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Systematic Review

A Scoping Review of the Barriers to Self-Advocacy for People with Intellectual Disability in Bronfenbrenner's Process–Person–Context–Time (PPCT) Model

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Abstract

Self-determination and self-advocacy are critical components of quality of life, and the instruction of these skills continues to emerge as an important outcome for Disabled people, specifically people with intellectual disability (ID). The purpose of this scoping review examined the perspectives of adults with ID and the experienced barriers when self-advocating, making choices, and goal setting. This scoping review searched multiple databases for empirical research, which collected the perspective of people with intellectual disability and what they identified as barriers to self-advocacy. Results included 30 articles with an international perspective available within the English language. The authors utilized Bronfenbrenner's process–person–context–time (PPCT) model to identify how these barriers are experienced in various relationships and environments and throughout time. The barriers identified fell into the various aspects of the PPCT model. Understanding these barriers provides insights into ways to begin to dismantle them, and this review details recommendations for research, policy, and practices.

Keywords: self-advocacy; intellectual disabilities; collaboration; self-determination; scoping review

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1. Introduction

Self-advocacy, or the ability to articulate one's wants, needs, or goals, is essential to building confidence to speak up (Chong et al., 2024), fostering self-worth and pride (I. Smith & Mueller, 2022), increasing engagement for themselves and in the community (Chong et al., 2024; I. Smith & Mueller, 2022), and improving quality of life (Kober, 2010; Schalock et al., 2005; Wehmeyer, 2020). While self-advocacy is important for all individuals across the lifespan, it is especially important for Disabled people, as their self-advocacy efforts are often dismissed (Chong et al., 2024; I. Smith & Mueller, 2022). The authors use identity-first language, or naming the identity of the person first (i.e., Disabled), when globally referring to Disabled people, as well as person-first language, or placing a person before a disability descriptor, when referring to individuals with intellectual disability (ID), as this population advocated for this terminology to acknowledge their personhood (Grech

et al., 2023). The authors used both identity-first language and person-first language to honor and acknowledge the Disability community and speak to the unique needs of people with ID.

The prevalence of eugenics ideology throughout the world in the beginning of the 20th century oppressed Disabled people, questioning their rights as humans (Rembis et al., 2018). Social institutions have long implemented policies and practices that historically marginalize the Disabled population through exclusion from education, participation in their community, access to human rights, and even criminalization of the existence of Disabled people (Heumann & Joiner, 2020; Nielsen, 2012; Schweik, 2009; Rembis et al., 2018). During the disability rights movement, powerful Disabled advocates, such as Judy Heumann, Ed Roberts, and Brad Lomax called out injustices and reformed laws to create greater inclusivity and access to basic human rights (Heumann & Joiner, 2020; Nielsen, 2012). The work of Disabled advocates helped to dismantle discriminatory laws and practices and implemented more inclusive policies, such as Section 504 of the Rehabilitation Act, the Individuals with Disabilities Education Act, and the Americans with Disabilities Act in the United States (Heumann & Joiner, 2020; Nielsen, 2012). The United Nations Educational, Scientific, and Cultural Organization (UNESCO), the Spanish government, and the delegates of the World Conference on Special Need Education presented the Salamanca Statement (UNESCO, 1994) urging nations across the world to provide an education to all children, youth, and adults with disabilities. Additionally, the United Nation's Convention on the Rights of Persons with Disabilities (UNCRPD) (UNCRPD, 2016) established a set of principles as an international human rights treaty to advance the respect, dignity, and equality for Disabled people through honoring Disabled people's many identities, their autonomy, and greater inclusion in society. Although legal advancements and more inclusive access and protections exist in nations across the world, ableist ideologies are woven into the fabric of societies, which stymies self-advocacy and socially just opportunities for Disabled people (Nario-Redmond, 2019; Nielsen, 2012; Rembis et al., 2018).

Ableism, or "ideas, practices, institutions, and social relations that presume able-bodiedness, and by doing so, construct persons with disabilities as marginalized, oppressed, and largely invisible 'others'" (Chouinard, 1997, p. 380), negatively impacts Disabled people socially, emotionally, educationally, economically, and physically (Chouinard, 1997; Nario-Redmond, 2019). Further, ableist ideologies within education limit graduation and diploma attainment for Disabled students, thereby compromising future opportunities of seeking advanced education or employment (Nario-Redmond, 2019). Additionally, ableism fosters paternalistic behaviors, with non-disabled people making decisions for Disabled people before because they 'know best' (Chouinard, 1997; Nario-Redmond, 2019). Although ableism is the foundation for systemic oppression of Disabled people, people with intellectual disability ("a lifelong condition where significant limitations in both intellectual functioning and adaptive behavior emerge during the developmental period"; [The Arc, 2019, para 1]) are the among individuals who are especially impacted by ableism due to the historical marginalization resulting from institutionalization, eugenics, medical model discourses causing low expectations for people with intellectual disabilities (ID), and individualistic ideologies (Gappmayer, 2021; Kober, 2010; Schalock et al., 2005). One way to combat the pervasive negative impact of ableism, however, is by teaching and honoring self-advocacy.

1.1. Rationale

There is a growing body of research reporting the effectiveness of interventions on developing self-advocacy skills among Disabled students in US education systems (Alsaeed et al., 2023; Lee et al., 2015; Raley et al., 2018; Wehmeyer, 2020). Additionally, through the

implementation of principles of UNCRPD, international education focuses on the development of self-determination skills in Disabled people (Burke et al., 2024). Despite these interventions, Disabled people—especially people with ID—are less likely to have desirable outcomes including (a) engaging in shared/support decision making (Bigby et al., 2021), (b) employment (Avellone et al., 2021), (c) independent living (Zambri et al., 2023), and overall quality of life (Kober, 2010; Schalock et al., 2005; Wehmeyer, 2020). Research documents several barriers that prevent actualization of self-advocacy leading to a high quality of life for individuals with ID, including (a) lack of knowledge and skills to self-advocate (Test et al., 2005; Shogren et al., 2017), (b) lack of opportunity for decision making or communicate their wants or needs (Shogren & Raley, 2022), (c) limited power to enact decisions due to guardianship over the person with ID (Shogren & Raley, 2022), (d) difficulty communicating (Shogren et al., 2017), and (e) low expectations (Shogren et al., 2017). Commonly cited research on barriers to self-advocacy are centered on the limitations of individuals with ID, problematizing the very nature of a Disabled individual's existence, as opposed to ableist systems and structures that limit self-advocacy (Gappmayer, 2021). Further, commonly cited research on barriers to self-advocacy are largely from the perspectives of professionals (e.g., teachers, service providers in adult services [Shogren et al., 2017]) or parents, families, or caregivers of individuals ID (Shogren et al., 2017; Shogren & Raley, 2022), as opposed to the person most impacted by barriers to self-advocacy—individuals with ID themselves. This practice not only reinforces ableist structures and practices through epistemicide, which Patin et al. (2020) defines as, "the killing, silencing, annihilation, or devaluing of a knowledge system" (p. 2) but also compromises the social validity and effectiveness of efforts to increase self-advocacy.

1.2. Objectives

Learning about barriers to self-advocacy from the perspectives of individuals with ID can inform meaningful approaches to self-advocacy resulting in a high quality of life by addressing underlying issues that undermine self-advocacy among this population. Given that research supports self-advocacy instruction and intervention, people with ID continue to not be heard. The objective of this scoping review was to understand barriers identified by people with ID across the globe and understand how people with ID experience these barriers through the process–person–context–time model of human development to inform future research, practices, and policies that are moving in the direction of justice and inclusiveness.

2. Conceptual Framework

We used Bronfenbrenner's (2005) process–person–context–time (PPCT) model of human development, which provides a way to understand how reciprocal bioecological contexts influence human development over time (Bronfenbrenner, 2005; Bronfenbrenner & Morris, 2007; Xia et al., 2020). The PPCT model centers a person, including their personality traits, biopsychosocial characteristics such as any disabilities, genetic factors, physical appearance, or feeling emotions such as depression or happiness, within five contextual systems: the micro, meso, exo, macro, and chronosystems. The research team selected the PPCT model to analyze the barriers described because the PPCT model goes beyond locating the barriers within various contextual environments. The PPCT model considers the interaction among a person's characteristics, relationships, and interactions within the microsystem, the context, and the impact of time (Xia et al., 2020). The microsystem involves environments and individuals in which the person interacts immediately (e.g., parents, siblings, teachers, neighborhood). Further, the PPCT model highlights the proximal processes that occur between microsystem factors and the person at the center of the model through "progressively more complex reciprocal interactions" (Bronfenbrenner &

Morris, 1998, p. 996). The mesosystem involves interactions that occur among microsystem structures (e.g., home/school, work/community). The exosystem involves structures that indirectly influence the person at the center of the model (e.g., school board, work or service agency policies, state and federal laws). The macrosystem involves societal belief systems and ideologies (e.g., ableism, paternalism, racism, beauty). Finally, the chronosystem involves the impact of time and changes over time on human development (e.g., life transitions, changes in environments over time, historical events). Proximal processes, the last element of the PPCT model, involves the "progressively more complex reciprocal interaction between an active, evolving biopsychological human organism and the persons, objects, and symbols in its immediate external environment" (Bronfenbrenner & Morris, 1998, p. 996). When considering barriers to self-advocacy, understanding where barriers occur within bioecological systems can aid in developing meaningful approaches to addressing barriers across structures.

Bronfenbrenner and Morris (2007) discussed the importance of biological factors such as genetic factors, illness, brain function, and affect when considering the person engages with their environment. This scoping review also utilizes intersectionality to examine the many identities people have, including race, gender, sexual orientation, ability, sex, class, neurotype, etc., and how these identities intersect with one another causing overlapping systemic and institutional oppression (Collins, 2019; Crenshaw, 1991). Collins (2019) states that an intersectional lens examines how identities relate to power and privilege within the systems people access. Using intersectionality as an analytical tool presents critical action for a more socially just world.

3. Methods

The purpose of this scoping review was to understand what is known about the barriers to self-advocacy from the perspective of people with ID and map the existing knowledge to better understand the complexity of these barriers. The author team employed a scoping review approach to explore the breadth and depth of evidence surrounding barriers to self-advocacy (Munn et al., 2018). Using the JBI Manual for Evidence Synthesis (Peters et al., 2020), researchers engaged in the following steps: (1) identify the research questions, (2) identify relevant studies, (3) study selection, (4) assessing the data, (5) summarizing and reporting the data, and (6) presenting the results. Reporting followed the PRISMA-ScR guidelines (Tricco et al., 2018); the completed checklist is provided in Supplementary File S1.

3.1. Inclusionary and Exclusionary Criteria

3.1.1. Types of Participants

The articles reported the perspectives of people with intellectual disability, including Intellectual Disability (ID) (or 'Learning Disability,' the phrase used for Intellectual Disability in the UK), and common co-occurring developmental disabilities or associated syndromes such as Autism, Fragile X, Down Syndrome, and Rett Syndrome. Participants included those aged 14 years or older (the age at which high school typically starts as well as transition planning for adult life). Exclusionary criteria included participants with acquired disabilities after the age of 18 years of age, such as a traumatic brain injury, articles that did not state or disaggregate disability, and studies that included participants with disabilities other than ID.

3.1.2. Concepts

The overarching concept of this article is the barriers to self-advocacy; therefore, the articles must report barriers, challenges, obstacles, or factors to self-advocacy. The authors

used Test and colleagues' (Test et al., 2005) conceptual framework for self-advocacy to define the key constructs of self-advocacy as (a) knowledge of self (i.e., knowing strengths, goals, preferences, needs, responsibilities), (b) knowledge of rights (i.e., personal, community, legal, educational, human rights), (c) communication (i.e., body language, listening, form of communication, assertiveness), and (d) leadership (i.e., advocating for self and others, action, knowledge of resources).

3.1.3. Context

Given that the purpose of this scoping review is open to discovering the knowledge related to the barriers to self-advocacy, the articles could be from any geographic location. The articles must be written in English (the researchers were monolingual). The researchers did not apply any other limitations or boundaries on the dates of publications.

3.1.4. Types of Evidence Sources

Inclusionary criteria included peer-reviewed empirical research studies that include specific information about participant disability and age. The research team also included dissertations retrieved from ProQuest. The research team did not include inaccessible full text or policy briefs. The team also excluded literature reviews as secondary research. Further, research that utilized proxy reports was also not included.

3.2. Search Strategy

In collaboration with the social sciences research librarian from George Mason University, the team conducted searches in Proquest, EBSCO, PubMed, and Web of Science to gather research across various disciplines (e.g., education, psychology, medicine). The EBSCO database search also included other databases within its search including APA, Cinahl, ERIC, Education Complete, Medline, Psychology and Behavioral Sciences, and these databases fall under the EBSCO heading within the PRISMA chart. The following Boolean phrases, informed by Test et al.'s conceptual framework (Test et al., 2005), were used in each search: ("mental retardation" or "intellectual disabilit*" or "developmental disabilit*" or "developmental delay*" or IDD or syndrome* or autism) AND ("self advocacy" or "self advocat*" or "self determination" or "self efficacy" or "decision mak*" or autonomy) AND (barrier* or obstacle* or challenge* or factor*) AND (adult* or teen* or "high school*" or "college student*" or "postsecondary age"). The search occurred on 5 March 2025. Hand searches were not conducted as a part of the search strategy given the range of databases covering topics across disciplines to consider self-advocacy completed throughout a person's life.

3.3. Screening, Selection, and Data Extraction

The researchers imported search findings into Covidence (2024), a web-based software program to complete a systematic review of the literature. The review protocol was developed in Covidence, and it was not registered. The first author trained all the researchers on the scoping review and inclusionary and exclusionary criteria. The research team met weekly throughout the course of the scoping review. All nine researchers screened titles and abstracts, followed by full-text review using inclusionary and exclusionary criteria for data extraction. If two members of the research team did not align at each stage of the review process, conflicts were resolved by a third member of the team. Reconciliation of these conflicts occurred at our weekly meetings. Title/abstract screening was conducted independently with consensus resolution among the team. We did not calculate inter-rater reliability. However, through a collaborative process, 100% agreement was achieved by at least two members of the team.

Through Covidence, each of the first five authors of this review utilized a review protocol and completed a data extraction of the following components: (a) method of research, (b) participant information, (c) barriers identified, and (d) bioecological factors. Data-extraction occurred individually at first, and then collectively until the team reached full consensus. We did not monitor or formally calculate the inter-rater reliability with formal statistics because we achieved 100% consensus after each data extraction among the first five authors as a research collective.

Table 1 shows the codebook definitions used by the research team for consistency during the extraction stage. After the identification of all the articles, the first author identified all the barriers from the perspective of people with ID within the article. The first and second authors reviewed the barriers identified and applied the concepts of the PPCT model to identify the bioecological factors. The authors coded each barrier with a component of the PPCT model (which often involved studies including more barriers across two more portions of the PPCT model). Through an iterative process, the authors ensured the understanding of the contextual information surrounding the barriers to best identify the PPCT component. When conflicts occurred, the first and second authors went back to the original article and consulted the primary article to best determine the PPCT component. We did not compute a formal reliability coefficient for PPCT coding; however, through this iterative process and consultation with the original article, at least two members of the research team reached a 100% agreement.

Table 1. This table shows the codebook used by the research team during extraction.

Factors	Definitions	Salient Example
Individual Factors	Factors related to Disabled individual(s) (e.g., characteristics, identities, abilities) that participants with ID identify as a barrier to self-advocacy.	Social skills, emotional and behavioral regulation, or anxiety management at work prohibited a person with ID from being their full authentic selves at work (Sinclair et al., 2024)
Microsystem Factors	Factors related to structures that come into ongoing, direct contact with Disabled individuals (e.g., family, neighbors, coworkers, classmates, direct support providers) that participants with ID identify as a barrier to self-advocacy. For the purposes of this study, the researchers organized proximal processes, or interactions between a Disabled individual and microsystem structures that participants with ID identify as a barrier to self-advocacy within the microsystem.	"...we have to wait [to attend activities] because our parents tell us "we'll see if you can go or not'" (Callus et al., 2019, p. 353)
Mesosystem Factors	Interactions (or the absence of interactions) between/among microsystem structures (e.g., family members, families, and direct support providers) that participants with ID identify as a barrier to self-advocacy.	Doctors directing questions to caregiver accompanying individual with ID during appointments (Iriarte et al., 2014)
Exosystem Factors	Factors/structures that indirectly interact/impact or individuals with disabilities (e.g., laws, school system, organizational policies and practices, community) that participants with ID identify as a barrier to self-advocacy.	People with ID are under-represented in the media (Björnsdóttir & Johannesson, 2009)
Macrosystem Factors	Overarching factors related to societal views, beliefs, or values (e.g., stigma, biases, valorized identities) that participants with ID identify as a barrier to self-advocacy.	"People [in general] might think we are slow because we have a disability" (Carbone, 2016, p. 108)
Chronosystem Factors	The influence of time, timing, and life events (e.g., transitions, social movements, age and aging) that participants with ID identify as a barrier to self-advocacy.	Aging and decline of parents and caregivers (Strnadová & Evans, 2015)

4. Results

The database search yielded 23,379 articles after duplicates were removed. A review of titles and abstracts resulted in 195 studies to be reviewed for full text. During the full text review, 30 articles met the inclusionary criteria. Figure 1 provides a PRISMA flow diagram outlining the review process.

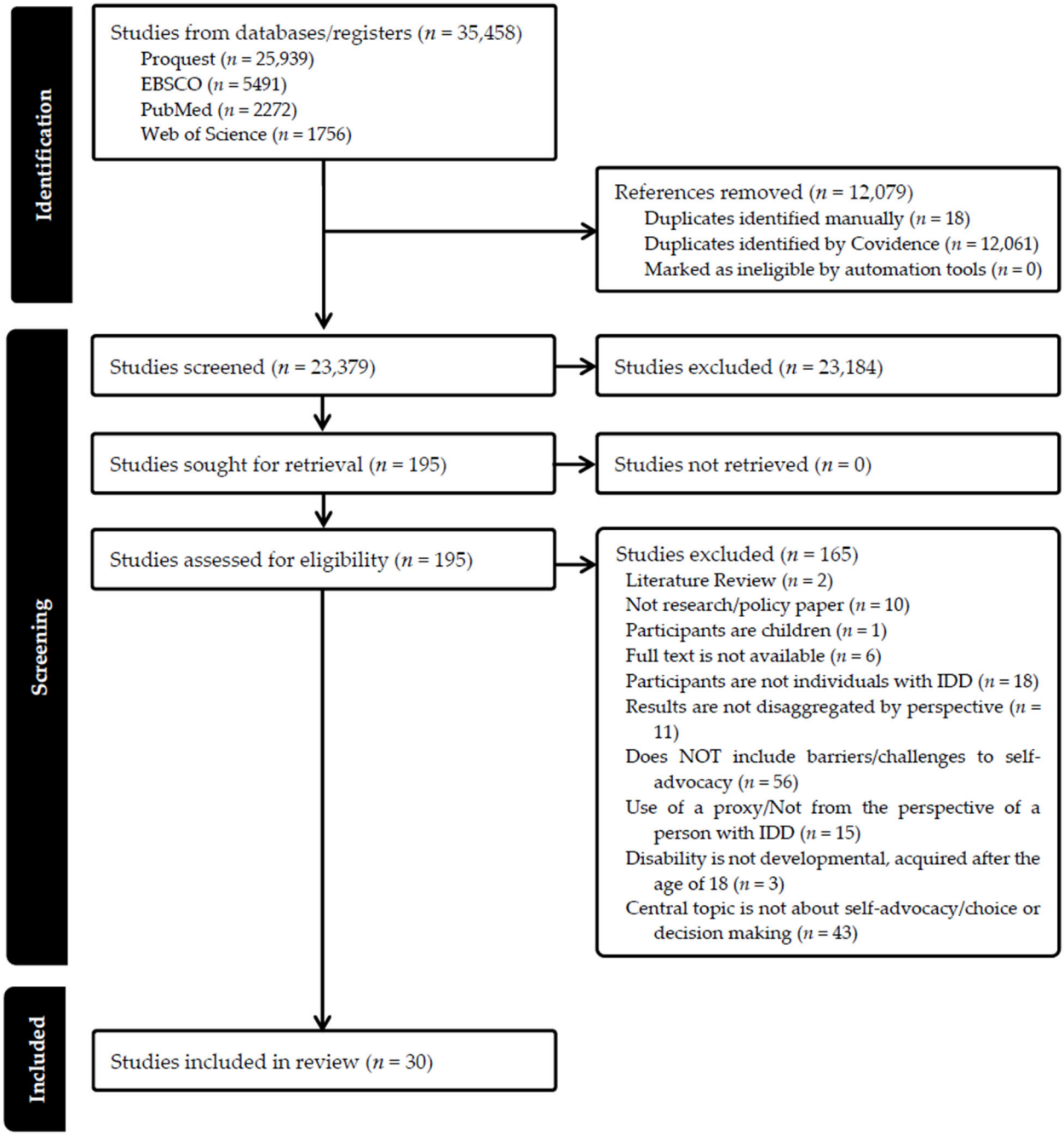


Figure 1. This PRISMA Flow Diagram shows the various stages of this scoping review, and the number of studies retained at each stage.

4.1. Study Samples and Methodological Approaches

Table 2 provides study locations, methodologies, and self-advocacy related topics under investigation. Studies were conducted in 13 countries (inclusive of two studies conducted in multiple countries). Of the 30 articles reviewed, the (n = 28) employed qualitative methods, and, of these 28 studies, about 28%, (n = 8) implemented participatory

methods or approaches. One study utilized survey and qualitative methods, and one study employed a mixed method case study.

Table 2. This table displays study location, methodology, and study topic for included studies.

Reference	Location (Setting)	Methodology (Sample Size)	Topic Under Investigation
1. Azzopardi-Lane and Callus (2014)	Malta (community based self-advocacy group)	Qualitative methods utilizing participatory research methods (n = 40)	Sexuality and relationships
2. Bellon et al. (2025)	Australia (community based self-advocacy group)	Mixed method case study (n = 27)	Social engagement and inclusion
3. Björnsdóttir and Johannesson (2009)	Iceland (community)	Qualitative (n = 6)	Discursive themes of self-advocacy
4. Callus et al. (2019)	Malta (community)	Qualitative (n = 15 in Phase 1; n = 12 in Phase 2)	Overprotection by parents
5. Carbone (2016)	US (agency served)	Qualitative (n = 8)	Self-determination experiences within services
6. Chapman et al. (2011)	England (self-advocacy group)	Qualitative methods utilizing participatory research methods (n = 17)	Understanding of advocacy
7. Curryer et al. (2018)	Australia (community)	Qualitative (n = 8)	Choice and control of the family
8. Dew et al. (2019)	Australia (community)	Qualitative (n = 26)	Planning for people with complex support needs
9. Groves et al. (2017)	England (community)	Qualitative (n = 8)	Identity
10. Hughes (2024)	US (community)	Qualitative methods utilizing participatory research methods (n = 23)	Gender and sexual identity and self-determination
11. Iriarte et al. (2014)	Ireland (community)	Qualitative methods utilizing participatory research methods (n = 168)	Everyday decision-making
12. Li et al. (2024)	Taiwan (community)	Qualitative (n = 10)	Self-determination
13. Miller et al. (2022)	US (members of a national self-advocacy board)	Qualitative methods utilizing participatory research methods (n = 12)	Conceptualization of self-advocacy
14. Mogensen et al. (2024)	Australia (adults who just exited school)	Survey and Qualitative (n = 27)	Transitioning to adulthood
15. Nonnemacher and Bambara (2011)	US (self-advocacy group)	Qualitative (n = 10)	Self-determination with staff
16. Parchomiuk et al. (2025)	Poland (community)	Qualitative methods utilizing participatory research methods (n = 23)	Environmental challenges and self-determination
17. Petner-Arrey and Copeland (2015)	US (community)	Qualitative (n = 10)	Autonomy in support relationships
18. Potvin et al. (2019)	Canada (community)	Qualitative (n = 13)	Annual health examinations
19. Pouls et al. (2024)	Netherlands (community)	Qualitative (n = 11)	Primary care access

Table 2. *Cont.*

Reference	Location (Setting)	Methodology (Sample Size)	Topic Under Investigation
20. Puyaltó and Pallisera (2020)	Spain (community)	Qualitative (n = 22)	Barriers and support to exercising rights
21. Ruef and Turnbull (2002)	US (community)	Qualitative (n = 11)	Behavioral challenges
22. Scott et al. (2014)	Australia (community)	Qualitative (n = 12)	Social engagement and inclusion
23. Shogren and Broussard (2011)	US (self-advocacy conference)	Qualitative (n = 17)	Self-determination
24. Sinclair et al. (2024)	US (community)	Qualitative (n = 18)	Self-determination and employment
25. E. M. Smith et al. (2024)	Australia (community)	Qualitative methods utilizing participatory research methods (n = 8)	Gender and Sexual identity and self-determination
26. Strnadová and Evans (2015)	Australia and Czech Republic (community)	Quantitative (n = 55)	Autonomy
27. Strnadová (2019)	Australia (community)	Qualitative (n = 17)	Transition of elderly
28. Vaucher et al. (2020)	Switzerland (residential settings)	Qualitative methods utilizing participatory research methods (n = 10)	Self-determination in residential settings
29. Wass et al. (2021)	Norway (employment support center)	Qualitative (n = 9)	Employment
30. Witwer et al. (2025)	US and Canada (focus groups)	Qualitative (n = 13)	Mental health and psychotherapy

Note. The term "community" indicates that the research was completed in the community, as opposed to a specific location (e.g., school).

Participant Information

Of the 30 studies, 19 studies reported participants with intellectual disability only (#1, #2, #3, #4, #7, #9, #11, #14, #15, #16, #17, #19, #20, #23, #25, #26, #27, #28, #29). Nine studies reported participants had intellectual disability and developmental disabilities or other co-cooccurring disabilities (#5, #8, #10, #12, #13, #18, #21, #24, #30). One study used the UK's term "learning disability" for intellectual disability (#6). One study used the term "Down Syndrome" to describe participants' disability (#22). Of the 30 studies, 19 reported dichotomous participant gender demographics (#1, #4, #6, #7, #9, #11, #14, #16, #17, #18, #19, #20, #22, #23, #24, #26, #27, #29, #30) and only three studies (10%) reported diverse gender identities (e.g., used gender-expansive terminology; #10, #13, #25). These three studies were the only ones who investigated intersections between demographics (i.e., race, gender, sexuality). Thirteen studies reported the places in which participants lived (i.e., at home with family, independent, group home, supported (#4, #6, #7, #9, #11, #15, #16, #17, #20, #21, #22, #25, #30). Only 8 studies (26.6%) reported race demographics (#6, #8, #10, #13, #21, #23, #24, #30). Ten studies reported the services participants accessed (i.e., day programs, Medicaid waiver services [#1, #5, #6, #12, #13, #14, #17, #23, #25, #27]). Two studies identified that the participants were active in a self-advocacy group (#2, #13), and one study identified if the participants were engaged in social activities (#3). Eight studies identified co-occurring neurodevelopmental disorders and/or mental health conditions (e.g., ADHD, anxiety, bipolar; [#8, #10, #12, #13, #18, #21, #24, #30]). Regarding age, five articles identified the age of the participants as 18 and older (#2, #10, #11, #17, #25). Five articles reported young adults within the range of 18–40, (#3, #14, #22, #24, #30). Ten articles

considered middle age between a participant's 20s to 50s (#1, #4, #7, #9, #12, #13, #20, #21, #28, #29). Three articles had participants with age of participants including a range of 18–70 (#6, #8, #16). Two articles had participants with an age range of 40–80 (#26, #27). Five articles had participants whose age ranged from 22 to 65 years old (#5, #15, #18, #19, #23).

4.2. Barriers Identified Within PPCT Model

4.2.1. Person

Table 3 displays the 11 articles identified barriers involving the person with ID (#7, #9, #18, #19, #20, #21, #22, #23, #24, #25, #28). Examples of barriers within this level are self-imposed limits to decision-making due to their capacity for independent decision-making (#7), a desire to be 'normal' (#9), communication challenges such as difficulty talking about abuse or speaking when others are upset (#9, #21), needing assistance to complete tasks (e.g., scheduling an appointment, attaining transportation, navigating complex systems such as insurance or social services [#18]), recognizing or assessing their own health concerns (#19), not feeling prepared for living or working independently (#20 #22), not having the social, emotional, or self-regulation skills to manage anxiety or fear (#25, #28), not knowing how to achieve goals/dreams (#23), sensory needs (e.g., noise aversion [#21]), hearing, speech, or physical limitations (#24), and poverty (#22).

Table 3. This table displays PPCT Model components represented across studies.

	PPCT Model					
Reference	**Person**	**Micro [1]**	**Meso [2]**	**Exo [3]**	**Macro [4]**	**Chrono [5]**
1. Azzopardi-Lane and Callus (2014)		X		X	X	
2. Bellon et al. (2025)		X		X	X	
3. Björnsdóttir and Johannesson (2009)			X	X	X	
4. Callus et al. (2019)		X		X	X	
5. Carbone (2016)		X		X	X	X
6. Chapman et al. (2011)		X		X		
7. Curryer et al. (2018)	X	X				
8. Dew et al. (2019)		X		X		
9. Groves et al. (2017)	X	X		X	X	
10. Hughes (2024)		X		X	X	
11. Iriarte et al. (2014)		X	X	X	X	
12. Li et al. (2024)		X		X	X	
13. Miller et al. (2022)		X		X	X	
14. Mogensen et al. (2024)		X		X		
15. Nonnemacher and Bambara (2011)				X		
16. Parchomiuk et al. (2025)		X		X	X	
17. Petner-Arrey and Copeland (2015)		X		X		
18. Potvin et al. (2019)	X			X		
19. Pouls et al. (2024)	X			X		
20. Puyaltó and Pallisera (2020)	X	X		X		X
21. Ruef and Turnbull (2002)	X	X		X		
22. Scott et al. (2014)	X	X		X		
23. Shogren and Broussard (2011)	X	X		X		
24. Sinclair et al. (2024)	X			X		

Table 3. *Cont.*

	PPCT Model					
Reference	**Person**	**Micro [1]**	**Meso [2]**	**Exo [3]**	**Macro [4]**	**Chrono [5]**
25. E. M. Smith et al. (2024)	X	X		X	X	
26. Strnadová and Evans (2015)		X		X	X	X
27. Strnadová (2019)		X		X		
28. Vaucher et al. (2020)	X	X		X		
29. Wass et al. (2021)		X		X		
30. Witwer et al. (2025)		X		X		
Total *n*=	11	25	2	29	13	3

Note. This table states barriers within each component of the PPCT model. [1] = microsystem, [2] = mesosystem, [3] = exosystem, [4] = macrosystem, [5] = chronosystem.

4.2.2. Microsystem

As demonstrated in Table 3, 25 studies identified barriers within the microsystem (#1, #2, #4, #5, #6, #7, #8, #9, #10, #11, #12, #13, #14, #16, #17, #20, #21, #22, #23, #25, #26, #27, #28, #29, #30). Notably, only one study, #14, referenced teachers as part of a microsystem barrier—the rest universally referenced family members (e.g., parents, siblings) and direct support providers (e.g., residential support staff). Fifteen studies reported barriers related to the constrainment of decision-making regarding social engagement, employment, finances, living arrangements, and sexuality and relationships and assuming authority (#1, #2, #4, #5, #6, #7, #8, #10, #11, #12, #14, #16, #17, #26, #29). Similarly, three studies indicated that families or direct service providers required participants with ID to seek permission to make daily decisions or to engage in relationships (#9, #12, #29). In addition, two studies reported barriers related to a reliance on families for financial and logistical support such as transportation (#1, #21) and five studies described family and direct service provider overprotection such as unnecessary over-assistance and not allowing participants with ID or make decisions that they perceive as incorrect or risky which led to tension and dependence (#1, #8, #17, #23, #28). Four studies expanded on the ways in which conflict with family members or direct service providers (e.g., controlling siblings, disagreeing with rules) diminished opportunities for self-advocacy (#7, #11, #12, #22).

Seven studies focused on barriers in education, including families and service providers limiting education about adult concepts such as financial planning, health literacy, sexuality, transportation (#1, #9, #10, #14, #16, #17, #26). Studies also reported families or direct service providers not supporting advocacy (#13), dismissing or limiting self-advocacy efforts that they perceived disruptive to routines or expected behaviors (#2, #11, #16), and ignoring self-advocacy efforts (#2, #11, #12, #16, #21, #29, #30) or gender and sexuality identities (#10, #25). Additional barriers within the microsystem included low expectations among family and direct service providers, such as: (a) assuming there is no need to include people with ID in meetings about their future (#2, #4, #29), (b) assuming people with ID are incapable of choice-making (#2), and (c) not believing people with ID can achieve their goals and dreams (#23). In addition, misaligned desires/decisions among family members or direct service providers and the person with ID (#7, #11, #12, #22) and bullying by peers, family, or direct service providers (#5, #22, #23, #26) as barriers to self-advocacy.

These studies reflected proximal processes occurring within microsystem structures. For example, the act of family members or direct service providers preventing a person with ID to make financial decisions or health decisions disallowed them from self-advocating and completing tasks independently (#2, #4, #8, #12, #13, #14, #16, #17, #23, #29). Likewise, participants with ID indicated that family members or direct service providers ignored or

silenced their advocacy efforts (#2, #11, #12, #16, #21, #29, #30) or made decisions for the person with ID (#7, #9, #14, #20, #27, #29, #30).

4.2.3. Mesosystem

The mesosystem refers to interactions between two or more microsystem structures (Bronfenbrenner, 2005; Bronfenbrenner & Morris, 2007; Tudge et al., 2022). There were two articles (n = 2) that identified barriers falling within the mesosystem (#3, #11). These studies identified barriers where the individual with ID was ignored or undervalued while the community person (i.e., doctor or news reporter) addressed the non-disabled person or caregiver accompanying the person with ID.

4.2.4. Exosystem

Twenty-nine studies identified barriers within the exosystem (#1, #2, #3, #4, #5, #6, #8, #9, #10, #11, #12, #13, #14, #15, #16, #17, #18, #19, #20, #21, #22, #23, #24, #25, #26, #27, #28, #29, #30) (See Table 3). Identified barriers focused on structural constraints such as organizational culture, hierarchies, and policies impacting people with ID including: (a) systemic issues such as staff turnover among service providers (#2, #6, #14, #16, #17, #20, #28), (b) a lack of familiarity or knowledge about the participant among staff due to ineffective policies (#5, #6), (c) inaccessible or unavailable organization staff (#15, #20, #29, #30), (d) policies that block or disregard voices of people with ID (#9, #11), and (e) a lack of resources (#15, #16, #23). Participants with ID were also limited by (a) services that were planned around the service organization, rather than being person-centered and led by individuals with ID (#2, #5, #6, #9, #12, #25) and practices and policies that infringed on personal freedoms such as making decisions about relationships, living spaces, or activities (#1, #13, #17, #21). Six studies also reported systemic financial barriers due to not being paid enough through Social Security Income (#11, #15) and limited employment opportunities (#4, #22, #24, #29). Individuals with ID also reported barriers within the healthcare system, including negative interactions with healthcare providers (#18, #19, #30), lack of approachability from providers and feeling rushed during appointments (#18, #19), lack of accommodations (#19, #30), and difficulty navigating the healthcare system (#18, #19, #30). Eleven studies reported barriers related to feeling isolated or excluded by policies, practices, or outward discrimination by structures such as community employers, group homes, and social settings such as LGBT+ affinity groups (#3, #8, #9, #10, #13, #15, #16, #21, #26, #27, #28).

4.2.5. Macrosystem

Table 3 shows the 13 studies that included barriers within the macrosystem (#1, #2, #3, #4, #5, #9, #10 #11, #12, #13, #16, #25, #26). Thirteen studies identified ableism and discrimination (#1, #2, #3, #4, #5, #9, #10, #11, #12, #13 #16, #25, #26) as negatively impacting participants. For example, participants in study #3 described the implications of "battling disability" to advocate (p. 440), and participants in study #4 described the stigma associated with being in the community with other people with disabilities. Similarly, three studies reported additional discriminatory practices based on their race or sexuality, including being perceived as dangerous or deviant as a Black male with ID (#10, #13). Participants with ID further described how overarching ableism and stigma associated with disability and other historically marginalized identities (e.g., minoritized races, sexualities) contributed to low income and employment opportunities (#16), families and service providers maintaining low expectations and denying rights (#12, #16), and the lack of consideration of the needs and perspectives of individuals with ID within service systems (#11).

4.2.6. Chronosystem

Table 4 shows three studies that identified barriers in the chronosystem (#5, #20, #26). Barriers identified within this system included a decline of natural support as parents age (#5), as well as participants' social networks (e.g., school, sports, leisure, employment) declining over time (#20). Additionally, #26 identified that participant aging impacted health and independence over time.

Table 4. This table includes the different barriers identified in the studies in categories and subcategories. It also includes the number of studies referenced.

PPCT Model	Subcategory	Barriers [1]	References	No. Studies Referenced
Person	Internalized ableism	Self-imposed limitations of choice and control	#7	*n* = 1
		A desire to be normal	#9	*n* = 1
	Communication	Difficulty expressing or sharing information	#9, #21	*n* = 2
	Healthcare	Assistance needed to communicate Disability-related barriers to getting to healthcare appointments	#18	*n* = 1
		Recognizing and assessing mental health needs	#19	*n* = 1
	Independent living	Unprepared to live independently	#20, #23	*n* = 2
	Employment	Limited work experiences	#22	*n* = 1
		Disability-related needs and challenges Gaps in skill employment-related skills	#24	*n* = 1
	Goal planning	Uncertain how to achieve dreams	#23	*n* = 1
	Sensory	Environmental aversions	#21	*n* = 1
	Emotions	Lack of confidence, fearful of disability manifesting in public or of negative reactions	#25, #28	*n* = 2
Microsystem	Social	Limited social engagement outside of family	#1, #14, #20	*n* = 3
	Relationship barriers	**Constraint [2]**	**#1, #2, #4, #5, #6, #7, #8, #10, #11, #12, #14, #16, #17, #26, #29**	***n* = 15**
		Reliance on family for material and logistical support [2]	#1, #21	*n* = 2
		Overprotection [2]	#1, #8, #17, #23, #28	*n* = 5
		Lack of education provided to the person with ID [2]	#1, #9, #10, #14 #16, #17, #26	*n* = 7
		Low expectations [2]	#2, #4, #8, #12, #13, #14, #16, #17, #23, #29	*n* = 10
		Dismissal of self-advocacy Dismissal of gender or sexuality [2]	#2, #11, #16 #10, #25	*n* = 3 *n* = 2
		Perceptions of self-advocacy as disruptive [2]	#2	*n* = 1
		Employer/Co-worker impatience and micromanagement [2]	#5	*n* = 1
		Limited shared decision-making or support for independent decision-making [2]	#7, #9, #14, #20, #27, #29, #30	*n* = 7
		Conflict with family and/or service providers [2]	#7, #11, #12, #22	*n* = 4
		No support for advocacy [2]	#13	*n* = 1
		Bullying [2]	#5, #22, #23, #26	*n* = 4
	Limited knowledge of person	Direct support providers not attending meetings [2]	#2, #5, #30	*n* = 3
	Unheard decisions	Ignoring self-advocacy [2]	#2, #11, #12, #16, #21, #29, #30	*n* = 7
	Permission	Requirement to ask permission/denying permission [2]	#9, #12, #29	*n* = 3

Table 4. *Cont.*

PPCT Model	Subcategory	Barriers [1]	References	No. Studies Referenced
Mesosystem		**Professionals directing communication to caregivers instead of people with ID**	**#3, #11**	***n* = 2**
Exosystem	Structural barriers	**Structural constraints**	**#2, #6, #14, #16, #17, #20, #28**	***n* = 7**
	Service barriers	Organizational lack of familiarity of the person with ID	#5, #6	*n* = 2
		Inaccessible staff members across organization	#15, #20, #29, #30	*n* = 4
		Lack of organization resources	#15, #16, #23	*n* = 3
		Limited inter-agency collaboration	#6	*n* = 1
		Services not person-centered	#2, #5, #6, #9, #12, #25	*n* = 6
		People with ID feeling unheard or unsupported by organizations	#9, #11	*n* = 2
		Organizational policies infringing on personal freedoms and decision-making	#1, #13, #17; #21	*n* = 4
		Underpayment/unpaid work	#4, #11, #15, #16	*n* = 4
		Limited employment opportunities	#4, #22, #24 #29	*n* = 4
		Policy of controlled income by parents/families and service providers due to SSI	#11, #15	*n* = 2
		Limited accommodations	#19, #30	*n* = 2
		Unapproachable medical providers and hurried appointments	#18, #19	*n* = 2
		Difficulty navigating the healthcare system	#18, #19, #30	*n* = 3
		Discrimination by structures such as community employers	#8, #9, #16, #15,	*n* = 4
		Isolation resulting from living in group homes	10, #21 #27, #28	*n* = 4
		No involvement in community affinity groups	#10, #13, #26	*n* = 3
		Unrepresented in mass media	#3	*n* = 1
Macrosystem		**Ableism and disability discrimination**	**#1, #2, #3, #4, #5,#9, #10, #11, #12, #13 #16, #25, #26**	***n* = 13**
		Race and sexuality discrimination	#10, #13, #25	*n* = 3
		Stigma being with people with ID	#4	*n* = 1
	Cultural and religious beliefs	Beliefs about disability sex	#1, #12	*n* = 2
	Institutional and family practices	Ableism impacting employment status and income	#16	*n* = 1
		Denying rights	#12, #16	*n* = 2
		Difficulty navigating services due to societal norms	#11	*n* = 1
Chronosystem	Impact of time	A decline of natural support as parents age	#5	*n* = 1
		Decline in social networks over time	#20	*n* = 1
		Aging impacting health and independence	#26	*n* = 1

[1] Barrers listed reflect key concepts reported in studies. [2] Indicates barriers that examples of proximal process (i.e., interaction patterns within the microsystem). *Note.* Barriers that occur most frequently across studies in each component of the PPCT are in bold font.

5. Discussion

The objective of this scoping review was to understand barriers identified by people with ID across the globe and understand how people with ID experience these barriers through the PPCT model of human development. The research team identified various barriers to self-advocacy from the perspective of people with ID, including challenges a person experiences (e.g., not having a specific skill), relational conflicts among family or

service providers, structural barriers in how services are implemented, societal beliefs and expectations, and barriers due to aging. People with ID have the capability and power to advocate for their wants and needs, and the people (e.g., parents, families, caregivers, service providers) and the systems (e.g., education, adult service providers) that support people have a responsibility to understand the ways in which they hinder and support self-advocacy.

5.1. Notable Findings

This scoping review included articles from 13 countries providing support that barriers to self-advocacy is not a US-specific problem, but an international phenomenon. Studies most commonly occurred, however, in Europe (primarily in western Europe) North America (US and Canada), and Australia. Only one study occurred in Asia (Taiwan), and no studies occurred in South America or Africa (see Table 2). This may be, in part, because of differing cultural perceptions of disability and expectations for self-advocacy, individualistic vs. collective societies, the existence and/or nature of disability policies, as well as resources available in high vs. medium/low-income countries (Abera et al., 2025). Further, over half of the studies were published between 2019 and 2025. This further reinforces that investigating self-advocacy from the perspectives of people with ID is a relatively recent topic of investigation. Despite limited international representation in this review, the represented countries are far from a monolith, which increases the potential to advance an understanding of commonly experienced barriers across countries. In addition, Table 2 displays the wide variety of topics under investigation (e.g., sexuality, decision-making, parenting, healthcare), which further reinforces the importance of considering the barriers identified in this scoping review across compressive aspects of self-advocacy within community living and participant contexts (e.g., employment, education, relationships, living arrangements) at every level of the PPCT model of human development. On the other hand, the majority of studies included in this review utilized qualitative methods (see Table 2). Although qualitative research is not intended to be generalized (Maxwell, 2022), it is important to again consider the influence of specific cultures, communities, and policies when considering the applicability to findings. Conversely, nearly 30% of the qualitative studies incorporated participatory research methods (i.e., #1, #6, #10, #11, #13, #16, #25, #28) and the other two studies incorporated qualitative and quantitative approaches to data collection and analysis. Research in partnership with people with ID that is by, for, and with, rather than on people with ID, centers their voices and empowers people with ID (Balcazar et al., 1998; Call-Cummings et al., 2024). Additionally, partnering with people with ID through participatory approaches to share in the power of developing research questions, collecting data, and making meaning of the data can enhance participation, and also centers the research design, implementation, and meaning-making with and by people with ID (Balcazar et al.,1998; Call-Cummings et al., 2024). In short, although the studies identified in this review are not globally or methodologically representative, reciprocal learning among an international community has the potential to expedite more effective and meaningful self-advocacy research and practices.

Organizing barriers within PPCT model can inform ways in which to address the most salient issues compromising self-advocacy. Participants most frequently identified barriers within the exosystem (structures that indirectly influenced the person with ID; see Table 4) such as organizational culture, hierarchies, policies, and staff turnover (see Table 4). Exosystem barriers identified in this review reflect overwhelming evidence of disparate occurrences of community living and participation outcomes such as (a) competitive employment, (b) postsecondary education, (c) community living, and (d) relationships and community contemporaries are not comparable to other populations (ACL, n.d.; Mc-

Callion et al., 2023; Milot et al., 2021). In addition, the microsystem, including proximal processes (i.e., interactions and perceptions of family members, service providers) was the second most frequent context in which barriers occurred (see Table 4). Decades of research documents the influence of family members and direct service providers have on the outcomes of individuals with ID, as these individuals often look to families and direct service providers for guidance and support (e.g., Friedman, 2022; Luitwieler et al., 2021; McCausland et al., 2021; Milot et al., 2021; Turnbull et al., 2022). Unfortunately, barriers associated with these structures were among the most prevalent barriers reported (e.g., assuming authority, overprotection, low expectations; see Table 4). In addition, educators are also key microsystem structures found to influence self-advocacy and post-school outcomes among individuals with ID (Ferlazzo, 2022). Interestingly, apart from some minor discussion in #14, educators did not emerge as a key barrier to self-advocacy in this review, despite research indicating that school-related barriers such as low expectations among educators often forestalls self-advocacy among individuals with ID (Buchner et al., 2021; Gross et al., 2025; Francis et al., 2020). Although the absence of discussions on educators contributing to barriers to self-advocacy is encouraging, the age of participants (ranging from 18 to 80 across studies) may have curbed discussions about school. Similarly, a large body of research reports the negative impact of limited communication and collaboration among families, educators, and service providers (i.e., interactions found within the mesosystem), as well as interagency communication and collaboration on community living and participation outcomes among individuals with ID (Gross et al., 2025; McCausland et al., 2021). It is surprising that so few studies identified barriers within this system (n = 2).

Finally, intersectionality focuses on the intersection of the constructs of race, class, ability, gender, culture, and sexual orientation with power and privilege (Collins, 2019). Of the 30 articles examined, only eight reported on the race of their participants. Over 60% (n =19) of studies reported the sex of their participants in dichotomous gender, and only three articles included gender expansive terms (#10, #13, #25). Eight articles did not report on gender. The lack of robust reporting of participants' identities, culture, race, gender, and class creates a barrier to understanding the intersectional experiences of Disabled people including people with ID. Participants in the three studies that did examine these intersections (#10, #13, #25) identified that race and/or sexual identity (e.g., gender and sexual identity being dismissed by service provider or families, self-advocacy regarding self-expression being rejected and limited, fear of discrimination), resulting in overlapping and interlocking forms of discrimination and oppression across the PPCT contexts. Identifying and naming such inequalities within society is the first step in understanding how power and social injustices exist and are reproduced.

5.2. Implications for Future Research

Although the pervasive existence of barriers to self-advocacy is acknowledged in the disability field (Nowakowska & Pisula, 2021; Shogren & Raley, 2022), this scoping review only yielded 30 articles that reported barriers that prevented or stymied self-advocacy from the perspective of those most impacted, people with ID. This lack of information compromises the meaningfulness and efficacy efforts to enhance self-advocacy (e.g., curriculum, interventions, policies), if they do not address underlying barriers that Disabled people identify as impacting self-advocacy. Further, Asian, Latin/South American, and African studies were not represented in this review, highlighting a need for international research. Further, most articles in this review utilized qualitative methods, which is an important way to support the voices of people with ID (Call-Cummings et al., 2024). Increased use of mixed methods (e.g., questionnaire, sorting, photovoice, adapted research methods) may enhance participation among people with ID in self-advocacy research (Glaser & Strauss,

1966). Service providers play important roles in the lives of people with ID. Despite the literature and public policies supporting and advocating for collaboration among families, educators, and professionals (Kinnunen et al., 2023; Lokman et al., 2023), this review uncovered few barriers within the mesosystem. Future research should continue to investigate the ways in which people with ID view collaboration and how collaboration grounded in encouraging and honoring self-advocacy can not only increase quality life but can also address barriers such as ableist policies and service systems. In addition, although barriers related to proximal processes were well-defined within the studies included in this scoping review, there was no discussion of the interactions within other systems or descriptions of the "trickle down" effect of ableism and discrimination on other factors such as policies within the exosystem, low expectations among microsystem structures, or internalized ableism by the person at the center of the PPCT model. More deeply understanding the relationships between and bidirectionality of barriers identified in this review can inform practices to disrupt pathways the perpetuate barriers.

Examining the nature of barriers to self-advocacy among ID demands a critical lens. Future research needs to utilize critical perspectives to understand the structural oppression, which exists for Disabled people and specifically for people with ID. The use of critical theories such as DisCrit, intersectionality, and/or critical disabilities studies can help examine barriers to self-advocacy. Because disability is a human experience (Heumann & Joiner, 2020; Linton, 1998) that impacts people from all classes, genders, sexualities, and races, disability issues demand an intersectional lens (Harkins Monaco et al., 2024). Together, intersectionality and the PPCT model advance the understanding of the complexity of human development with a critical lens. Intersectionality uncovers the systems of power based on one's intersecting identities, powers, and relational processes (Collins, 2019). DisCrit (Annamma et al., 2013) utilizes both critical race theory and intersectionality and its tenets consider the forces of racism and ableism to challenge the notions of normalcy, while privileging the multiple identities, experiences, and voices of Disabled people.

5.3. Implications for Practice and Policy

Individuals with ID often report that family members, especially parents, are key supports (e.g., advocacy; Francis et al., 2020), as well as sources of tension and conflict (as noted in this review). Given that families are the first and most consistent supporters in a person's life, focusing on teaching families how to support self-advocacy among their children with ID from an early age has the potential to maximize the natural long-term support families provide. Person-centered planning (e.g., Making Action Plans, Circles of Support) is one culturally responsive research-based approach to creating collaborative, sustainable systems of support built around the needs, goals, preferences, and priorities of an individual with ID (Haines et al., 2017; Lockman Turner et al., 2022). This approach has the potential to mitigate many barriers to self-advocacy identified in this review (e.g., dismissal of advocacy efforts, constraint, limited opportunities for decision-making), by centering all planning decisions on the input of individuals with ID. Likewise people with ID engaging in daily supported decision-making is another approach to honor the interdependent nature of decision-making of all people by providing an intentional way Disabled people, particularly those with ID, and their allies can collaboratively discern choices (The Center for Public Representation, 2025), within and outside of meetings. In addition, dignity of risk, or a person's right to make choices and take reasonable risks to live a self-directed life (Mental Health and Developmental Disabilities National Training Center, 2020), is an additional approach to that can prevent or counteract overprotection among families and direct service providers, a frequently cited microsystem barrier (see Table 4). In addition, professionals (e.g., educators, service providers, administrators)

would benefit from professional development in ways to recognize and address ableism and other systemic forms of discrimination associated with race, heteronormativity, and other social constructs leading to systematic oppression. Such programs may include addressing implicit biases and positionality/reflexivity practices. Training for families, educators, and service programs can address how to acknowledge and value the intersectionality of people with ID through identifying their many identities of race, gender, sexual orientation, and cultural background (Harkins Monaco et al., 2024), and how people within the microsystem can reflect and build critical consciousness identifying the systemic barriers impacting these individuals and work within their own capacity to dismantle them (Collins, 2019). Barriers within this review included dismissal of gender or sexuality identity, people experiencing both racism and ableism, which indicated layered oppression (Collins, 2019).

Results from this scoping review also hold policy implications (see Table 5), including the potential for calling for person-centered planning approaches and supportive decision-making into education, service organizations, and healthcare policies and practices. In the same vein, service providers and healthcare providers require higher education preparation and/or professional development to support self-advocacy among individuals with ID.

Table 5. This table includes implications for practitioners and policy makers within the PPCT Framework.

Stage	Process	Implications
Process	Microsystem/ Proximal Process	• Teaching families how to support self-advocacy from an early age. • Center the person with ID in everyday decision-making. • Families and service providers can reflect on and engage in dignity of risk.
Person	Intersectionality	• People with ID can identify their many identities, and families and service providers can honor these identities. • Family members and service providers can reflect on the position of these identities within society and how the person with ID can experience discrimination within systems.
Context	Microsystem	• Training for families and service providers to avoid overprotection and low expectations.
	Mesosystem	• Building collaborative networks of support between the person with ID, families, and service providers.
	Exosystem	• Developing policies that value the advocacy of people with ID in person-centered meetings. • Organizational expectations to honor the dignity of risk, open communication, staff engagement, and active partnership with people with ID. • Organizational policies and compensation to promote staff retention.
	Macrosystem	• Implementing disability justice into training and education to further the rights, freedoms, and liberties defined in the UNCRPD.
Time	Chronosystem	• Consider the changing needs due to aging and the socio-historical context.

5.4. Limitations

First, the research team excluded the literature not written in English, subsequent studies that may have occurred since the database search in spring 2025, and other forms of publication influenced by the pool of analyzed information. Further, although the research team included "learning disability" (a phrase used for ID in the UK and Australia), they did not include this phrase as a search term. Additionally, the research team did not complete forward and backward hand searches, and this could have limited the information. Moreover, it is

possible that the search and screening practices may have inadvertently excluded studies that did not include inclusionary criteria within titles and abstracts. When extracting data, the research team pulled the barriers of people with ID from the articles. Some articles utilized multiple perspectives (i.e., dyads), and the researchers only selected the barriers of people with ID mentioned within the article. Additionally, the research team utilized the information represented within the article to determine the PPCT context. Vague descriptions of barriers also may have resulted in the researchers misclassifying a barrier. For example, articles reported bullying or discrimination by "others." In these instances, however, the researchers returned to the article for greater context to understand the barriers described.

6. Conclusions

Despite international mandates protecting self-advocacy as a fundamental human right, people with ID continue to encounter compounding layers of systemic barriers to enacting their agency. With self-advocacy serving as a critical driver to an individual's quality of life, it is imperative to identify and redress the environmental barriers and ableist ideologies that perpetuate the exclusion and silencing of the Disability community. Therefore, the purpose of this scoping review was to center the perspectives of people with ID to identify barriers to self-advocacy, thus understanding current exclusionary approaches to self-advocacy while challenging the field's historical reliance on proxy reports.

In analyzing the barriers identified by the Disability community through the PPCT model, this review found the majority of barriers exist predominantly in the exosystem (e.g., policies, staff turnover, etc.) and the microsystem (e.g., low expectations, overprotection, etc.). While these barriers exist in an individual's external system, their limiting effects trickle down into the individual's microsystem through the proximal, reciprocal processes that are influenced by ableist ideologies and other systems of oppression.

Furthermore, this scoping review highlights the current limited understanding of the barriers to self-advocacy for the Disability community due to a lack of identifying and analyzing intersectionality in research practices, as well as lack of global representation. To more comprehensively understand the lived reality of people with ID and the breadth of barriers that inhibit one to self-advocate, future research must examine how intersecting identities, especially multiply marginalized identities, compound the layers of barriers that individuals experience.

Self-advocacy cannot be actualized through interventions that solely target the individual, rather it requires a collective commitment to redesigning exclusionary practices and environments by removing barriers, prioritizing the ones identified in this review. By centering the perspectives and voices of people with ID in this process, researchers and practitioners can advance beyond the dehumanizing and ableist practices of problematizing the individuals and begin the necessary and critical work of problematizing and fixing systems.

Supplementary Materials: The following supporting information can be downloaded at: https://www.mdpi.com/article/10.3390/educsci16010097/s1, File S1: Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR).

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Abbreviations

The following abbreviations are used in this manuscript:

ID	Intellectual Disability
PPCT	Process-person-context-time
US	United States

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