Community Participation for Transition-Aged Youth with Intellectual and Developmental Disabilities

A Systematic Review

Tania Santiago Perez
Brandi M. Crowe

Abstract

All people, including individuals with intellectual and developmental disabilities (IDD) deserve to actively participate in the community in which they live. For transition aged-youth (TAY) with IDD, attaining successful community participation can be difficult. The purpose of this systematic review was to identify and synthesize the literature specific to recreational therapy interventions in the U.S. aimed at improving community participation among TAY with IDD. Literature specific to two domains of community participation were explored: a) interpersonal life; and b) community, civic and social life. Eight studies were reviewed using a thematic synthesis approach to identify common themes across studies. Findings revealed three themes: 1) programs with collaboration and community supports, 2) leisure education, and 3) social skills training. Facilitators, barriers, and promising approaches regarding community participation of TAY with IDD are described. Implications and limitations of the current literature are also addressed.

Keywords

Community participation, developmental disability, intellectual disability, recreational therapy, transition-aged youth

Tania Santiago Perez is an assistant teaching professor of Recreational Therapy at Clemson University as well as an instructor of Recreational Therapy at Florida International University.

Brandi M. Crowe is an assistant professor of Recreational Therapy in the Department of Parks, Recreation, and Tourism Management at Clemson University.

Please send correspondence to Tania Santiago Perez, tsantiag@fiu.edu
Introduction

The United States (U.S.) Department of Health and Human Services (2016) has identified “participation in community activities” as one of the health goals for people with disabilities. Community participation among individuals with intellectual and developmental disabilities (IDD) transitioning from adolescence to adulthood can be difficult; as individuals with IDD age, they participate less frequently in the community, have less environmental support, and tend to participate in more isolated, solitary, and passive activities (Watts et al., 2017). Throughout the lifespan, but particularly when transitioning from school to community life, adolescents with IDD need support and initiatives to achieve successful community participation. Recreational therapy is one profession positioned to enable engagement in meaningful recreation and leisure activities in the community to improve the community participation among transition-aged youth (TAY) with IDD. The purpose of this systematic review was to identify and synthesize the literature specific to recreational therapy (RT) interventions in the U.S. aimed at improving community participation among TAY with IDD.

Literature Review

Being an active member of the community is important in the development of all young people, including TAY with IDD. Community participation is a major focus of policies in the U.S. and international treaties intended to create a better quality of life for people with disabilities, by mandating structural accessibility, access to public programs and services, and employment opportunities in a non-discriminatory environment for individuals with disabilities. Examples of these policies include: the Americans with Disabilities Act (1990), the Supreme Court Olmstead v. L.C. decision (1999), the Workforce Innovation and Opportunity Act (2014), the Home and Community Based Services Final Rule of 2014 (Centers for Medicare and Medicaid Services, 2014) and the United Nations Convention on the Rights of Persons with Disabilities (2006). Likewise, the World Health Organization’s (WHO) World Report on Disability (2011), the American Association on Intellectual and Developmental Disabilities’ (AAIDD) Community Living Statement (2016), the U.S. Department of Health and Human Services’ Healthy People 2020 (2012), the Arc’s Life in the Community position statement (2012) and the United Nations Disability and Development Report Sustainable Development Goals (2018), have increasingly identified community participation of people with IDD as a main objective. Despite several decades of these policies and efforts, literature describing successful evidence-based approaches to improving community participation among TAY with IDD is limited (Adair et al., 2015).

Community Participation

Participation according to the WHO's (2001) International Classification of Functioning, Disability and Health (ICF) is defined as “involvement in a life situation” (p. 10). The ICF model is an important framework for community participation as it considers the individual’s impairment, as well as the potential barriers or supports related to personal and environmental factors that impact an individual’s activity and participation (WHO, 2001). Based on the ICF model, Verdonschot et al. (2009) defined community participation as “the performance of people in actual activities in four social life domains through interactions with others in the context in which they live” (p. 304). The four social life domains in Verdonschot et al.’s community participation
definition include: (a) domestic life; (b) interpersonal life; (c) education and employment; and (d) community, civic, and social life. The domestic life domain involves daily home chores and activities of daily living with family members. The interpersonal life domain includes formal and informal social relationships such as family relationships, friendships, and intimate relationships. The education and employment life domain involves pre-vocational and vocational training, post-secondary or higher education, and remunerative work. The community, civic, and social life domain includes participation in religion, politics, recreation and leisure, hobbies, socializing, sports, arts, and culture. This manuscript will focus only on the interpersonal life and community, civic, and social life domains of Verdonschot et al.’s community participation definition as those two domains fall within the scope of practice and expertise of recreational therapists in supporting community participation for TAY with IDD. Using the recreational therapy process (i.e., assessment, planning, implementation, evaluation, and documentation), recreational therapists provide recreation and activity-based interventions to improve or maintain the physical, cognitive, social, emotional, and spiritual functioning of individuals in order to facilitate full participation of individuals in life (American Therapeutic Recreation Association, n.d.; National Council for Therapeutic Recreation Certification, n.d.). Recreational therapists are ideally positioned to be at the forefront of helping individuals with IDD achieve community participation through interpersonal life and community, civic, and social life.

Individuals with Intellectual and Developmental Disabilities

The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) defines intellectual disability (ID) as a neurodevelopmental disorder that significantly impacts intellectual and adaptive functioning, and has an onset during the developmental period (American Psychiatric Association [APA], 2013). Individuals with ID have deficits in intellectual functioning two standard deviations below the norm, or an intelligence quotient (IQ) below 70±5, which results in limitations in learning, reasoning, and problem-solving (American Association on Intellectual and Developmental Disabilities [AAIDD] Ad Hoc Committee on Terminology and Classification, 2010; APA, 2013). Individuals with ID experience limitations in adaptive behaviors including impaired communication and social skills, and difficulties performing activities of daily living at home, school, work, and in community settings (AAIDD, 2010; APA, 2013; The Arc, n.d.). ID is identified as mild, moderate, severe, or profound, and affects about 1% of the population; 85% of whom have mild ID (Parekh, 2017). The most common conditions associated with ID are autism spectrum disorder (ASD), Down syndrome, fragile X syndrome, and fetal alcohol spectrum disorders (The Arc, n.d.).

Developmental disabilities (DD) is a term that represents ID and other disabilities that occur during childhood, before age 22, and continue throughout an individual’s lifespan. DD is a broader category of chronic disabilities that can result in impaired intellectual and/or physical functioning (AAIDD, 2010). A person with DD may or may not have below average IQ. In contrast, all individuals with ID have below average IQ (The Arc, n.d.). Individuals with DD experience limitations specific to language, mobility, learning, and self-care skills required for independent living (Centers for Disease Control and Prevention [CDC], 2015; Developmental Disabilities Assistance and Bill of Rights Act [DD Act], 2000). Down syndrome, cerebral palsy, ASD, fetal alcohol spectrum disorder, spina bifida, and brain injury are some of the most common DDs.
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(CDC, 2015; DD Act, 2000). For the purpose of this manuscript, intellectual and developmental disabilities (IDD) will be the term used to represent individuals who have an intellectual and/or developmental disability.

**Transition-Aged Youth with IDD**

Transition refers to the period of time in which an adolescent moves from behaving primarily as a student to assuming emergent adult roles in the community (Alabama State Department of Education, 2014; Jacobs et al., 2018). The Individuals with Disabilities Education Act (2004) mandates transition services to start the year in which a student with a disability turns 16, or younger if determined appropriate by the student's individualized education plan (IEP) team, and continue through high school graduation, up to the student's 22nd birthday (U.S. Department of Education, 2017). There are some variations in transition services based on age, depending on the state. For example, Florida begins transition services as early as age 14 (Florida Department of Education, 2018); and Michigan provides transition services up to age 26 (Michigan Department of Education, 2018). For the purpose of this manuscript, TAY with IDD will be defined as individuals ages 14 to 26 transitioning from adolescence to adulthood, from high school to community life, and/or from living with caregivers to independent living (American Association of People with Disabilities, 2016).

**Barriers to Community Participation for TAY with IDD**

Research indicates that TAY with IDD experience lower levels of community participation in comparison to their peers without disabilities or other disability groups, have fewer environmental supports, and tend to participate in more isolated, solitary, and passive activities (Verdonschot et al., 2009; Watts et al., 2017). Significant barriers to community participation among TAY with IDD include the lack of appropriate or available programs; and environmental barriers such as accessibility issues, family socio-demographics, financial resources, limited community supports, and negative discriminatory attitudes within the community (Andrews et al., 2015; Becker & Dusing, 2010; Murphy & Carbone, 2008).

Results from a secondary data analysis of a nationally representative cohort using the National Longitudinal Transition Study 2 in which TAY with ASD, their parents/caregivers and school administrators and personnel were interviewed (n=17,818 individuals with ASD) revealed that intrinsic and extrinsic characteristics were significantly associated with community participation in this population. Extrinsic characteristics such as higher family incomes and utilization of case management services were significantly associated with improved community participation, while intrinsic characteristics such as low cognitive functioning, increased behavioral difficulties, and communication problems were associated with an increased risk of social isolation and reduced social participation (Myers et al., 2015). Factors including the impact of clinical symptoms and the severity of one's disability, social demands of community-based activities, and the limited ability of people with IDD to communicate and form social relationships in the community can also restrict community participation of TAY with IDD (Andrews et al., 2015; Fennick & Royle, 2003; King et al., 2003; Oates et al., 2011; Tint et al., 2017).
Facilitators of Community Participation for TAY with IDD

Facilitating community participation among TAY with IDD is complex, and often requires the attention and support of multiple disciplines. Adair and colleagues (2015) completed a systematic review of seven studies facilitated by health, psychology, and educational professionals in which various programs and therapeutic interventions (i.e., aquatic therapy, creative drama, fitness, and exercise programs) were implemented for the purpose of improving participation outcomes in children and adolescents with IDD. Collectively, results indicated that participation outcomes specific to home, school, and community settings were enhanced by providing individually tailored, one-to-one and group-based programs that incorporated coaching, mentoring, and opportunities to practice social skills (Adair et al., 2015). Andrews and colleagues (2015) also conducted a systematic review of interventions focused on community participation for TAY with IDD. Thirteen studies reflective of interventions led by professionals in health sciences, occupational therapy, education, and social work were included in the review; interventions included recreational programming, friendship clubs, community art, and social skills programs. Results indicated that community participation is enhanced among TAY with IDD when interventions facilitate friendships through recreation programming, include typically developing peers, consider the activity preferences of participants, and provide accommodations based on individual needs (Andrews et al., 2015).

Bigby and colleagues (2018) conducted a scoping review of 17 articles specific to community participation programs for adults with IDD to determine what program features are effective in supporting community participation. Results indicated that programs aimed at increasing community participation should offer: (a) participation through social relationships, (b) convivial encounters, and/or (c) a sense of belonging and identity. Community participation through social relationships refers to programs that support individuals with IDD in developing relationships, enlarging their social network, and socially interacting with others during activities and community groups (Bigby et al., 2018; Harlan-Simmons et al., 2001; Ward et al., 2012; Ward et al., 2013). Community participation through convivial encounters are programs in which people with IDD join mainstream community groups, undertake volunteer work or engage in social interactions in commercial or public places. These programs require that encounters occur in non-segregated public places with others who do not have a disability, and who might be assigned mentorship roles (Bigby et al., 2018; Craig & Bigby, 2015). Community participation achieved through a sense of belonging and identity occurs when programs for individuals with IDD promote participation in activities that help individuals create a new identity such as being an artist, a craftsperson, an actor or athlete (Bigby et al., 2018). Through these types of programs, the engagement in activities and the new social roles allow individuals to be a part of their communities (Darragh et al., 2016; Hall, 2013; Harada et al., 2011; Mcclimens & Gordon, 2009; McConkey et al., 2013). Professionals working with TAY with IDD can use social identity theory and social role valorization to design interventions that promote community participation through a sense of belonging and identity.

Purpose

The aforementioned reviews related to community participation for TAY with IDD describe the use of recreation and leisure-based programs as approaches to im-
prove the community participation of TAY with IDD (Adair et al., 2015; Andrews et al., 2015; Bigby et al., 2018; Verdonschot et al., 2009). However, programs described did not report involving Certified Therapeutic Recreation Specialist (CTRS®)-led programs or interventions. The purpose of this systematic review was to identify and synthesize the literature specific to recreational therapy (RT) interventions aimed at improving community participation among TAY with IDD.

**Methods**

**Search Strategy**

Authors reviewed the titles of articles listed in the table of contents in the *Therapeutic Recreation Journal*, the *American Journal of Recreation Therapy*, and the *American Therapeutic Recreation Association's Annual in Therapeutic Recreation*, seeking peer-reviewed empirical and conceptual articles related to community participation and TAY with IDD. Authors completed the systematic review in 2019, thus the initial review focused on articles published within the previous 10 years (2008-2018) in an effort to capture recent and up-to-date literature. However, due to limited RT-specific literature related to community participation and TAY with IDD published within the 2008-2018 time frame, authors widened the review to include RT literature published in the last 28 years. Researchers elected to widen the search to include articles published as early as 1990, as this was the earliest date of published articles within the three RT journals to which the researchers’ universities could provide access. Researchers’ reviewed articles published between 1990 and 2018 for the *Therapeutic Recreation Journal* and *ATRA Annual in Therapeutic Recreation*. Researchers’ only had access to, and reviewed articles published between 2004 and 2018 for the *American Journal of Recreation Therapy*.

Researchers reviewed the article titles in each of the three journals’ table of contents, seeking out titles that included keywords related to: youth, adolescents, or young adults with intellectual and/or developmental disabilities; terms related to transitioning, transition-aged individuals, and community participation were also sought out. The title for 1,054 articles were reviewed by researchers (see Figure 1). Abstracts of article titles that seemed applicable to our topic were reviewed to confirm whether the articles were focused on TAY with IDD. Based on title and abstract review, 27 articles were identified as being related to the systematic review topic. Researchers completed a full-text review of these 27 articles to confirm whether the articles met inclusion criteria. Eight of the 27 articles reviewed met inclusion criteria and were included in the systematic review sample (see Table 1).

**Search Criteria**

Articles included in the systematic review sample: (a) were peer-reviewed and published in one of the three RT journals; (b) involved TAY with IDD between the ages of 14-26; and (c) involved CTRS® supervised programs that utilized community-based experiential learning opportunities to improve the interpersonal lives, and/or community, civic and social lives of TAY with IDD. Articles excluded from the systematic review sample: (a) focused on children (ages 13 or under) or adults (ages 27 and up); (b) focused on participation in activities of daily living, employment, or education; (c) reflected parent, caregiver, or practitioner perspectives rather than TAY with IDD’s perspective; and/or (d) did not address the interpersonal life and/or the community,
civic and social life components of Verdonschot et al.’s (2009) community participation definition. Research articles reflective of qualitative, quantitative, multi- and mixed-methods research were eligible for inclusion in the systematic review sample; gray literature (i.e., unpublished thesis or dissertation research) was not included in the review.

Analysis

Two researchers independently reviewed each of the eight articles, focusing on the content and process of CTRS®-led programs provided to TAY with IDD for the purpose of improving their interpersonal lives, and/or community, civic, and social participation. Using thematic synthesis (Ryan et al., 2018; Thomas & Harden, 2008), researchers coded data from each of the eight articles specific to the program components that authors attributed to positive participant outcomes. Similar codes developed across the eight studies were clustered together to form themes reflective of the common characteristics utilized within RT interventions aimed at improving community participation among TAY with IDD. After independently reviewing the literature and developing codes, the two researchers met together to compare and discuss codes. The discussion facilitated researchers confirming that the data were interpreted the same
<table>
<thead>
<tr>
<th>Authors</th>
<th>(Publication)</th>
<th>Research Design</th>
<th>Purpose of Study &amp; Sample</th>
<th>Sample Size</th>
<th>CTRS®-Led Program</th>
<th>CTRS®-Led Program Outcomes</th>
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<tbody>
<tr>
<td>Bedini et al.</td>
<td>(1993)</td>
<td>Multi-method; experimental pre/post-test design with control group &amp; qualitative case study interviews</td>
<td>Research study assessing impact of leisure education on successful transition from school to adult life for individuals with IDD (ages 17-22). Thirty-eight participants completed quantitative data; nine completed qualitative interviews. Twenty-four of 38 participants were in the experimental group; 14 were in the control group.</td>
<td>38</td>
<td>CTRS®-Led Program</td>
<td>Improvements in leisure awareness, activity initiation, self-confidence, social skills, perceived freedom, and leisure appreciation.</td>
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<td>Ashton-Shaeffer et al.</td>
<td>(1995)</td>
<td>Multi-method; qualitative interviews, quantitative functional assessment battery, and observations/field notes</td>
<td>Research study evaluating impact of leisure education on two individuals (ages 16 and 21) with IDD’s leisure skills, self-confidence, self-determination, and social skills.</td>
<td>2</td>
<td>Home-school-community Leisure Education Program</td>
<td>Increases in leisure skills, independence and self-determination.</td>
</tr>
<tr>
<td>Hoge et al.</td>
<td>(1999)</td>
<td>Quantitative, pre/post-test design</td>
<td>Research study evaluating impact of TRAIL leisure education on perceived freedom among youth with IDD (ages 15-20). Nineteen individuals were in the experimental group; 21 were in the control group.</td>
<td>38</td>
<td>TRAIL Leisure Education Program</td>
<td>Increased perceived freedom in leisure.</td>
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<tr>
<td>Dattilo</td>
<td>(2002)</td>
<td>Qualitative, semi-structured interviews</td>
<td>Research study examining impact of TRAIL leisure education on perceived freedom among twelve youth with IDD (ages 15-20).</td>
<td>12</td>
<td>TRAIL Leisure Education Program</td>
<td>Participants reported that leisure education allowed them to &quot;(a) get out in the community, (b) try new things, (c) overcome barriers to leisure, (d) make new friends, (e) overcome new things, (f) overcome barriers to leisure, and (g) have fun with funny people.&quot; (p.55).</td>
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<tr>
<td>Study</td>
<td>Methodology</td>
<td>Research Design</td>
<td>Population</td>
<td>Outcomes</td>
<td>Notes</td>
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<td>Miller, et al. (2002)</td>
<td>Qualitative focus groups, and observation/field notes</td>
<td>Research evaluating benefits of individuals with IDD’s participation in an inclusive volunteer program (with peers w/o a disability). Ten participants had an IDD; over the course of two academic semesters, 20 participants without a disability partnered with participants with an IDD.</td>
<td>Building Community through Inclusive Volunteering</td>
<td>Positive emotional outcomes “such as excitement of a job well done, enjoyment, increased involvement, eagerness to participate” were reported (p.252). Additional results related to communication and social skills, activity-specific skill development, feelings of pride, ownership, and empowerment.</td>
<td>Note: IDD=Intellectual and Developmental Disability; ASD=Autism Spectrum Disorder</td>
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<td>Crawford et al. (2012)</td>
<td>Multi-method; Observation, parent questionnaire, homework assignments, phone and email communication logs</td>
<td>Research study evaluating social skills training and leisure education program for eleven youth with ASD (ages 16-19).</td>
<td>School/Community/Home (SHC) Model of Social Skills Development</td>
<td>Outcomes reported included improved social skills, leisure skills development, and improved social networks.</td>
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<tr>
<td>Kunstler et al. (2013)</td>
<td>Multi-method; fitness measures (e.g., weight, BMI), open-ended fitness questionnaire</td>
<td>Overview of FreshenUp inclusive recreation program for individuals with disabilities (ages 15-18). Data represented 136 participants of 235 who participated in one of three FreshenUp program.</td>
<td>FreshenUp</td>
<td>Outcomes reported included improved social skills, and increased participation in physical activity and leisure.</td>
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<td>Wilder et al. (2014)</td>
<td>Multi-method; Case study example</td>
<td>Described TREK Program; a RT-based transition service focused on transitional needs of students (grades K-12) with disabilities. A single participant is presented as a case example.</td>
<td>Leisure Education within Therapeutic Recreation Empowering Kids (TREK) Program</td>
<td>Increased social skills, assertiveness, leisure activity initiation, and self-advocacy.</td>
<td>Note: IDD=Intellectual and Developmental Disability; ASD=Autism Spectrum Disorder</td>
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way in reference to the purpose of the systematic review. Based on consensus among the two researchers, codes were translated into final descriptive themes.

Limitations of the Systematic Review

Researchers did not have access to articles published prior to 1990 for the *Therapeutic Recreation Journal* and ATRA Annual in Therapeutic Recreation, or access to articles published prior to 2004 in the *American Journal of Recreation Therapy*. It is possible that articles published prior to 1990 or 2004 in each of these journals met inclusion criteria for the systematic review. Additionally, researchers only searched these three RT-specific journals. It is possible that there are peer-reviewed articles reflective of CTRS*-led programs focused on community participation and TAY with IDD that have been published in non-RT journals that are not included in this systematic review.

Researchers selected articles for the systematic review sample based on inclusion and exclusion criteria. A quality appraisal checklist was not used to assess the quality and credibility of the research included in the sample. Also, due to an inconsistent use of terminology (e.g., community participation vs. community integration) in the literature, it is possible that articles that met systematic inclusion criteria were unintentionally excluded from the review as a result of their using terminology that differed from the ICF-based definition of community participation that framed this study.

Authors originally targeted research that involved CTRS*-led programs focused on TAY with IDD and community participation as a primary outcome. However, authors were unable to locate any articles in which community participation was a primary outcome addressed by CTRS’s. This required authors to broaden the scope of the systematic review, to include CTRS*-led programs that addressed community participation as one component of broader RT programs, to improve participants’ interpersonal, community, civic, and social lives. It is possible that there is additional RT-specific literature that involves community participation as a component of programming that was excluded from this systematic review if programming extended beyond the ICF-based definition of community participation that framed this study.

**Results**

Eight studies related to CTRS*-led programs and interventions that intended to improve the interpersonal lives, and/or community, civic, and social lives of TAY with IDD were included in the review. Thematic synthesis of the eight studies revealed three themes: 1) programs with collaboration and community supports, 2) leisure education, and 3) social skills training.

**Programs with Collaboration and Community Supports**

Recognizing that leisure participation can lead to community engagement and the development of life skills necessary for successful post-high school transition, all eight studies discussed the importance of community supports and collaboration when working to develop social skills and a healthy leisure lifestyle among TAY with IDD (Ashton-Shaeffer et al., 1995; Bedini et al., 1993; Crawford et al., 2012; Dattilo, 2002; Hoge et al., 1999; Kunstler et al., 2013; Miller et al., 2002; Wilder et al., 2014). Involvement of natural supports and partnerships with members of the community occurred in efforts to help TAY with IDD transition to a more engaged community life post-graduation. Collaborative partners included school systems, local communities and organizations, parents/guardians, and peers without disabilities.
School Systems

Seven studies highlighted CTRS® supervised programs that occurred in collaboration with schools and special education programs of TAY with IDD (Ashton-Shaeffer et al., 1995; Bedini et al., 1993; Crawford et al., 2012; Dattilo, 2002; Hoge et al., 1999; Miller et al., 2002; Wilder et al., 2014). Working with school teachers and students’ IEP team members, CTRSs® identified how and in what ways leisure-based programs and interventions could assist participants in achieving IEP goals and developing skills necessary for successful transition after high school. As a result, the needs of TAY with IDD were being addressed through outcomes-driven, individualized leisure-based programming.

Four of eight studies involved partnerships with local university recreational therapy departments, undergraduate and/or graduate students (Ashton-Shaeffer et al., 1995; Kunstler et al., 2013; Miller et al., 2002; Wilder et al., 2014). This helped fulfill staffing and resource needs required of facilitating the recreational therapy programs with TAY with IDD and provided a sustainable model for school administrators interested in providing CTRS®-led transition services for students with disabilities (Kunstler et al., 2013; Miller et al., 2002; Wilder et al., 2014). Simultaneously, these partnerships provided college students an opportunity to apply their classroom knowledge and skill in a real-world setting, while obtaining a greater understanding of the needs, interests, behaviors, supports and challenges encountered by TAY with DD (Miller et al., 2002). Recreational therapy students were provided a hands-on opportunity to assess participants, develop individualized treatment goals, plan and implement recreational therapy programs, and evaluate participant and program outcomes (Ashton-Shaeffer et al., 1995; Kunstler et al., 2013; Miller et al., 2002; Wilder et al., 2014).

Local Communities and Organizations

Each of the CTRS®-led programs discussed in the eight studies involved an experiential learning component within participants’ home communities that required CTRS’s and school personnel to network with community-based organizations that provide leisure-related programs, or access to leisure-related programs (e.g., public transportation) (Ashton-Shaeffer et al., 1995; Bedini et al., 1993; Crawford et al., 2012; Dattilo, 2002; Hoge et al., 1999; Kunstler et al., 2013; Miller et al., 2002; Wilder et al., 2014). Learning in their communities resulted in increased social interaction and social skills among TAY with IDD (Crawford et al., 2013; Miller et al., 2002; Wilder et al., 2014), opportunities to overcome barriers to participation (Dattilo, 2002), increased participation/involvement (Bedini et al., 1993; Kunstler et al., 2013; Miller et al., 2002), and increased leisure skills (Ashton et al., 1995; Bedini et al., 1993; Crawford et al., 2012; Hoge, 1999; Kunstler et al., 2013; Wilder et al., 2014). The benefits of collaborating with the local community and community organizations were not exclusive to TAY with IDD; community organizations and stakeholders also benefited from these partnerships as it increased their awareness of TAY with IDD, and positively influenced perceptions and attitudes regarding the abilities and inclusion of TAY with IDD (Kunstler et al., 2013; Miller et al., 2002).

Parents/Guardians

While several studies obtained data from parents/guardians to determine participants’ progress toward individualized goals, four studies significantly involved par-
participants’ parents/guardians in the program planning and/or implementation process (Ashton-Shaeffer et al., 1995; Bedini et al. 1993; Crawford et al., 2012; Wilder et al., 2014). During planning, CTRS® supervised personnel-gathered information from parents/guardians regarding the participant as well as the participants’ family units. This information allowed a better understanding and targeting of the needs of the participant based on the sociocultural context in which they live, including their individual and family-based leisure interests, and their access (or lack of) to programs and resources. Parents/guardians were also involved in the implementation phase as they assisted TAY with an IDD in practicing learned skills, completing application-based homework assignments, and/or by role playing and modeling behaviors.

**Peers without Disabilities**

Three studies highlighted the importance of pairing TAY with IDD with a typically developing peer (Crawford et al., 2012; Kunstler et al., 2013; Miller et al., 2002). The purpose in pairing TAY with IDD with peers without disabilities, was to provide TAY with IDD an opportunity to develop social skills, understand differences in social connections (e.g., acquaintance vs. activity buddy vs. best friend), and establish social supports in an inclusive environment (Crawford et al., 2012). Peers without disabilities also provided mentorship to TAY with IDD during community outings, helping them build skills necessary for activity involvement including technical activity skills, problem-solving skills, confidence, assertiveness, and autonomy (Kunstler et al., 2013; Miller et al., 2002).

Two studies provided leisure coaches to TAY with IDD (Dattilo et al., 2002; Hoge et al., 1999). Leisure coaches were peers without disabilities trained to advocate for, and assist TAY with IDD with identifying, accessing, and engaging in community activities (Dattilo et al., 2002; Hoge et al., 1999). Prior to the experiential learning opportunities provided to TAY with IDD, leisure coaches met with community partners and the parent/guardian of TAY with IDD to ensure physical and emotional supports were established such that the participant experienced positive, successful recreation and leisure participation. As TAY with IDD became more independent and competent in their skills and abilities, leisure coaches slowly transitioned out of their coaching roles (Dattilo et al., 2002; Hoge et al., 1999).

**Leisure Education**

Six of eight articles identified leisure education as a CTRS® supervised, school-based intervention used to address the transition needs of TAY with IDD (Ashton-Shaeffer et al., 1995; Bedini et al., 1993; Crawford et al., 2012; Dattilo, 2002; Hoge et al., 1999; Wilder et al., 2014). Five leisure education programs were introduced across the six articles, including: the Wake Leisure Education program (Bedini et al., 1993); the home-school-community based leisure education program (Ashton-Shaeffer et al., 1995); the Transition through Recreation and Integration for Life (TRAIL) program (Dattilo, 2002; Hoge et al., 1999); the School/Community/Home Model of Social Skills Development (SCH) program (Crawford et al., 2012); and the Therapeutic Recreation Empowering Kids (TREK) program (Wilder et al., 2014) (See Table 2 for a summary of each leisure education program).
## Summary of Leisure Education Programs

<table>
<thead>
<tr>
<th>Table</th>
<th>Program Name</th>
<th>Authors</th>
<th>Setting &amp; Participants</th>
<th>Program Format &amp; Length</th>
<th>Assessments Used</th>
<th>Curriculum Content</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>Wake Leisure Education Program</td>
<td>Bedini et al. (1993)</td>
<td>Public school system in Wake County, NC 38 high school students ages 17-22 with ID receiving special education</td>
<td>26 weeks, 2 sessions per week</td>
<td>- Leisure Inventory Update&lt;br&gt;- Student survey: assertiveness, independence, self-esteem, communication and social barriers, competence, perceived control, leisure satisfaction, life satisfaction-leisure awareness, leisure definition.</td>
<td>Ten-unit curriculum:&lt;br&gt;1) Leisure awareness.&lt;br&gt;2) Self-awareness in leisure.&lt;br&gt;3) Leisure opportunities.&lt;br&gt;4) Community resources awareness.&lt;br&gt;5) Barriers.&lt;br&gt;6) Personal resources and responsibility.&lt;br&gt;7) Planning.&lt;br&gt;8) Planning an outing.&lt;br&gt;9) The outing.&lt;br&gt;10) Outing evaluation: future plans.</td>
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<tr>
<td>3</td>
<td>Home-school-community Leisure Education Program</td>
<td>Ashton-Shaeffer et al. (1995)</td>
<td>School, home and community in a large city in the southeastern United States 2 TAY with IDD, ages 16 and 21</td>
<td>Participant 1: 7 months, 1x week&lt;br&gt;Participant 2: 12 weeks, 2x week, 1-hour per session</td>
<td>- Student: Curriculum Based Measures&lt;br&gt;- Parents: Inventory for Client and Agency Planning (ICAP): social &amp; communication, community living, personal adjustment scales, situational inventory, and personal leisure interest/satisfaction inventory&lt;br&gt;- Teachers: ICAP: social &amp; communication, community living, and personal adjustment scales</td>
<td>School Community-Leisure Link Curriculum with Leisure Action Plan:&lt;br&gt;1) Four modules of leisure awareness.&lt;br&gt;2) Two modules of leisure decision-making.&lt;br&gt;3) Three modules of leisure communication.&lt;br&gt;4) Two modules of leisure resources.</td>
</tr>
<tr>
<td>4</td>
<td>Transition Through Recreation and Integration for Life (TRAIL) Leisure Education Program</td>
<td>Hoge et al. (1999)</td>
<td>3 high schools in two counties of a southeastern state 19 TAY with ID in the experimental group, ages 15 to 20</td>
<td>18 weeks, 3x week 1-hour classroom sessions followed by home community sessions with a leisure coach for up to six months, 2x per week 1-hour sessions</td>
<td>Short Form A of Leisure Diagnostic Battery</td>
<td>Five units of instruction:&lt;br&gt;1) Leisure appreciation &amp; enjoyment.&lt;br&gt;2) Leisure resources.&lt;br&gt;3) Leisure opportunities.&lt;br&gt;4) Leisure appreciation &amp; enjoyment.&lt;br&gt;5) Leisure appreciation &amp; enjoyment.</td>
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</tbody>
</table>
Table 2 (cont.)
Transition Through Recreation and Integration for Life (TRAIL) Leisure Education Program

<table>
<thead>
<tr>
<th>Program</th>
<th>Setting</th>
<th>Participants</th>
<th>Format</th>
<th>Curriculum Components</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dattilo (2002)</td>
<td>3 schools in the northeast section of a southern state</td>
<td>12 TAY with IDD, ages 15 to 20</td>
<td>18 weeks, 3x week 1-hour sessions</td>
<td>- Short Form A of Leisure Diagnostic Battery</td>
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<tr>
<td></td>
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<td>Five units of instruction: 1) Leisure appreciation. 2) Social interaction and friendship. 3) Leisure resources. 4) Self-determination. 5) Decision-making.</td>
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<td>Leisure education within the School/Community/Home (SCC) Model of Social Skills Development</td>
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<td>Curriculum based on School-Community Leisure Link Project; components included: 1) Building awareness of leisure patterns and attitudes. 2) Assessing leisure interests and preferences. 3) Facilitating knowledge of leisure resources. 4) Teaching leisure and recreation skills. 5) Facilitating participation in activities at home, school, and in the community.</td>
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<tr>
<td></td>
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<td>Leisure Education within Therapeutic Recreation Empowering Kids (TREK) Transition Services</td>
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<tr>
<td>Wilder et al. (2014)</td>
<td>Public school system in New Hampshire with community components</td>
<td>1 case study example</td>
<td>5 years. Students received weekly sessions with a CTRS, with 2-3 hours of leisure education homework assigned each week. Bimonthly social club outings also occurred; a total 400 hours of intervention were provided each year.</td>
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<td>Leisure education content: 1) Valuing of the leisure experience and of health and wellbeing. 2) Social interaction and social skills in leisure. 3) Leisure resources. 4) Leisure awareness. 5) Recreation skill development. 6) Self-advocacy and self-image. 7) Self-determination and independence.</td>
</tr>
</tbody>
</table>

Note: ID=Intellectual Disability; IDD=Intellectual and Developmental Disabilities; TAY=Transition Aged Youth; ASD=Autism
All five leisure education programs emphasized the importance of 1:1 skill instruction and individualized content. The duration of leisure education programs ranged from 12 weeks to continuous instruction over 10 years (i.e., beginning in elementary school, through high school graduation); most programs were offered in 60-minute increments, two to three times a week. Across the five leisure education programs, curricula content focused on self-awareness in leisure, leisure opportunities, leisure resources, barriers to leisure, leisure and recreation skill development, leisure planning, social skills, leisure decision-making, self-determination, self-advocacy, and self-image. Participants’ progress was measured using qualitative and quantitative data, including the use of standardized and non-standardized assessments, interviews, and observation collected from participants, participants’ parents/guardians, school personnel, program facilitators or peer mentors involved in leisure education programming. Outcomes of participation in the leisure education programs included participants’ increased leisure awareness, community involvement, decision making and problem-solving skills, initiative and assertiveness, self-determination, perceived freedom, and independence.

**Experiential Learning in the Community**

All five leisure education programs incorporated individual or group experiential learning in the community into their curricula. For example, the Wake Leisure Education program (Bedini et al., 1993) included four units of leisure education in the community; the home-school-community based leisure education program (Ashton-Shaeffer et al., 1995) included home and community-based training in real life situations; and the TRAIL program (Dattilo, 2002; Hoge et al., 1999) included home and community sessions that allowed participants to engage in programs within their community. Similarly, the SHC program (Crawford et al., 2012) included bimonthly social club outings for community activities and events; and the TREK program (Wilder et al., 2014) involved participation in community experiences to foster recreational and social skill instruction, self-determination, independence, and supports for post-secondary education and/or vocation. While the frequency and duration of applied learning opportunities in the community varied across studies, all leisure education curricula focused on participants practicing the skills they had learned during traditional classroom, 1:1 or group sessions in a real-world environment. For example, program participants engaged in outings to restaurants, sporting or cultural arts events, and sports, dance, or music lessons to practice communication, problem-solving and decision-making skills (Ashton-Shaeffer et al., 1995; Bedini et al., 1993; Crawford et al., 2012; Dattilo, 2002; Hoge et al., 1999; Wilder et al., 2014). The experiential learning component of the leisure education programs ultimately facilitated community participation among TAY with IDD.

**Social Skills Training**

Based on pre-existing literature, and insight from parents/guardians and teachers of TAY with IDD, social competence was identified as a precursor for successful transition and community participation of TAY with IDD in all eight studies (Ashton-Shaeffer et al., 1995; Bedini et al., 1993; Crawford et al., 2012; Dattilo, 2002; Hoge et al., 1999; Kunstler et al., 2013; Miller et al., 2002; Wilder et al., 2014). Thus, all seven programs included a social skills training component and individualized goals related to interpersonal skills as authors indicated the need and critical importance of
social interactions, social networks, and friendships among TAY with IDD before, during, and after high school graduation (Ashton-Shaeffer et al., 1995; Bedini et al., 1993; Crawford et al., 2012; Dattilo, 2002; Hoge et al., 1999; Kunstler et al., 2013; Miller et al., 2002; Wilder et al., 2014). For example, Bedini and colleagues incorporated four units of social skills instructions in which TAY with IDD were taken into their respective communities to practice interacting with others and developing friendships. Likewise, the curriculum described by Hoge et al. incorporated one unit of instruction on social interaction and friendships as well as lessons on communication and social interaction skills including how to listen and speak to others, and how to develop friendships. The TREK program progressed from basic to intermediary social skill instruction, and utilized college students in allied health disciplines to engage in academic service relationships with TAY with IDD, which enabled students with disabilities to expand their social relationships (Wilder et al., 2014). TREK program curriculum focused on skills, attitudes, and awareness necessary for successful social interactions including enhancement of one’s ability to communicate about themselves and with others, development of appropriate relationship-building skills, social etiquette, self-advocacy, and self-image.

One of the programs reviewed incorporated an inclusive volunteering approach to help TAY with IDD practice and develop social skills (Miller et al., 2002). Miller and colleagues described an inclusive volunteering program that brought together TAY with IDD and college students without disabilities to participate together in a community service project. Authors emphasized that the design of the program allowed individuals to create relationships with other community members, thus benefiting them psychosocially. Outcomes related to social skills for this program included an improved ability to approach, initiate interaction, and communicate with people with disabilities among college students. Similarly, FreshenUp (Kunstler et al., 2013) was an inclusive fitness program that paired TAY with IDD with college students to facilitate the practice of social skills in a natural community setting. One of the goals of the program was to increase participants engagement in inclusive fitness in a socially and age-appropriate manner. This goal was a precursor to the overarching program goals of creating inclusive communities, and enhancing self-sufficiency among TAY with IDD.

Finally, Crawford et al. (2012) described an intervention focused on social skills training in which each participant had target social behaviors to work on based on individual goals. The intervention incorporated a Friendship Circles Model and a bi-monthly social club based on the Trio Model in which one adult staff member, one TAY with IDD, and one typically developing peer participated together in community activities. The curriculum was designed to use RT services to teach social skills to TAY with IDD for the purpose of nurturing relationships, friendships, and the accompanying effects of social acceptance and belongingness. Authors noted that systematic leisure education and social skill instruction can help TAY with IDD develop the skills necessary for successful participation in school and community environments. Authors asserted that “in the social world of work and life, only those who have mastered social relationships can be truly successful” (Crawford et al., 2012, p.32), which accentuates the imperative role of social skills and social competence in successful community participation.
Discussion

Results of the systematic review suggest that CTRS*-led programs incorporate many of the components identified in pre-existing literature as necessary for teaching TAY with IDD skills necessary for successful community participation. For example, in addition to offering individualized programs for TAY with IDD (Adair et al., 2015; Andrews et al., 2015), CTRS*-led programs included in the review involved typically developing peers (Andrews et al., 2015) and provided TAY with IDD opportunities to receive coaching and mentoring when engaging in leisure activities and social interactions in the community (Adair et al., 2015). Also, several programs included in the review involved TAY with IDD volunteering or contributing to community service campaigns, reflective of the importance of convivial encounters in community participation (Bigby et al., 2018; Craig & Bigby, 2015). By teaching TAY with IDD skills required for community participation and facilitating opportunities for them to apply and practice their skills in their local communities, TAY with IDD are able to establish and expand their social network (Bigby et al., 2018; Harlan-Simmons et al., 2001). Through collaborative programs that incorporate natural community supports, TAY with IDD can learn about resources in their own communities and develop social relationships that can be accessed post-graduation, leading to more engaged community lives as adults.

Systematic review findings suggest that several barriers associated with transition and community participation of TAY with IDD post-graduation can be decreased through participation in CTRS*-led leisure education and social skills programs. For example, a lack of accessibility and natural community supports, as well as negative perceptions of individuals with disabilities often make community participation difficult for individuals with disabilities (Andrews et al., 2015; Becker & Dusing, 2010; Murphy & Carbone, 2008). In addition to TAY with IDD receiving benefits of experiential and hands-on learning in their local communities, the CTRS*-led programs highlighted in this systematic review indicated that the community partners who collaborated with CTRS’s to offer programming to TAY with IDD also benefitted. Specifically, CTRS*-led programs reported that community partners experienced a greater awareness of the needs of TAY with IDD, an increased understanding of how to support them through accessible programming as well as an increased desire to participate in inclusive programming (Kunstler et al., 2013; Miller et al., 2012).

Implications for Recreational Therapy

The studies included in this systematic review demonstrate the importance of CTRS’s working in school settings, in collaboration with or as a member of the IEP team of TAY with IDD. CTRS’s should continue to advocate for positions in school settings. Also, CTRS’s working in schools should take the lead in targeting community participation as a primary IEP goal and treatment outcome for TAY with IDD through the facilitation of leisure education and social skills training programs. Results of the systematic review also indicate how critical it is for all members of the support network of TAY with IDD, including school personnel, community providers, parents/guardians, and IEP team members or therapists (including CTRS’s), to work collaboratively to help TAY with IDD learn and practice skills necessary for successful transition and engagement in community, civic, and social life post-graduation.
CTRS’s should also encourage support networks of TAY with IDD to involve peers without disabilities, and university students studying RT to serve as coaches or mentors to TAY with IDD. In doing so, individuals without disabilities have an opportunity to learn about the strengths, interests, and needs of TAY with IDD and how to best support them. Also, students studying to become CTRS’s have an opportunity to learn about the role of RT within schools, how to co-treat with other IEP team members, and develop professional skills related to planning and implementing leisure education and social skills training programs for TAY with IDD. This has the potential for peers without disabilities and university students to become advocates for accessibility and inclusion of TAY with IDD, while providing TAY with IDD an opportunity to establish and maintain friendships with peers outside of school.

**Future Research Recommendations**

A number of the studies included in the systematic review are not up to date (i.e., were published more than 10 years ago) but are the best currently available RT evidence on community participation for TAY with IDD. Authors recommend researchers investigate current practices among CTRS’s working with TAY with IDD to improve the clinical relevance of the evidence on this topic. Future research should evaluate the role and impact of CTRS-led services on community participation among TAY with IDD. Researchers should also work to identify the components within leisure education and social skills training programs that lead to successful transition and community participation of TAY with IDD post-graduation, so that a standardized curriculum can be developed. Dosage regarding the frequency, duration, and length of time TAY with IDD engage in CTRS-led services specific to community participation should be determined as well. Additionally, fidelity measurements of leisure education and social skills training programs are warranted to examine the extent to which delivery of interventions adheres to protocols or program models.

Finally, this systematic review only included CTRS-led programs that addressed two of the four components of community participation (Verdonschot et al., 2009). A comprehensive systematic review reflective of how and in what ways CTRS-led programs address all four components of community participation: domestic life; interpersonal life; education and employment; and community, civic, and social life (Verdonschot et al., 2009) is recommended.

**Conclusion**

The successful transition from adolescence to adulthood among TAY with IDD requires their active participation in community life. To the authors’ knowledge, this is the first systematic review of literature specific to RT interventions aimed at improving community participation among TAY with IDD. Findings of this review indicate that CTRS-led programs for TAY with IDD such as leisure education, social skills training, inclusive recreation, and inclusive volunteering incorporate components (i.e., mentorship/coaching, convivial encounters) that align with evidence-based facilitators of community participation. Results suggest that CTRS-led interventions can help decrease barriers to community participation of TAY with IDD such as accessibility issues, limited community and natural supports, and negative perceptions of individuals.
with disabilities among community members. Findings also indicate that community participation among TAY with IDD requires collaboration among all members of the support network of TAY with IDD (i.e., school system, IEP team, parents/guardians, peers with and without disabilities, community organizations). While CTRS’s are ideally situated to provide leisure education and social skills training interventions to help TAY with IDD become active members of their communities, more up-to-date research identifying best practices associated with CTRS-led leisure education and social skills programs for TAY with IDD is needed.

References


Jacobs, P., MacMahon, K., & Quayle, E. (2018). Transition from school to adult services for young people with severe or profound intellectual disability: A systematic re-


