Family role in the development of self-determination for youth with intellectual and

developmental disabilities: A scoping review

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Abstract

The development of self-determination is promoted by supportive contexts during adolescence; families are a key part of this context. In adolescent populations, research suggests families can support self-determination in a number of ways, yet less is known about how self-determination is promoted within families of youth with intellectual and developmental disabilities (IDD). To address this knowledge gap, we conducted a scoping review to examine the existing evidence pertaining to the role families of youth with IDD play in supporting the development of self-determination. A review of 24 publications revealed that existing research has focused on understanding family perspectives on self-determination, but there is a lack of studies investigating how families provide supports for self-determination in the home context for youth with IDD. Additionally, little intervention work has focused on supporting families to promote self-determination. Based on the findings, implications for future research and practice are provided.

Adolescence is a time when young people begin to determine their direction in life and define their path. At the same time, young people are still developing, and often need guidance from their support network, which typically includes family members, teachers, friends and peers, professionals, and others close to the person. While support networks typically promote healthy psychological growth, the degree to which families promote development of self-determination through supporting basic psychological needs (i.e. autonomy, competence, and relatedness; Ryan & Deci, 2000) is related to adolescent participation and academic success (Grolnick, 2009). Family members are critical to supporting the development of self-determination and empowering youth with intellectual and developmental disabilities (IDD; Leal, 1999).

Self-determination has become a frequent focus of study in disability and education literature and has been linked to positive adult outcomes, such as employment, community living, and quality of life, which makes self-determination a critical focus of supports for adolescents (Dean et al., 2016; Lachapelle et al., 2005; Shogren et al., 2015; Test et al., 2009). However, research does not always clearly define self-determination. This study uses two related theories to conceptualize self-determination: Self-Determination Theory (SDT; Ryan & Deci, 2000) and Causal Agency Theory (Shogren et al., 2015). Figure 1 depicts the relationship between the theories. SDT describes three psychological needs, the satisfaction of which drives internal motivation to engage in self-determined action: autonomy (acting based on interests); competence (mastery of important self-identified tasks); and relatedness (interacting and being connected to others; Ryan & Deci, 2000). According to SDT, a person develops internal motivation when environments are supportive of satisfying their psychological needs. Since family is an important aspect of an adolescent's context, researchers have identified family

practices corresponding to SDT that promote satisfaction of these needs. Supporting autonomy,

competence, and relatedness has longstanding effects for the youth. Research has shown that

youth who perceive their psychological needs are supported have better academic outcomes,

more open parent-child communication, school engagement, social competence, and higher

sense of self-worth (Brummelman et al., 2015; Grolnick, 2009; Grolnick et al., 2015; Jang et al.,

2010; Vasquez et al., 2016).

<<Insert Figure 1 about here>>

Causal Agency Theory was developed to explain how people develop the abilities for

engaging in actions and beliefs associated with self-determination, and draws on SDT to describe

the role of environments and that are supportive of autonomy, competence, and relatedness in

creating the conditions for the development and expression of self-determination abilities. For

the purpose of this review, we use the definition of self-determination cited within the literature

on Causal Agency Theory (Shogren et al., 2015), which is a reconceptualization of the functional

model of self-determination (Wehmeyer et al, 1996). Causal Agency Theory defines self-

determination as:

> a dispositional characteristic manifested as acting as the causal agent in one's life. Self-
>
> determined people (i.e. causal agents) act in service to freely chosen goals. Self-
>
> determined actions function to enable a person to be the causal agent in his or her life.
>
> (Shogren et al., 2015, p. 258)

The literature on Causal Agency Theory describes self-determination as a personal

characteristic that develops across the lifespan (Shogren et al., 2015). As mentioned previously,

according to Causal Agency Theory, a person is motivated to act to satisfy basic psychological

needs (i.e. autonomy, competence, and relatedness). A person's context, which in the case of

adolescents could be their home, school, or community, provides barriers and supports to a person satisfying their psychological needs and developing self-determination abilities (i.e., goal setting, problem solving, decision making). When psychological needs are met, a person is more able to direct their actions (and therefore their life) in response to contextual demands. The person is supported to develop self-determination abilities, which are defined as engaging in actions that are volitional (intentional and based on the person's interests and preferences), agentic (goal-directed), and driven by action-control beliefs (a belief that the action will lead to furthering one's goals; Shogren et al., 2015). Put another way, self-determined people make or cause things to happen in their life, and contexts can support the development of self-determination by addressing basic psychological needs. These abilities develop over time through engagement in opportunities to use the abilities, direct instruction, and adequate supports.

Although the majority of the existing research is focused on parents, we refer to "family members" in this paper to respect the diverse structure and roles within family units. It is important to note that individual family members may contribute to the development of self-determination in different ways and that every family's unique culture and values may influence how self-determination is supported (Shogren & Wehmeyer, 2017). For example, family expectations for the future have been shown to predict postsecondary outcomes such as employment among youth with disabilities (e.g., Carter et al., 2012; Doren et al., 2012; Kirby, 2016). Research suggests one mechanism for this association is that family expectations contribute to how families support young people to make decisions about post-secondary transition planning and preparation activities (Holmes et al., 2018). Thus, a wide range of family factors contribute to predicting postsecondary outcomes for youth with disabilities,

demonstrating the importance of understanding the role of family in the development and promotion of youth self-determination.

Study Purpose

Support from families is considered essential for the development of self-determination for youth with disabilities (Morningstar & Wehmeyer, 2008; Palmer, 2010). Although research in general adolescent populations suggests families can support self-determination in a number of ways, there is little research pertaining to families of youth with IDD — who have been found to have lower levels of self-determination compared to peers without disabilities, perhaps because of restricted environmental opportunities and supports (Shogren & Turnbull, 2006). In 1999, Field and Hoffman published an article describing the importance of families in the promotion of self-determination for youth with autism spectrum disorder (ASD) and other IDD and identified a strong need for further research and the development of evidence-based practices. These recommendations were made twenty years ago, yet it is unclear what progress has been made in this area. Given the importance of family support in the development of self-determination, we conducted a review of the self-determination literature focused on the role of families of youth with IDD.

Our review was initially guided by an overarching aim to examine evidence about how family members can support self-determination for youth with IDD. Through an iterative process (described further below), we developed the following specific questions for our review:

1. What are the characteristics of studies that focus on family members' perspectives on self-determination for youth with IDD?

2. To what degree are theory and evidence-based measures of self-determination utilized in research on family members' perspectives on self-determination for youth with IDD?

3. What does existing literature report as family members' perspectives on self-determination for youth with IDD?

4. What interventions exist that support families to promote self-determination?

Method

We conducted a scoping review of existing research to answer our research questions. Scoping reviews are a systematic method to develop a broad understanding of previous literature on a topic (Levac et al., 2010). Whereas systematic reviews seek to understand the quality of the studies reviewed, a scoping review is appropriate to understand how a concept or construct is understood across a broad range of research. Given the relative paucity of research in this area, a scoping review was appropriate to gain a broad understanding. Consistent with a scoping review process, we used an iterative process to refine our methods and research questions as we became more familiar with the literature (Peters et al., 2017). For example, our initial focus was planned to be on family involvement in the development of self-determination for youth with IDD, however upon initial review of the literature we also found a body of literature examining family member perspectives about self-determination.

Search Strategy and Article Inclusion

To identify articles, we searched CINAHL, MEDLINE, PubMed, PsycINFO, and ERIC databases. Table 1 lists the search terms used. Search terms were developed based on terms associated with our research questions and inclusion criteria, namely: diagnostic categories, age range, self-determination, and study participant. To identify articles on self-determination or closely related skills of self-determination, we used terms associated with or defined in Causal Agency Theory (Shogren, et al., 2015).

This search produced a total of 1,888 articles. The first author screened the articles by analyzing the titles and abstracts related to the following inclusion criteria: 1) the article focused on adolescents (ages 10-19) or young adults (ages 18-35) who had ASD, intellectual disability, or other developmental disabilities, 2) study addressed the topic of self-determination, or closely-related concepts (e.g., autonomy, goal setting, problem solving), and 3) the study examined family role in self-determination or contained a family member's perspective on self-determination. Then, the first and second authors jointly reviewed the abstracts of the resulting studies and came to agreement on article inclusion using the same criteria as the screening. We only included original research articles from English language peer-reviewed journals. If the title and abstract did not allow for determination of inclusion or exclusion, the full-text of the article was retrieved and the first and second authors assessed the article against the inclusion criteria. Some articles required additional discussion and a consensus decision; examples included those related to caregiver concerns about transition or articles that used caregiver-report measures of self-determination but were not clearly examining family member roles or perspectives. See Figure 2 for a flow diagram of article selection; the process resulted in 24 included publications.

<Insert Figure 2 about here>

Coding Procedure

We then systematically coded the included articles, using a coding procedure developed for this review. To address Research Question 1, we analyzed each article based on design of study, sample, year of publication, type of family member, and location of the study. For design, we coded based on whether qualitative (interview or focus group) or quantitative (observational, survey, or assessment) data was collected. The sample, year of publication, type of family member, and location of the study were recorded as reported in the study.

To answer Research Question 2, we divided the articles and coded for inclusion of key aspects of two core constructs: self-determination and family role as well as for details of the studies including the design, samples, and application of a SDT. We initially reviewed all articles for each self-determination search term listed in Table 1. To be coded as using one of the self-determination terms, the article had to specifically identify the term as a key focus of the research. However, our coding team only identified four of the terms (autonomy, decision making, goal setting, problem solving) in the studies. Additionally, several articles referred to self-determination in general, and these were defined as Global Self-Determination. See Table 2 for definitions of the terms.

To answer Research Question 3, we coded each article for family role based on SDT (see Table 2 for definitions). Further, after the coding process, we noticed two distinct features of articles describing the family perspective. Articles either described family members' perspective on the importance of self-determination, barriers to promoting self-determination, or both. Because of this and because this aspect was discovered after the coding process, we divided the perspective section of the findings into two categories: importance of self-determination and barriers to promoting self-determination.

For Research Question 4, articles were further coded as intervention or not intervention. For those coded as intervention, the design of the study was recorded.

Interrater Reliability

For coding, the second and third authors divided the articles to code. The primary author trained the researchers by introducing the definitions of the codes, jointly coding 20% of articles with the researchers, and meeting to discuss similarities and differences in codes. Based on this process, definitions of codes were iteratively refined until researchers met agreement on coding

definitions. Further, to ensure consistency with coding, the first author jointly coded 50% of all articles. We calculated interrater reliability using Cohen's kappa statistic, which is calculated by adding the total number of agreements and divided by the total number of agreements and disagreements (McHugh, 2012). Calculated agreement was 80%. Final coding decision was made by consensus for any disagreements. Lastly, our research team identified broad themes in the included body of literature that addressed our research questions. The themes represent commonalities among the research articles and were identified during research team meetings. Researchers discussed the articles to identify common elements, which were the team then came to consensus about inclusion as a theme.

Results

The purpose of this review was to better understand the literature studying the role of families with developing the self-determination of youth with IDD. The search process resulted in 24 included articles. Of note, many of the articles did not set out to study self-determination specifically but were included because they contained results relevant to self-determination. For example, almost a third of the articles studied family experiences with transition from high school, and self-determination emerged as a common element in family members' experiences (Bianco et al., 2009; Cheak-Zamora et al., 2017; Hatfield et al., 2017; Leonard et al., 2016; Pilnick et al., 2011; Rueda et al., 2005; Van Hees et al., 2018). Consistent with our research questions, the results section is divided into four sections, which focus on study characteristics, theory and measurement related to self-determination, family perspectives on self-determination, and family supports and interventions for self-determination. Further, the family perspectives section is divided into two sub-sections based on themes emerged that emerged from analysis: the importance of self-determination and barriers to promoting self-determination.

Study Characteristics

Half of the articles (n=12) were from the United States, with additional articles from the

United Kingdom (n=4), Australia (n=2), Canada (n=2), Belgium (n=1), Lithuania (n=1), South

Korea (n=1) and Spain (n=1). Publication years ranged from 2003 to 2018. The most common

research method was a qualitative approach (n=13); additional methods included surveys (n=5),

case studies (n=2), and one randomized controlled trial (RCT). Some articles focused on a single

IDD-related disability group (e.g. only students with intellectual disability; ID), while others

looked at multiple groups (students with ID or ASD); studies included families of youth with

intellectual disability (ID; n=15), ASD (n=8), , other IDD (n=3), and high or low incidence

disabilities which included IDD (n=1). Table 3 contains details about study characteristics.

Among those studies that reported family member relationship, over 75% of study participants

were mothers.

<insert Table 3 about here>

Theory and Measurement Related to Self-Determination

Related to use of theory and measurement of self-determination, only three studies

focused on self-determination overall, while most studies focused on specific aspects of self-

determination. Decision making was the most frequent aspect studied (n=15), followed by

autonomy (n=13), goal setting (n=7), and problem solving (n=5).

Even among articles that were specifically investigating self-determination, few cited a

theoretical basis. Only ten articles described or cited a specific theory of self-determination. Of

these, Wehmeyer's (1999) Functional Model of Self-Determination and Mithaug et al.'s (2003)

Model of Self-Determination were the most commonly used definitions. Similarly, few articles

measured self-determination using valid and reliable measures. Out of the seven articles that

used a survey or measure, only four of those used a validated measure of self-determination. Carter and colleagues' two 2013 studies used the *AIR Self-Determination Scale* (Wolman et al., 1994), while two intervention studies used *The Arc's Self-Determination Scale* (Wehmeyer & Kelchner, 1995).

Family Perspectives on Self-Determination

Importance of self-determination

Ten articles specifically focused on understanding the importance family members placed on self-determination. In general, this research suggested that families felt developing self-determination was important for their young person with IDD, but there were differences in terms of their perspectives on who should focus on promoting self-determination. For example, Grigal et al. (2003) surveyed parents of youth with high and low incidence disabilities and found that while parents felt self-determination is important, the schools should provide instruction in self-determination, particularly regarding planning individualized education program (IEP) meetings and expressing choice and interest. Additionally, Pilnick et al. (2011) found that while parents acknowledged the importance of involving youth with intellectual disability in the transition planning meetings, decision making priority was often influenced more by parents' opinions and perspectives. Moreover, one study of health-care transitions of youth and adults with ASD found that family members believed autonomy with health-related decision making was important, but were uncertain about how to gauge and support autonomy in this context (Cheak-Zamora et al., 2017). Finally, two quantitative articles by Carter and colleagues found that parents rated self-determination as "very important" and most felt that their child or young adult needed additional supports to continue to build self-determination skills (Carter et al., 2013a, 2013b). However, these studies also found contextual factors that contributed to lower

perceptions of self-determination, such as little opportunity for learning in inclusive classrooms, presence of challenging behavior, and family member perception of severity of disability. While these articles demonstrated a disconnect between family beliefs and practices during transitions, Martínez-Tur et al. (2018) found that family members of students with intellectual disability were more likely to favor self-determination when professionals communicated with families and explained the construct of self-determination.

The role of cultural influences on family perspectives was explicitly considered in three studies. Zhang et al. (2010) compared differences in views of self-determination from culturally diverse groups of parents (i.e. African Americans, Asian Americans, European Americans, and Hispanic Americans). While differences existed between these groups related to understanding self-determination as a construct, most parents did involve their young person in decision making (Zhang et al., 2010). While Zhang et al. discovered similarities in involvement of young people in decision making, two articles specifically studied Latina family members and found there were cultural influences of supporting self-determination. Specifically, Latina mothers felt it was important to involve their young adults in transition-related decision making, but valued family involvement over independence (Rueda et al., 2005; Shogren, 2012).

Barriers to Promoting Self-Determination

While the Carter et al. (2013a, 2013b) articles described previously addressed factors associated with performance of self-determination as part of a larger study, fourteen articles focused on barriers that parent's faced in promoting participation. These barriers ranged from societal perceptions to family members' need to balance self-determination with protection. Related to societal perceptions, Vaicekauskaite (2007) reported that parents of youth with disabilities in Lithuania felt the youth's social exclusion (i.e. stigma, isolation, inadequate

support, and lack of vocational opportunities) made it difficult for parents to support autonomy,

and that social exclusion influenced the family members' perception of capacity for autonomy.

Parents in other studies voiced that systemic factors (e.g. family values, family perception of

risk, limited time of professionals to support goal setting, lack of training for professionals and

family members, service and funding models that prohibit involvement in goal setting) impeded

family desires for providing more support for goal setting and autonomy for their youth with

ASD (Hodgetts et al., 2017) and ID (Bianco et al., 2009; Pownall et al., 2011; Saaltink et al.,

2012). Parents also reported that youth factors, such as cognitive and language abilities

influenced parent support (Hodgetts et al., 2017; Mitchell, 2012). Relatedly, during the

transition to adulthood, Van Hees et al. (2018) found that the adolescents with ASD and their

parents had difficulty redefining their relationship. From the adolescent perspective, this

difficulty stemmed from their changing social identity and urge for independence while also

having a desire for parental involvement.

Related to balancing the need for self-determination and safety, two studies interviewed

parents of youth with ID and found that parents described a conflict between empowering and

protecting their children by making decisions for them (Almack et al., 2009; Millar, 2007).

Sometimes this protection stemmed from concerns about the child's capacity for decision

making (Leonard et al., 2016). One study of parents and teachers of youth with ASD, parents

described the importance of promoting high aspirations and preparation during transition

planning by supporting autonomy, decision making, and goal setting (Hatfield et al., 2017). In

this study, parents identified that real-life experiences (e.g. employment and volunteering) along

with a cohesive and collaborative transition team helped their young adults develop

understanding about their long-term goals.

A common theme reported in these studies was the desire of family members to protect their youth. For example, Saaltink and colleagues (2012) studied decision making for youth with ID in a family context. Echoing a theme from other studies in this review, the authors found that protection was sometimes prioritized over autonomy, but that family members also used adaptations to support choice-making. Mitchell (2012) also found various factors that influenced family members' perspectives on decision-making, such as the youth's understanding of the situation, the nature of the choice (including the level of risk), the parents' desires to protect the youth, and the involvement of professionals.

As noted earlier, publication dates of the included articles ranged from 2003-2018. In general, earlier studies, family members in general seemed to be more skeptical about self-determination; they tended to restrict self-determined behaviors for safety reasons and due to beliefs that they knew what was best for the youth (e.g., Almack et al., 2009; Rueda et al., 2005). However, in studies published in more recent years, parents demonstrated more appreciation for the value of self-determination for their youth (e.g., Carter et al., 2017; Hodgetts et al., 2017; Pilnick et al., 2017).

Family supports and interventions for self-determination

Three articles described implementation of interventions related to family support and self-determination. Using a person-centered planning intervention (Specific Planning Encourages Creative Solutions; SPECS; Cotton & Boggis, 2007) for transition planning with ongoing career development support. Hagner et al. (2012) conducted a randomized control trial (RTC) with 47 youth with ASD. In Hagner and colleagues' multi-component intervention, there was a component of parent training as well as facilitated, family-centered transition planning. Their intervention was associated with increased youth self-determination and vocational decision-

making as well as increased youth and family parental expectations for the future, gains that

were not seen in a waitlist control group. These findings demonstrate the feasibility of family-

centered interventions affecting self-determination and suggest a need for further research.

Similarly, Kim & Park (2012) found that implementation of the Self-Determined Learning

Model of Instruction (SDLMI) combined with parent training demonstrated better student

outcomes in terms of academic engagement and goal attainment than a group who received the

SDLMI without parent involvement. The third intervention study was part of a case study that

measured the changes in self-determination status and occupational performance for one youth

with ID. The intervention involved the parent and youth in the planning of direct task-specific

intervention, which was performed by the researcher (Harr et al., 2011). While noting several

limitations in the study, the author did find that the participant's self-determination increased

over the course of the four-month study.

Processes such as Supported Decision Making were also considered in this body of

literature. In particular, one case study describing one family's experience with Supported

Decision Making and highlighted the parents' belief that guardianship would not support their

goal of a self-determined life for their son with ID (MacLeod, 2017). These parents discussed the

importance of presuming competence and supporting their son to set goals and make decisions.

<div align="center">**Discussion**</div>

Enhanced self-determination is a key characteristic for the achievement of postschool

outcomes (e.g. employment and community living) for adolescents with IDD; (Shogren et al.,

2009). Yet, people with IDD often have limited opportunity and may need structured support to

develop self-determination. This article summarizes the existing research in the IDD field

pertaining to family perspectives on and involvement in promoting self-determination. Overall,

this study finds that this line of research is still underdeveloped. The majority of articles we found for this review were descriptive in nature, which has yielded important information about family perspectives and practices related to developing self-determination. However, most of the articles where family perspectives on self-determination emerged were not explicitly studying self-determination. Rather, the researchers were studying aspects of related topics, such as transition or IEP planning, and themes related to self-determination emerged. This study also found that little research exists on how to effectively support families in promoting self-determination, which is a critical component of successful adult outcomes (Shogren et al., 2015; Wehmeyer et al., 2019).

Characteristics of Studies

Timeframe

The publication years of the included studies spanned from 2003 to 2018, which allowed us to examine possible changes in family perceptions across time. During this timeframe, much research and education was being done related to understanding, measuring, and developing interventions to promote self-determination. Our finding that family members in more recent articles tended to demonstrate more appreciation of their child's self-determination is a positive development and may be related to the increased emphasis and information dissemination on self-determination during the transition planning process over time. However, despite increased support for self-determination, studies suggest that family members were often confused about self-determination or uncertain about how to support it for youth with IDD.

Family members involved in research

It is also important to consider what types of family members were included in studies examining family perspectives on self-determination. In this review, respondents from most

studies were mothers, with minimal involvement from other family members involved in the

research. This is not surprising given that most disability parenting research focuses on mothers

(Neely-Barnes & Dia, 2008), and is consistent with traditional family practices in which mothers

are the primary caregivers of children. However, the notion of the traditional family is changing

in Western cultures, as are traditional gendered roles within families (e.g. fathers are taking more

active roles in raising children; Doucet, 2018). Additionally, siblings can often play a key role in

the lives of youth and adults with IDD, yet may not be involved in transition planning (Heller &

Caldwell, 2006). Based on this review, it is evident that more research is needed to understand

the perspectives of diverse family members regarding self-determination.

Theories and Measures of Self-Determination

This review also allowed us to examine the various measures used to study self-

determination, as well as the theories used to guide research on this topic. Few articles cited

theory related to self-determination and the majority of articles studied specific aspects of self-

determination, such as autonomy or decision making. Newer conceptualizations of self-

determination, such as Causal Agency Theory (Shogren et al., 2015), were not identified in the

reviewed articles. This is understandable given the timeframe of the review and the recent

publication date of the Causal Agency Theory.

Related to measurement, we found that few studies used measures of self-determination.

This finding is not surprising given that many of the studies in this review studied aspects of self-

determination (e.g. problem solving, decision making) and not self-determination overall. As

self-determination becomes a more commonly used term and construct in research and practice

related to people with IDD, authors may feel less need to clearly incorporate clear

conceptualizations of self-determination and may proceed without theoretical grounding.

However, incorporation of theory and specific measures of self-determination allows for more clear hypotheses, more rigorous studies, and an understanding of changing trends over time. For example, the *Self-Determination Inventory: Student Report* (SDI:SR; Shogren et al., 2017), which is aligned with Causal Agency Theory and is a self-report self-determination assessment for youth with and without disabilities aged 13 through 22. There is a parallel version of the SDI:SR, called the *Self-Determination Inventory: Parent/Teacher Report* (SDI:PTR) which is to be completed by adults who know the youth being assessed well to provide their perspective on self-determination. Use of self-determination measures such as the SDI:SR and SDI:PTR would be an effective starting point for family members to objectively think about their child's self-determination, to measure change in students and parents over time, and to plan for supports and opportunities to promote self-determination aligned with their family and cultural backgrounds at home and in community.

Family Perspectives of Self-Determination

Some studies in this review focused on specific cultural groups, which allowed us to draw some conclusions on how cultural values may influence family involvement in self-determination development. Many aspects of families such as parenting styles (Zhang et al., 2005), family structure (Frankland et al., 2004), and roles are influenced by cultural factors. Families from different background may foster self-determination-related behaviors in different ways or to differing degrees (Zhang et al., 2005). Cultural practices and beliefs around which families engage can impact their perceptions toward self-determination and how they support children to develop, refine, and practice knowledge and skills related to self-determination. As such, the manner in which families support self-caused and autonomous action can vary across cultural contexts (Wehmeyer et al., 2017). For example, families valuing individualism may

place emphasis on independence, while families valuing collectivism my emphasize a greater

degree of family involvement. Research exploring culture and self-determination puts an

emphasis on supporting self-determination in ways that are aligned with each person's personal

culture (Wehmeyer et al., 2017). More research studying self-determination within diverse

cultures, as well as development of interventions that are culturally responsive are needed.

Interventions to Promote Self-Determination

In general, this research suggests that while families embrace the need to promote self-

determination, they need new strategies to feel competent in supporting self-determination. Self-

determination interventions have been shown to be effective for enhancing youth self-

determination (Shogren et al., 2015) as well as increasing teacher perception of capacity for self-

determination (Shogren et al., 2014)). However, few interventions exist that explicitly teach

parents or other family members about how to support self-determination for youth with IDD.

Those that do exist (e.g., Hagner et al., 2012, Kirby et al., 2019) are at early phases of research

and require further testing to determine efficacy and effectiveness.

There is a strong need for intervention research in this area. Only three articles meeting

inclusion for this scoping review were intervention studies. The body of literature suggests that

families find self-determination to be an area of importance, but families do not know how to

best facilitate self-determination for youth with IDD. Intervention research should be guided by

theory in self-determination to ensure relevance to the construct, which has been tied to

important outcomes.

Although we found minimal research on interventions, there is existing literature that

could inform future studies about ways families of youth with IDD can creating opportunities for

practicing self-determination. For example, research shows that families can teach he

foundational skills of self-determination in early childhood. Families can provide opportunities for young children to make age-appropriate choices, indicate preferences, and practice self-regulation skills (Palmer et al., 2013). In adolescence, families can encourage participation and support autonomy by exploring the youth's preferences and strengths to promote internal motivation (Grolnick, 2009). Additionally, competence support can be enhanced by building partnerships between home and school to establish individualized practices to promote foundational skills of self-determination across contexts (Turnbull et al., 2015). Families and school professionals can share information on what self-determination practices have worked or not worked to continue to refine and implement self-determination practices across different contexts. While these suggestions align with theories of self-determination (e.g. Causal Agency Theory and SDT), rigorous intervention studies are needed to test if and how these approaches can be applied in populations of youth with IDD.

Additionally, interventions that specifically target development of self-determination abilities have been used extensively in schools and could be adapted to involve family members as well. One example, which was used in the Kim & Park (2012) study in this review, is the Self-Determined Learning Model of Instruction (SDLMI: Shogren et al., 2018), which is used to support youth to set and achieve transition-related goals. The SDLMI is designed to support youth to repeatedly work through a three-phase problem-solving model focused on setting a goal based on the individual's interests, developing an action plan to achieve the goal, and reflecting on the process, which affords the person the opportunity to develop self-regulated problem-solving skills related to the essential characteristics of self-determination (i.e. agentic action, volitional action, and action-control beliefs). As Kim & Park (2012) found, having families of youth with IDD involved with the SDLMI along with teachers had positive effects on academic

engagement and goal attainment. This work could be studied in a more rigorous trial to better understand the benefits of involving parents in the SDLMI process.

Finally, person-centered planning (PCP), which was used as a component of Hagner et al.'s (2012) RTC, may be effective components of complex interventions designed to support the self-determination of people with IDD. PCP processes are designed to support a person with a disability to envision a future for themselves and develop a plan with specific action steps to achieve their envisioned future. While the person with a disability is the focal point of the meetings, and the primary decision maker, involvement of family members can support the planning – and thereby support the person's autonomy and competence. Examples of person-centered planning approaches include the McGill Action Planning System (MAPS) (Vandercook, York, & Forest, 1989), the Person-Centered Planning with Supports Intensity Scale (Thompson et al., 2017), and the Charting the Lifecourse (Gotto et al., 2019). Each approach has unique aspects, but for them all, the person with a disability is the causal agent, with trusted advisors serving as supporters. Future research could extend the evidence supporting explicit family involvement in these models by studying the effects on youth self-determination.

Limitations

This study systematically investigated the existing research that has been done on understanding family involvement with promoting self-determination. While little research has focused on family involvement in promoting self-determination among youth with IDD, the current scoping review outlines the existing research and also related topics that may be important to advance research and practice in this area. However, several limitations should be noted when considering implications. First, we used a scoping review since little is known about

this topic and a scoping review is useful to provide a broad overview of research. Using this approach, we analyzed qualitative and quantitative research with little regard to methodological rigor. This approach allowed us to focus on key themes from existing research but complicates interpretation in terms of the quality of the research base. Additionally, it is worth noting that in the majority of articles in this review, the studies were not explicitly examining family involvement in the promotion of self-determination. Rather, self-determination emerged as an important aspect of the research. This limits the conclusions that can be drawn and highlights a potentially fruitful line of research related to better understanding effective methods of involving families in promoting self-determination.

Implications for Research

This scoping review included 24 articles that provide insight into the current state of research on the perspectives of families and their role in promoting self-determination for youth with IDD. Despite the recognized importance of families in this process and many studies about family perspectives on self-determination, there is not a sufficient evidence-base regarding promoting self-determination, for youth with IDD in the home, an issue frequently noted by families themselves. As noted in this study, this is particularly true for culturally diverse families. As was observed in multiple studies, families can at times restrict self-determination opportunities to balance risk and protection. Therefore, for optimal outcomes, practitioners need to fully involve family members when working with youth with IDD to promote self-determination; and as described throughout the discussion, interventions that align with current theory, enhance family involvement, and target youth self-determination need to be developed and tested. Further, future studies should take advantage of measurement tools for self-determination, which have advanced in recent years. Overall, this study shows that future

research is needed to best understand how families can best support youth with IDD to promote

self-determination in meaningful and culturally and contextually responsive ways.

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Table 1

Search Terms

Diagnostic terms	Age-related terms	Topic terms	Participant terms
autism	adolescent	self-determination	parent
asd	adolescence	agency	parental
autism spectrum	young adult	autonomy	caregiver
disorder	transition	self-initiation	family
Asperger	middle school	pathways thinking	siblings
hfa	high school	self-direction	grand*
intellectual disability	teenage	self-regulation	
developmental		agentic action	
disability		volitional action	
		action-control	
		control-expectancy	
		Psychological	
		self-realization	
		self-management	
		goal setting	
		problem solving	
		decision making	
		choice making	
		self-advocacy	
		self-awareness	
		self-knowledge	

Note. grand* exploded (e.g., grandparents, grandmother, grandfather).

Table 2

Definition of Self-Determination and Family Role Coding

Code	Definition
Self-Determination (Shogren et al., 2015)	
Global Self-Determination	Self-determination is about acting as the causal agent in one's life. Causal agents are people who make or cause things to happen in their lives.
Autonomy	Freedom of external control or influence. Being the primary director of action.
Decision Making	Decision-making is a process of identifying various options and weighing the adequacy of various options. Decision-making is broader than choice-making as it involves weighing different outcomes and picking the best one.
Goal Setting	Identifying a direction (or goal) to move toward.
Problem Solving	In problem solving, a solution is not previously known and must be identified. Problem solving would include the process of helping the youth to: 1) Define the problem and determine the need for a solution, 2) Identify one or more solutions, 3) Implement solution(s), and 4) Evaluate the effectiveness of the solution(s).
Family Role (Grolnik, 2009)	
Autonomy Support	Providing opportunity for choice, listening to the young adult's perspective, and supporting problem solving.
Competence Support	Family members offer clear expectations, an appropriate level of support, and constructive feedback
Relatedness	Relationship building between parent and adolescent
Family Perspective	If none of the above family support characteristics were coded, code if family perspective was included.

Table 3

Summary of Included Articles

Article	Study Design	Sample*	SD Theory	Aspects of SD	Family Role
Almack et al., 2009	Qualitative interviews	17 mothers, 3 fathers, 7 couples, and 1 sibling (n=28) of 28 youth w/ ID (18-19yrs)		A, DM	Autonomy & competence
Bianco et al., 2009	Qualitative interviews	8 mothers and 1 couple (n=9) of 9 adults (n=9) w/ ID (24-27yrs)		DM	Autonomy & competence
Carter et al., 2013a	Survey using AIR SD Scale and questions on importance of SD	531 mothers, 71 fathers, and 17 other family members (n=627) of youth w/ ID or ASD (5-18yrs)	✓	A, DM, GS, PS	
Carter et al., 2013b	Survey using AIR SD Scale and questions on importance of SD	52 mothers, 10 fathers, 6 grandparents (n=68) of youth w/ ID or ASD (19-21yrs)	✓	A, DM, GS, PS	
Cheak-Zamora et al., 2017	Qualitative interviews	21 mothers, 3 fathers, and 3 other family members (n=27) of 27 youth & adults w/ ASD (16-25yrs)		A	Autonomy & involvement
Grigal et al., 2003	Survey using a unique parent SD scale	194 mothers, 23 fathers, 14 grandparents, 4 legal guardians (n=234) of youth with high or low incidence disabilities (16-21yrs)	✓	DM, GS	
Hagner et al., 2012	RCT with delayed-exposure control group	47 parents of 47 youth w/ ASD (16-19yrs)		General	
Harr et al., 2011	Case study involving an intervention, used The Arc's SD Scale	Father of 1 youth w/ ID (20yrs)	✓	General	Autonomy, competence, & involvement
Hatfield et al., 2016	Qualitative interviews	6 parents of 6 youth w/ ASD (14-21yrs)		A, DM, GS	Autonomy & involvement
Hodgetts et al., 2017	Qualitative focus groups	6 mother, 1 father (n=7) of 4 youth w/ ASD (14-18yrs)	✓	GS	Autonomy & competence

Kim & Park, 2012	Pretest-posttest with control group	10 mothers, 1 father, 1 grandparent (n=12 parents in experimental group; parents were not included in the control group) of 24 middle school students with ID or ASD *(ages not provided)*	✓	GS	Autonomy, competence, & involvement
Leonard et al., 2016	Survey including questions about parental worries about transition	Parents of 340 youth and adults w/ Down syndrome or ID (15-29yrs)		DM	Autonomy & involvement
MacLeod, 2017	Case study	Parents of 1 adult w/ ID (29yrs)		DM	Autonomy, competence, & involvement
Martinez-Tur et al., 2018	Survey including questions about SD attitudes	845 family members of 845 individuals w/ ID *(ages not provided)*	✓	General	
Millar, 2007	Qualitative focus groups	9 mother, 2 fathers (n=11) of 11 adults w/ ID (19-22yrs)		DM	Involvement
Mitchell, 2012	Qualitative interviews	11 mothers, 3 fathers (n=14) of 11 youth w/ ID (14-21yrs)		DM	
Pilnick et al., 2011	Qualitative analysis of transition planning meetings	7 mothers, 4 fathers (n=11) of 8 youth w/ ID (18-19yrs)		A, DM, GS	Autonomy, competence, & involvement
Pownall et al., 2011	Qualitative interviews	8 mothers of 8 youth w/ ID (17-19yrs)		A	Autonomy & involvement
Rueda et al., 2005	Qualitative focus groups	16 mothers of 16 youth & adults w/ IDD (14-31yrs)		A, DM	Autonomy & competence
Saaltink et al., 2012	Qualitative interviews	4 mothers, 2 siblings (n=6) of 4 youth w/ ID (14-18yrs)		A, DM	Autonomy & involvement
Shogren, 2012	Qualitative interviews	7 mothers of 7 youth IDD (14-21yrs)	✓	A, DM, PS	Autonomy, competence, & involvement
Vaicekauskaite, 2007	Qualitative interviews	93 parents of 93 youth w/ disabilities (birth-18yrs), including 58 with ID		A	Autonomy

Van Hees et al., 2018	Qualitative interviews	34 mothers, 26 fathers (n=60) of 34 youth w/ ASD (average 17yrs)	✓	A, PS	Autonomy, competence, & involvement
Zhang et al., 2010	Qualitative interviews	20 parents of 20 youth w/ disabilities (15-19yrs), including 11 w/ ID or ASD	✓	A, DM, GS, PS	Autonomy, competence, & involvement

Notes. *Some studies included multiple respondent types (e.g., parents, professionals, individuals with disabilities); this table only presents the family member participants in each study. SD = self-determination; Aspects of SD: General (global measure used and/or no specific components described); A = autonomy; DM = decision making; GS = goal setting; PS = problem solving; ASD = Autism spectrum disorder; ID = intellectual disability; IDD = intellectual and developmental disabilities.

Figure 1 -
Causal Agency Theory (© 2020 Kansas University Center on Developmental Disabilities. Used with permission).

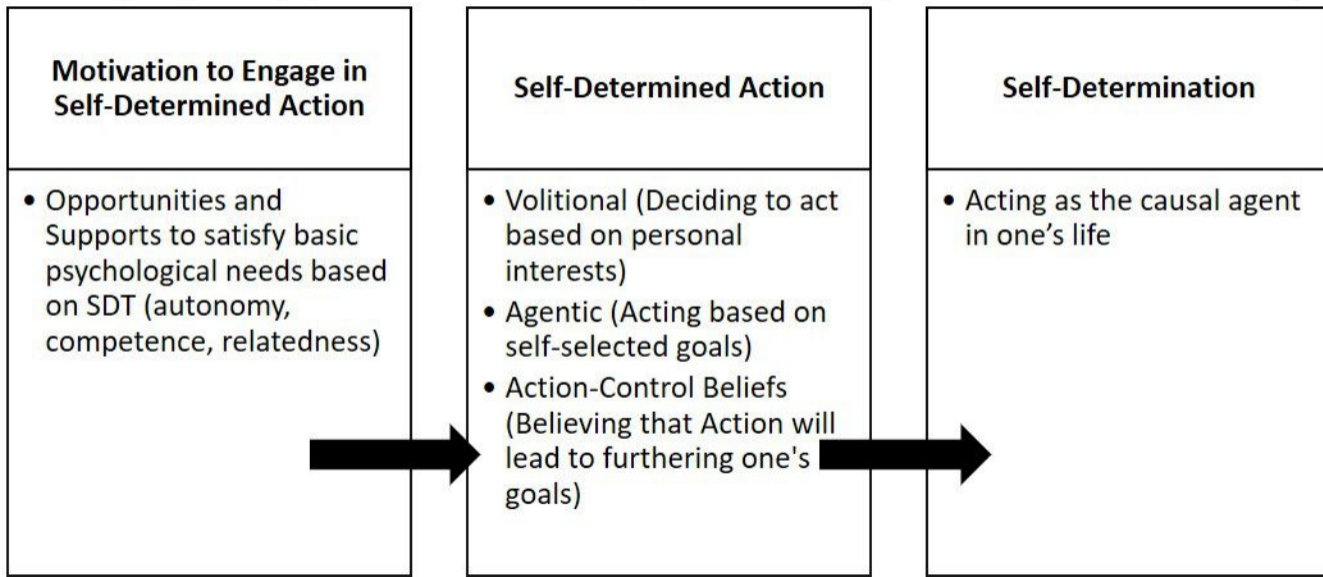| Motivation to Engage in Self-Determined Action	Self-Determined Action	Self-Determination
• Opportunities and Supports to satisfy basic psychological needs based on SDT (autonomy, competence, relatedness)	• Volitional (Deciding to act based on personal interests) • Agentic (Acting based on self-selected goals) • Action-Control Beliefs (Believing that Action will lead to furthering one's goals)	• Acting as the causal agent in one's life

Figure 2
Search and article selection flow diagram.

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *P*referred *R*eporting *I*tems for *S*ystematic Reviews and *M*eta-*A*nalyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097