:**
  - Semi-structured interviews were the main method of data collection, followed by mixed methods that included both interviews and surveys.
  - A wide variety of theories and frameworks were used.
  - Majority of included studies utilized criterion sampling to obtain their sample population.
- **Sample Characteristics:**
  - There is a wide distribution of sample sizes and age ranges represented in the studies.
  - The diagnoses included were ASD, DS, and ID.
  - About equal number of self-advocates (n=161) and caregivers (n=159) were sampled across all studies.
  - Study foci were evenly split between PA habits, PA barriers and facilitators, and PA experiences.
- **Methodological Rigor**
  - All included studies are of medium to high rigor for study transferability.
- **Barriers & Facilitators to PA Engagement in DD**
  - Personal: *Barriers* included Knowledge of existing programs, sensori-motor / physical abilities, time management. *Facilitators* included Sense of belonging, sense of achievement, enjoyment and satisfaction. *Both B&F* included intrinsic motivation and self-efficacy.
  - Social: *Main barrier was a* Lack of existing community PA programs. *Facilitators* included support of a family member/caregiver, friend, or a positive role model.
  - Environmental: *Barriers* included Safe environment for PA, weather changes, lack of transportation, and high cost of PA. *Main facilitator* included access to a PA facility/program.

CONCLUSIONS

- We identified several key barriers and facilitators to PA engagement in individuals with DD (i.e., ASD, DS, and ID).
- Multiple *barriers* in the personal (i.e., knowledge of existing programs, sensori-motor / physical abilities, time management), social (i.e., lack of existing community PA programs), and environmental (i.e., safe environment for PA, weather changes, lack of transportation, high cost of PA) domains were identified.
- Multiple *facilitators* in the personal (i.e., sense of belonging, sense of achievement, enjoyment and satisfaction), social (i.e., support of a family member/caregiver, friend, positive role model), and environmental (i.e., access to PA facility/program) domains were identified.
- Intrinsic motivation and self-efficacy were equally noted as *a barrier and a facilitator*.
- **Clinical/Community Implications:**
  - Clinicians should educate caregivers and self-advocates about the importance of PA.
  - Clinicians should develop and/or be involved in community PA programs that are inclusive and group-based that offer a sense of belonging, encouragement, and enjoyment.
  - Clinicians should advertise community resources on PA engagement to stakeholders.
  - PA facilities should be affordable, accessible, safe, sensory-friendly, and equipped with clear instructions/experts to support the needs of individuals with DD during PA activities.
- **Future Directions:**
  - We will be finishing the systematic review after including all papers obtained.
  - We will make recommendations to stakeholders based on our final review data.
  - We will utilize this information to develop a meaningful community PA program for individuals with DD.

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ACKNOWLEDGMENTS

- We thank UD DPT student, Hannah Starner, for her support in various steps of conducting this systematic review.
- AB, JR, and Dr. Bhat thank the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) scholars program for supporting their time on this project through a grant from the Maternal & Child Health Bureau (MCHB) of the Health Resources and Service Administration (HRSA) (DE LEND Program, PI: Beth Mineo).
- JC thanks the National Institutes of Health (NIH) for T32 funding (Grant #: T32HD007490, Predoctoral Training in Physical Therapy and Rehabilitation Research, Recipient: Corey; PI: Reisman).