Inclusive Community: What can Planners do to better serve adult children with intellectual and developmental disabilities and their parents with community recreational activities?

Aya Higuchi

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Inclusive Community:
What can Planners do to better serve adult children with intellectual and
developmental disabilities and their parents with community recreational activities?

by

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A creative component submitted to the graduate faculty
in Partial fulfillment of the requirements for the degree of
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Program of Study Committee:
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Ames, Iowa
2020

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Chapter 1. Introduction

People with intellectual and developmental disabilities can face a multitude of different challenges. Intellectual and developmental disabilities include a wide spectrum of various different disabilities, such as autism, intellectual disability, and cerebral palsy. The challenges for individuals with intellectual and developmental disabilities involve activities of daily living such as bathing, dressing, eating, toileting, challenging behavior, sensory sensitivity and insensitivity and so on. Because of these daily challenges, people with these disabilities often require assistance from caregivers. The caregivers are in charge of supporting and enhancing the quality of life of individuals with disabilities. This means that the caregivers are expected to “ameliorate as much as possible the medical, mental, and physical effects of the disabilities and to maximize the opportunities for active engagement” (Singh, 2016, p. 2).

Parents of people with intellectual and developmental disabilities tend to be the primary caregivers to the people with the disability. In fact, a lot of adults with these disabilities live with their aging parents who care for them throughout their lives (Heller, 2017). Adult children’s dependency on parents and parents’ long term caring for their children pose some difficulties to do things generally done without significant barriers like going out in public for recreational activities. Research shows that parents caring for children with a disability causes more stress than parents caring for children without one (Dhar, 2009). In addition to the difficulties and stress associated with caring for their children with these disabilities, there are limited services and supports in the community available to the parents (Association of University Centers on Disabilities (AUCD) and American Association on Intellectual and Developmental Disabilities (AAIDD), 2015).
Therefore, limited services and supports can restrict the developmentally disabled and their parents from fulfilling their needs and wants, and enjoying activities and amenities available in a community.

According to the Americans with Disabilities Act (ADA), it is prohibited to discriminate against individuals with any kinds of disabilities for “participating in basic civic activities” (U.S. Department of Justice, 2015, p.1). Even with ADA established, in a context of communities, people with intellectual and developmental disabilities and their families can face constraints on community inclusion due to lack of support and systems for them. *Family & Individual Needs for Disability Support (FINDS) Community Report* conducted a survey in 2017 in order to better understand the challenges families face and the support they need in terms of caring for people with intellectual and other developmental disabilities (Anderson, Hewitt, Pettingell, Lulinski, Taylor & Reagan, 2018). From this report, 83 percent of the respondents said they have challenges with “supporting friendships and inclusive community experience” (Anderson et al., 2018, p. 9) to meet the needs of family members with the disability. This result is similar to that reported in the previous survey conducted in 2010 (Anderson et al., 2018). In fact, the community experience people have can significantly influence their quality of life.

To better understand and provide the support needed, the majority of research conducted focuses on conditions and impacts to individuals with intellectual and developmental disabilities rather than on their caregivers. However, due to the fact that the people with intellectual and developmental disabilities are generally cared for and are assisted with daily activities by their parents, we have to better understand what needs to be been done to provide greater community inclusion for parents as caregivers. Even
though much research has done in consideration of improving quality of life of individuals with intellectual and developmental disabilities and their families in the fields of psychology, social science and disability studies, there is not much research on this topic in the field of community planning.

In the community planning profession, there has been discussion and research on planning issues with respect to minority and socioeconomically disadvantaged populations. Socioeconomically disadvantaged populations can include people with intellectual and developmental disabilities. Research has shown that throughout history, this population has been less likely to be included in the planning process. The issues and concerns within a community with socioeconomically disadvantaged populations are vast and complicated and thus, we need to pay more careful attention to their needs. Even though there has been more discussion on minority and socioeconomically disadvantaged people, not enough attention has been given to populations with disabilities, specifically to the needs of people with intellectual and developmental disabilities in planning. Community Planners can contribute to creating an integrated and inclusive community experience for those who tend to have less opportunity to do so by utilizing an inclusive planning process that shapes decision-making. As an example, the American Planning Association provides a set of ethical principles to planners which identify their responsibilities to the public. In the principles, it is stated that planners should “Strive to expand choice and opportunity for all persons, recognizing a special responsibility to plan for the needs of disadvantaged groups and persons” (American Institute of Certified Planners, 1992) and “shall urge the alteration of policies, institutions, and decisions that oppose such needs” (American Institute of Certified Planners, 2016, p.2).
Given the identified limitations in support and services available to this disabled population and their caregivers, there is a need for planners to contribute by creating more inclusive communities. However, the overall lack of research on, and therefore attention to, the intellectually and developmentally disabled within the field of planning, indicates that planners have overlooked this population and have yet to address this issue. Thus, there is a need for planners to conduct more research and consider this population as they plan for communities. All citizens have the right to thrive and enjoy the social interactions, activities, and amenities available in their neighborhoods and have an integrated and inclusive community experience. It is stated that “all State and local governments and all departments, agencies, special purpose districts, and other instrumentalities of State or local government” are responsible to ensure people are protected under ADA (U.S. Department of Justice, 2015, p. 1).

One of the aspects that can have an important role in influencing a positive and healthy community experience and improved quality of life is having access to leisure activities and amenities in the community. In other words, participating in recreation and leisure activities enhances physical health, leading to “development and expansion of skill repertoires, provides new outlets for hobbies, expands social networks, and contributes to a higher quality of life (Schleien, Rynders, & Green, 1994, p. 121). Furthermore, these opportunities must be ensured. This gives planners the responsibility to make sure that they understand the needs of community members with intellectual and developmental disabilities and their parents, so that communities can better plan for the needs of all community members. This also means the planners need to understand whether they are doing enough for the intellectually and developmentally disabled and
their caregivers to feel included and thrive in a community setting. As a result, this study intends to bridge the knowledge gap regarding the intellectually and developmentally disabled and their needs, and what actions planners can take to create more supportive/inclusive communities.

Scope of Study

This research report focuses on the parents of adult children with intellectual and developmental disabilities who are over 21 years of age, considering the public support these individuals can receive can get limited after the age of 21 including public education (Snow, 2015). The purpose of this study is to understand and describe their experiences with activities and community events outside of their home while they care for their adult children with intellectual and developmental disabilities. It aims to understand what kind of factors could influence the experience, decision-making, and range of actions to participate in community events and activities.

This research focuses on three main questions:

1. How do parents of adults with intellectual and developmental disabilities experience community events and activities in public places with their children?
   a. What does it mean to attend community events and engage in activities in public spaces for parents of adult children with intellectual and developmental disabilities?
   b. What are the thoughts, attitudes, feelings, concerns associated with community events and public activities?
2. How have experiences influenced parents' decision-making and range of action?
3. How can communities and local governments accommodate and support the families of people with intellectual and developmental disabilities?

An interview with service providers, an analysis of a municipal document, and a survey of parent caregivers will be conducted to answer these research questions. This research paper will review the literature that closely relates to this topic in the next chapter. Specifically, it will examine the definition of intellectual and developmental disabilities, history and milestones of the population, and previous research on quality of life and recreational and leisure activities for them and their families. Then, it will outline the methodological approach in Chapter 3. A pilot case study that involved a survey was utilized to investigate the matter of parents’ experiences. This pilot case study focuses specifically on public facilities, activities and events in the City of Ames, Iowa. Thereafter discussing the methodology, this research paper will continue on to discussion on research results in Chapter 4 and conclusions and recommendations in Chapter 5.
Chapter 2. Literature Review

In order to better plan for and integrate the intellectually and developmentally challenged into our communities, planners need to know more about this population and the challenges they face. This chapter will provide a definition of intellectual and developmental disabilities. Next, this chapter will examine the history of how this population has been treated within our society and communities and how this population transitioned to the current practice of community living. Then, this chapter will review the existing literature regarding people with intellectual and developmental disabilities, specifically examining topics related to quality of life, and leisure and recreational opportunities for people with these disabilities and their caregivers, parents.

Intellectual and Developmental Disabilities Defined

Developmental disabilities refer to a group of chronic conditions that are characterized by limitations with physical, learning, verbal, intellectual, and behavioral aspects (Centers for Disease Control and Prevention, 2019). This includes a mild to profound intellectual disability which is scaled with IQ tests, autism spectrum disorder, which can have sensory sensitivity and insensitivity, learning disabilities like dyslexia and dyscalculia, cerebral palsy, down syndrome, brain injury, fetal alcohol syndrome, and so on. These disabilities can occur in conjunction with other disabilities. An Intellectual disability is defined as “a significantly reduced ability to understand new or complex information and to learn and apply new skills” (World Health Organization, n.d.). It is regarded as one of the developmental disabilities (AAIDD, n.d.-a) and can be diagnosed before an individual reaches adolescence. People with an intellectual disability typically
have challenges with functioning, which is considered “the interaction of the person with his or her environment” (WHO, 2010, p.3). This means that people with the disability have limitations in intellectual functioning such as “learning, reasoning, problem solving” (WHO, 2010, p.3) and conceptual, social, and practical skills (AAIDD, n.d.-a).

History of Intellectual and Developmental Disabilities (IDDs)

In the United States, it is estimated that there are 7.37 million people (in 2016) with intellectual and developmental disabilities (Larson, Eschenbacher, Anderson, Taylor, Pettingell, Hewitt, Sowers, & Bourne, 2018). Historically, there were several terms that were used to describe people with intellectual disabilities, such as mental retardation or mental subnormality, but these terms are no longer used due to their insulting and discriminatory character. Instead terminologies like intellectual or learning disability are now typically used (WHO, 2010). Furthermore, over time there has been a shift in terms of care from models based on segregating the intellectually and developmentally disabled “in institutions to ones that give propriety to community-based living and social inclusion” (WHO, 2010, p. 2). The World Health Organization’s report explains the transition as

the older segregating model allows basic human rights to be violated and freedoms to be restricted. There is a growing research based consensus that institutionalization is an active source of harm and that institutions simply do not provide a suitable environment for any child to grow up, as they foster inhumane, dehumanizing, coercive and abusive forms of experience that systematically harm physical and mental health and can result in reduced life expectancy, or in the worst cases, in early death (WHO, 2010, p. 2).

The institution model was brought to the U.S. from Germany in 1800s (Spreat, 2017) and existed in practice until the mid 1960s, when the community service model was the
preferred practice as human rights for the population were advocated. These days, community-living services are provided to people with intellectual and developmental disabilities. These services are generally provided to them through federal funding utilizing a Medicaid waiver (Spreat, 2017). However, the Medicaid waiver system has a long waiting list, and individuals are not guaranteed to get it as soon as they need to start receiving the services. It is estimated that “there are more than 650,000 individuals on a Medicaid waiting list for needed home- and community-based services” (Horton, 2018, p. 4).

**Existing Research on Dependency and Burden on Parents**

It is said that adults with intellectual and developmental disabilities “have a higher likelihood of experiencing limitations in major life activities than persons with any other chronic mental, physical, or health condition” (LaPlante, 1991; Hayden & DePaepe, 1994, p. 173). In addition to this limitation, people with intellectual and developmental disabilities need continuous and lifelong assistance for basic daily activities (Hayden & DePaepe, 1994). This lifelong assistance is usually provided by family members, especially, parents. Wolfe (2014) states that parents of people specifically with autism, who were her study participants, see themselves as the primary caregiver of their children. Furthermore, the FINDS survey, conducted in 2017, reported that out of 2,905 respondents, 87 percent of caregivers of family members with intellectual and developmental disabilities, were parents (Anderson et al., 2018).

This finding illustrates the fact that family members, especially parents, intensively care for their children with intellectual disabilities. According to the
American Association on Intellectual and Developmental Disabilities (AAIDD), families of people with these disabilities “are overwhelmingly the primary, and often the major source of support” and approximately 75 percent of people with the condition live in their family home (n.d.-b). Yoong and Koritsas (2012) notes that more and more adults with an intellectual disability now have increased life expectancy and are not institutionalized, and “many of these adults now live in the community (Braddock et al. 2001), and this often brings the role of caregiver to the parents” (Ha, Hong, Seltzer & Greenberg, 2008, p. 610). While this specific finding occurred in Australia, this situation applies to the United States as well. In the United States, the number of individuals with intellectual disabilities were deinstitutionalized by eighty-five percent between 1965 and 2009 (Pollack, 2013). Pollack (2013) discusses the benefits of deinstitutionalization to individuals with intellectual and developmental disabilities, who were provided proper support and living opportunities with their families in their own communities. However, despite the reported benefits associated with deinstitutionalization, there were not adequate services provided to meet the needs of people with an intellectual disability due to “variable quality and cost-effectiveness of community-based services” (Pollack, 2013). Deinstitutionalization also increased the number of people, about 730,000, with an intellectual disability who live with caregivers age 60 and over (Pollack, 2013). This illustrates the increased burden on parents of people with an intellectual disability to take care of their children. Moreover, most caregivers for people with intellectual and developmental disabilities “provide more than 40 hours of care per week” (AAIDD, n.d.-b).
Inadequacy of Services

As identified from the research literature, the needs of people with an intellectual disability and their families are often not met because the support the community provides to them is not adequate. It is reported that “there is no comprehensive federal family support system in the U.S.” (AAIDD, n.d.-b). Therefore, communities are not meeting the needs of people with intellectual and developmental disabilities. Even when services are provided to individuals with intellectual and developmental disabilities in a local community, they might not be sufficient (Pollack, 2013; Horton, 2018; AAIDD, 2020). In addition to the lack of availability of services, financial constraints might also hinder the ability of families to receive needed services, and federal subsidies and other assistance to help get access to the services have limited availability as well (Horton, 2018). One in four caregivers reported that they were “waiting for government-funded services” (Anderson et al., 2018, p. 14), with 25 percent of respondents (1,248 caregivers) reporting that they have been waiting for services for less than a year while an additional 20 percent reported waiting for more than 10 years (Anderson et al., 2018). According to the American Association on Intellectual and Developmental Disabilities (AAIDD) (n.d.-b), the need for life-long caregiving negatively impacts the family financially in the long-term due to the expenses related to support and the fact that a family member often sacrifices employment opportunities in order to be a caregiver. In addition, even though “some states provide limited family support using state general fund dollars” (AAIDD, n.d.-b), or through Medicaid home and community-based services waivers, this financial assistance like Medicaid is not available for all individuals who is in need of these services at the time of their need. Issues of accessibility to services and
financial constraints also affects the caregivers, such as their parents and families, trying to meet the daily, intensive needs of the individual with intellectual and developmental disabilities.

**Community Participation and Inclusion**

People with intellectual and developmental disabilities “require support to perform basic daily activities and to achieve the national goals of equal opportunity, full participation, independent living, and economic self-sufficiency” (AAIDD, n.d.-b). This great involvement of caregivers with daily care and assistance and inadequate service availability and provision for them make it more likely for the caregivers of individuals with intellectual disabilities to have more difficulties and constraints with their daily lives than other community members without family members with the condition.

For individuals with developmental and intellectual disabilities, it is beneficial for their quality of life to have them integrated in a community. Expanding social interactions and participation in community activities and recreation gives individuals with intellectual and developmental disabilities opportunities to build relationships with peers, express themselves, and improve their skills by being integrated into their communities (Schleien, Rynders & Green, 1994, p.121). The expansion of recreation and leisure activities also brings people with the disability and their families benefits including “improved diagnostic assessment procedures; positive out-of-home placement policies; remedial programs; techniques for development and maintenance of personal, social, emotional, and physical functions; and respite opportunities for families” (Schleien, Rynders & Green, 1994, p. 123).
Throughout 1900s the provision of recreational services and programs for people with developmental disabilities was done at schools and were typically segregated from other students without the disability (Schleien, Rynders & Green, 1994). Having segregated programs for people with developmental disabilities can offer benefits such as providing interaction with peers, but the participants may have limited opportunities to overcome their challenges (Schleien, Rynders & Green, 1994, p. 125). Instead, being integrated in successful programs with peers without disabilities can help those with disabilities to develop and expand their social relationships. Recreation and leisure activities are shown to be some of the daily aspects that benefit the individuals and their families greatly but they are likely to have some limitations and struggle with coordinating and scheduling these activities. However, successful participation in community activities and recreational services does have a positive impact on an individuals’ community adjustment (Schleien, Rynders & Green, 1994). Unfortunately, research indicates that the effort of integrating individuals with developmental disabilities into recreational and leisure programs has had low priority (Schleien, Rynders & Green, 1994). Moreover, even though involvement and participation in leisure activities have empowered children and adults with developmental disabilities and helped individuals to become more productive and feel more fulfilled in life, there is significant room for improvement in terms of “quantity and quality of integrated recreation services for children and adults with developmental disabilities” (Schleien, Rynders & Green, 1994, p.122). In addition, enjoying community events and amenities is not as accessible and spontaneous for people with intellectual and developmental disabilities. Family members with a developmental disability tend to rely on family recreation, and the family
recreation inclines to requiring intensive planning and assistance outside of family, like a personal care attendant (Mactavish & Schleien, 2004). This means that the intensive planning and coordination with a third party to plan the activities can be very difficult.

As described, people with intellectual disabilities tend to be reliant on family members especially on their parents or other caregivers. Mactavish and Schleien (2004) state that people without a disability have established their own means of recreation by their adolescence. This means they adopt their own interests and groups for leisure activities by their teenage years. However, people with a developmental disability tend to rely on family recreation significantly from their childhood to adulthood and even after adulthood (Mactavish & Schleien, 2004). In the FINDS survey (Anderson et al., 2018), there are large number of caregivers (91 percent) who reported that they provide assistance with social and leisure activities for individuals with IDDs, and caregivers of individuals with intellectual disability and autism spectrum disorder (ASD) and those with ASD were more likely to find this assistance difficult or very difficult than other disabilities under the category of IDDs. It is also revealed that family recreation with family members with intellectual disability or developmental disability requires a lot of planning effort (Mactavish & Schleien, 2004). This need for significant planning constrains the range of family activities. It is explained that a lack of spontaneity made the family activities routine and predictable, which tends to make family recreation boring (Mactavish & Schleien, 2004). However, it is also explained by caregivers that “Getting out of the house, even for a short while and even though it takes more to organize, gives me and the kids a big lift. We don’t have to do anything really special once we get out there, just that change in scenery can be a big thing” (Mactavish &
Overall, families with a member with a developmental disability see family recreation activities as a positive for their family as a whole, and also for individuals within a family. Furthermore, the interactions that occurred through family recreation mainly involved mothers and the children (Mactavish & Schleien, 2004). Results from the study indicates the importance of recreational activities for the family with a member with a developmental disability and the significant burden on parents, especially on mothers, to manage such recreation.

There are intensive dependence and responsibility on their parents of people with IDDs, and it was reported that caregivers of IDDs think the most important aspect for well-being for those individuals is to “support for activities of daily living” (Anderson et al., 2018, p. 20). Considering this notion and discussions in previous paragraphs, it is apparent that we need to consider how communities/planners can better provide for those who need support and assistance for their daily life activities for people with intellectual and developmental disabilities and their caregivers. Therefore, planners need to pay more attention to the experiences and hardships that the parents of people with intellectual and developmental disabilities go through. Understanding their experiences and how those experiences affect the actions that they take is crucial to improving the environment where they live. Planners need to think about what communities and society as a whole can do to support these individuals, families and caregivers. What can planners do to accommodate and support these individuals and their families and thus, create more inclusive communities?
Existing Attempt to Fight This Issue and Gap to Fill in the Field of Planning?

In planning research, surprisingly there is little discussion focusing specifically on community planning and improvement for people with intellectual and developmental disabilities and their family. This is a huge gap that needs to be filled within planning research. On the other hand, in disability research, the majority of research focuses on quality of life (QOL) or factors that affect it for individuals with intellectual and developmental disabilities and not their parents. There is some research focusing on parents’ experiences, stress, and quality of life related to caregiving of their family members with intellectual and developmental disabilities. However, that research examines broad aspects of how caregiving influences their life and quality of life and one focuses on parents’ perspective on family leisure and recreational activities with individuals with intellectual and developmental disabilities. For instance, Mactavish & Schleien (2004) investigated parents’ experience and views on recreation. This research mainly looks at internal factors such as the nature of disabilities and age of the child and some external factors such as financial and time constraints, but it does not focus on other possible external factors of the physical and social environment. These factors of the physical and social environment can be essential to achieve accessibility to facilities that enrich one’s specific interactions with others.

Because of the constraints and limitations that parents experience, it is important to provide an understanding of specific experiences of their daily lives and activities outside their home in public spaces, in relation to the physical and social environment. Providing that understanding is crucial to creating an inclusive community and a better living environment that improves the quality of life of people with intellectual and
developmental disabilities and their families. The knowledge obtained from this research study aims to help connect planning professionals and community members to this community engagement effort and with the population with IDDs and their families. Therefore, it will explore the experience of parents of individuals with IDDs when they go out to community events and public spaces. This research study intends to encourage planners and policymakers to consider how they could be more responsive to meet the needs of people with the disabilities and their families.
Chapter 3. Methodology

This research focuses on understanding the experience of the parents of adult children with an intellectual disability with respect to public places, community events and activities in and around the City of Ames. This research project intends to help understand how their experiences at particular places influence their decision-making and range of action by asking the reasons of choice not to use or go to certain public facilities, community events and activities. To accomplish this, an explanatory case study is utilized in order to provide knowledge about the experiences of individual caregivers of adult intellectually and developmentally disabled children. This case study aims to understand how individual members and organizations in the community, and the municipal government can accommodate and support the parents and their adult children with intellectual and developmental disabilities by focusing specifically on settings in the City of Ames. It also aims to think about possible improvements and changes that the service providers, such as the City of Ames and other community organizations, can provide. To do so, an interview with two service staff providers to people with IDDs in Ames, an analysis of a municipal document, and a survey of parents of adult children with IDDs were conducted to investigate the discussed questions. The reasoning for choosing the methods will be discussed later on in this chapter.

As previously identified in chapter 1 there are three research questions along with two sub-questions asked in this study.

(1) How do parents of adults with intellectual and developmental disabilities experience community events and activities in public places with their children? From their experiences, a) what does it mean to attend community
events and engage in activities in public spaces for parents of adult children with intellectual and developmental disabilities? and b) what are the thoughts, attitudes, feelings, concerns associated with community events and public activities?

(2) How have experiences influenced parents’ decision-making and range of action?

(3) How can communities and local governments accommodate and support the families of people with intellectual and developmental disabilities?

To address these questions case study methodology will be utilized. Generally, a case study is a preferred method to use “when “how” or “why” questions are being posed, when the investigator has little control over events, and when the focus is on a contemporary phenomenon within some real-life context” (Yin, 2003, p. 1). In addition, “how” and “why” questions are likely to be more explanatory and “lead to the use of case studies” (Yin, 2003, p. 6). The research questions for this study is to understand “how” parents’ experience going to public places and community activities and “how” parents’ experiences influence their activities in a community. This is considered an explanatory case study which “explain the presumed casual links in real-life interventions” (Yin, 2003, p. 15). To answer the research questions, the case study utilized multiple sources of evidence including a survey, and an interview with service provider staff and an analysis of the City of Ames’ Parks and Recreation Programs and Facilities Guide were conducted as a means to answer the research questions. The pilot case study in the City of Ames was chosen especially because it provided the researcher with accessibility to participants
under this study, and also worked with the researcher’s time and financial constraints, as well as her limited geographical proximity. A pilot case study generally is selected for its “convenience, access, and geographic proximity” (Yin, 2003, p. 79). In Ames, there are many organizations that provide various services to people with intellectual and developmental disabilities. The primary investigator had better knowledge and access to these facilities who could help distribute surveys to the parents of people with IDDs. This ease of access to the facilities and convenience were the main reason for the selection of the research method and location. Secondly, the time frame in which the study needed to be completed and the limited resources the researcher had access to also influenced the choice of this research methodology and location. The convenience and accessibility to the facilities in Ames helped lessen the time and financial constraints for the researcher. In addition, the proximity to the facilities in the City of Ames allowed the survey distribution to be more feasible.

This research study is a single case study. It is a typical case that tries to “capture the circumstances and conditions of an everyday or commonplace situation” (Yin, 2003, p.41). The choice of single case study design is also because pilot case study may be used as the first step of a multiple-case study (Yin, 2003). This single-case pilot study will help to provide a basic understanding of how people experience their community activities and how planners and communities can help the population with IDDs and their families and also provide a research foundation for future studies in this area.
Pilot Case Study Details

As described briefly in the last paragraph, this pilot case study involves an interview, an analysis of a city document, and a survey. An interview was conducted with two staff members from one of the facilities who helped distributed the survey to the participants. The two staff members were the director and the case manager of an organization in the City of Ames who work closely with people with IDDs and their family and provide support services. The purpose of the interview was to understand the constrains and experience of parents of people with intellectual and developmental disabilities from the perspective of service providers. A municipal document of programs and facility guide of Ames’ parks and recreation was reviewed and analyzed to understand whether and to what degree support is offered by the City of Ames to accommodate the service users with IDDs and their families. Parents of adult children with intellectual disabilities were asked to take a survey to share the places, events, and their reasons of not using or going to certain facilities or events within the City of Ames. The survey also asks parents to share the reasons and factors related to their actions in question where the parents go and choose not to go. In detail, it asked respondents to share positive and negative aspects of going out to community activities in Ames with their adult children with IDDs. Other survey questions focused on investigating their previous experiences and reasons why they chose not to go to certain public places and community events in Ames. Furthermore, the respondents were asked to provide opinions and examples of other cities and organizations that provide support or services that help parents of people with IDD to go to public places and community events that they wish to
go. A copy of the survey questionnaire can be found in Appendix A at the end of this research report.

**Why Ames?**

The City of Ames was selected for this study for several reasons. In the state of Iowa, it is estimated that there are 118,575 noninstitutionalized Iowans aged over 18 years who “reported an independent living disability that made it difficult to go outside the home alone to shop or visit a doctor’s office” in 2018 (“Iowans with Disabilities: 2019”, 2019, p. 2). Furthermore, there are 136,126 Iowans “with limitation in cognitive functioning or who have a mental or emotional illness that interferes with daily activities” (“Iowans with Disabilities: 2019”, 2019). This includes a number of individuals with Alzheimer’s disease, intellectual disabilities, and mental illness such as anxiety and depression. Considering the challenges that people with disabilities have in their daily lives, it is important to support this population and prepare a safe and accessible living environment locally where they live and can thrive.

In the City of Ames, Iowa, there are several organizations such as ChildServe, Friendship Ark, Iowa Able Foundation, Lutheran Services in Iowa, Mainstream Living Inc., Optimae LifeServices, and The Arc of Story County who help people with intellectual and developmental disabilities with advocacy, habilitation, skill building, residential, vocational, recreational services, and financial assistance and variety of other services. Many of the organizations in Ames including ChildServe, Friendship Ark, Optimae LifeServices, and Mainstream Living Inc. provide supported community living services, day habilitation, and skill building programs. Lutheran Services in Iowa
provides a unique program called “Host Homes” which allows individuals aged 18 or older with disabilities to live in a private family home to build relationships with the family and better connections to their communities. Iowa Able Foundation specifically provides financial assistance and helps people with disabilities to be financially independent. Their services include providing assistive devices, home modifications, vehicle modifications, and service/support animal loans. It is crucial that not only these service providers, but the planners, the city, and the community as a whole, comprehensively and collaboratively support the population with the disabilities and their families through creating a more inclusive environment.

Before conducting the survey, an interview with two staff members/service providers, who advise and work closely with people with IDDs, and the analysis of an Ames Programs and Facilities Guide for Fall 2019 and Winter 2020 were carried out. The interview served to preliminarily understand the setting in Ames in terms of broad constraints and issues that parents of people with IDDs (intellectual and developmental disabilities) face in the community. The analysis of the municipal document was to examine the level of accommodation that the City of Ames provides on utilizing public facilities and activities to users with IDDs and their caregivers. The interview with the two staff members was conducted online on September 17, 2019, utilizing the Zoom application. The interview was informally structured inquiring about issues, constraints, and needs that the parents of people with IDDs have and lasted approximately an hour. The interview was guided by three open-ended questions, which will be discussed in detail in chapter 4. The two interviewees were selected based on their availability after the researcher contacted all the facilities/service providers to people with IDDs in Ames.
Simultaneously, a City of Ames’ Program and Facilities Guide was examined to see whether the city provides information regarding accommodating the participation of people with IDDs. The detail of this document review will be discussed in chapter 4 as well.

Survey participants were identified with the assistance of three organizations of the seven, that work with people with intellectual and developmental disability and their families in Ames. All three facilities and organizations assisted this study with distributing online survey links and mailing paper surveys to the service users, who are parents of individuals with intellectual and developmental disabilities. One agency sent 57 online surveys on December 3rd, 2019. A second agency sent 4 online surveys on December 4th, 2019 and the third agency sent 53 online surveys on December 5th, 2019. For those families who do not have any internet access, a paper format of the survey was distributed to 8 participants by the first agency on December 4th, 2019. A total of 122 surveys were distributed through both online and paper form. All the survey participants were selected based on the age of their adult children with intellectual disability being over 21 years old. This decision is due to the fact that after the age of 21 the public services, like educational services for people with intellectual disability, are no longer guaranteed. At the same time, caregivers tend to have concerns about the future of their family members with intellectual and developmental disabilities while they age and require care for themselves. For respondents who utilized the online survey, the responses were collected and stored directly to the Qualtrics system. For the paper form survey, facilities were asked to distribute the paper survey with an extra envelope and stamp ready so that the survey respondents could send the completed survey directly back to the
primary investigator of this research. There were 32 responses recorded to the Qualtrics system, and 26 responses were ultimately analyzed. This is due to the fact that six respondents did not complete all the survey questions, filling out only approximately half of the required questions and thus these surveys were not included in the analysis of the survey findings. No paper form surveys were returned to the investigator. As a result, the overall response rate is 21 percent.

Validity and Reliability of the Methodology

As identified previously, this research study utilizes case study methodology. All research methods have certain strengths and weaknesses and case studies are no exception. Some of the weaknesses associated with case study methodology include subjective measurements and judgements. For instance, this case study is likely to be subjective in measures and judgement used during data collection because of nature of case study (Yin, 2003). This is a concern for construct validity. To address this issue with construct validity, this methodology utilizes multiple sources of evidence including an interview, a document analysis, and a survey. By using several sources of evidence, the study is strengthened because it enables the researcher to triangulate the evidence and assess if the sources of evidence converge, thus addressing the construct and internal validity issue. It is also said that “any finding or conclusion in a case study is likely to be more convincing and accurate if it is based on several different sources of information” (Yin, 2003, p. 98).

In addition, an explanatory case study has a concern for internal validity. Internal validity is a concern for case study also because investigator makes a conclusion even though the event under study cannot be directly observed (Yin, 2003). To address internal
validity, multiple sources of evidence were converged and analyzed. The research then builds explanation in some details based on the evidence, which can be strengthened by gathering multiple experiences over the same phenomenon through interview or focus group. To address the trustworthiness of this study, chapters 4 and 5 consider and address contouring results and discussion to address the validity issues in this study.

In addition to these limitations already discussed, case studies are said to provide poor statistical generalizability, especially with a single case study. However, this case study relies on “analytical generalization”, and a single case study helps “identify the other cases to which the results are generalizable” (Yin, 2003, p. 37). In addition, because of the nature of a pilot case study, results will only be generalized under this study and with the existing research literature. Future studies will need to be conducted in order to replicate the results and be analytically generalized. The external validity should be ensured with the future studies that allows the sample size to be bigger along with a larger response rate. Compensating the participants could be another way to tackle external validity issue for the future studies and assist with increasing the response rate.

In relation to the external validity, another limitation associated with this study is that the survey was sent out and data collection occurred during December, which typically is a very busy time of the year for families. This time frame of survey collection might have limited the number of respondents. Due to the survey response rate being 21 percent, the results are unlikely to be representative of the larger population of people with intellectual and developmental disabilities.

In addition to the weakness mentioned above, this specific research study brings other limitations. This research study utilizes a survey and interview as part of the
research design, and these are biased as the interviewees and participants were recruited through service providers in the City of Ames. Furthermore, although the survey questions were designed to minimize biases in the responses, the survey questions could have had wording that limited answers. One of the questions asked the reasons why they chose not to go to places where they want to with their children with the disabilities. The specific question was worded that “If you check places you choose not to go, why do you choose not to go/ use to those places? Please select the same choices and describe your experience that have influenced your decision not to go to those places”. Numerous participants solely provided answers indicating the preference of the individuals with the disabilities instead of the related experience they have had in the past.

In this chapter and chapter 4, the validity issue is also addressed by clarifying the bias this methodology and the primary investigator can bring. Besides, a limitation of a survey question, “If you check places you choose not to go, why do you choose not to go/ use to those places? Please select the same choices and describe your experience that have influenced your decision not to go to those places” was discussed above. In regard to the wording of the question, it could have been improved by making the sentence more concise and ask specially their experience that might have influenced their decision of not using or going certain facilities or events in the community. In addition, the method can be improved by having another phase of qualitative method and analysis such as an interview or focus group with the parents of adult children with intellectual and developmental disabilities to better understand the detailed experience and reasons that might have influenced the decision.
Reliability and Research Protocol

The reliability for research study is determined by reducing error and biases, and one way to approach is to make research protocol. This way, the reliability can be ensured by being able to produce the same results by following the same procedures presented. Yin (2003) says that “The protocol is a major way of increasing the reliability of case study research” (p. 67). As shown in Figure 1, this research study followed 8 steps to conduct the case study. The first stage is to conduct the pilot case study by conducting an interview with service providers for people with IDDs, municipal document review, and surveying 26 parents of people with IDDs. The first stage was followed by the second stage of analysis of evidences obtained. Firstly, it examined key words and knowledge that was shared by the two service providers for people with IDDs in Ames. This helped inform the following steps of document analysis and survey development after knowing constraints and experiences of the parents of people with IDDs based upon service providers’ perspective and understanding. Next the municipal document review, complemented by knowledge from the interview and the literature reviews, was conducted. This helped understand the status quo of the community facilities and services in Ames, specifically examining the physical and social accessibility for people with IDDs and their families to utilize that can be seen in the municipal document. The survey was structured based on the insights and analysis from the interview and document review. Then the survey results were analyzed, and triangulated to identify if all three results from the interview, municipal document review,
and survey converged. Finally, through the converging and analyzing the three evidences, it draws conclusion and recommendation based on all three analysis.

In this chapter, the research methodology for this study - an explanatory pilot case study, was described. This pilot case study is a single case study encompassing an interview, a document review, and a survey. There are 118,575 noninstitutionalized Iowans aged over 18 years who have difficulties going outside of their home to meet their daily needs (“Iowans with Disabilities: 2019”, 2019), and there are significant needs in Iowa to better accommodate and serve people with disabilities. There are many organizations that help and support people with IDDs and their families in Ames. The site for this case study, Ames, Iowa, was selected due to the accessibility to participants and geography proximity that allowed to address time and financial constraints the study was subjected to. An interview was conducted with two staff members of a service provider organization that works with people with IDDs in Ames. Then, a municipal document review of Ames Programs and Faculties Guide for Fall 2019 and Winter 2020 was conducted. Next, the surveys were distributed both online and paper form with the assistance of three organizations in Ames. The construct, internal, and external validity
and reliability issues associated with this research were discussed and addressed in this chapter. To maximize the validity for this research study, multiple sources of evidence were collected and converge the results from all three sources. Furthermore, discrepant and countering results and discussion will be presented in chapter 4 and 5 to maximize the validity. The bias the researcher and method bring were discussed earlier in this chapter to address this research’s validity. Validity issues with one of the survey questions and lack of ability of the method to collect the detailed experiences from the participants were identified as well. Reliability issues were addressed by presenting the study protocol of this research study.
Chapter 4. Results

This chapter will discuss the findings from (1) an interview, (2) document review, and (3) survey detailed in chapter 3. All three stages of methodology complement each other to help understand the experience and answer the research questions. This chapter aims to converge and present the results “to build a coherent justification” (Creswell, 2003, p. 196). Overall results from all three analyses indicates that the City of Ames has room to improve physical and social accessibility of facilities, activities, and events in the city for people with intellectual and developmental disabilities (IDDs) and their families to utilize. The interview shows that there are some issues and constraints that the parents of people with IDDs face such as difficulties navigating through services and systems available and having understanding of the disabilities from others in public places. The municipal document review shows that there is not much accommodation in place to allow people with IDDs and their families to access the some of the recreational services provided by the city. The survey result shows there are some difficulties to access some places and activities in the community due to the facility’s accessibility issues in terms of unwelcomeness and physical environment that is not ready to accommodate the needs of people with IDDs and their families.

Interview Results

At the beginning of the data collection for this study, an interview was conducted with two staff members/service providers to people with intellectual and developmental disabilities and their families. These two staff members are from an organization who helped distributed surveys to the participants and work closely with people with IDDs
and their families. They were selected because of their availability and willingness to help the investigator for the interview after contacting all the facilities and service providers to people with IDDs in Ames. This interview lasted approximately an hour and was conducted in order to gather the service provider’s perspective and understanding of issues, constraints, and needs of parents in terms of caring for their children with ID disabilities. The interview was conducted through Zoom application on September 17, 2019. Three main questions were asked during the interview:

(1) Is there anything you, as a service provider, recognize as an issue that needs to be met?

(2) What do you hear from parents of people with IDDs most commonly in terms of challenges they face?

(3) What do you think communities can do to help parents, who provide care to their children with IDDs, have a better community experience outside home?

The staff members shared that parents of people with IDDs face issues with finding community placement for their children especially in their local area. They also mentioned that there are three agencies in the city that support employment for people with IDDs. However, there are not many business and employers who are willing to employ those with these disabilities. In addition, they mentioned that parents are often overwhelmed with caring for their children with IDDs. This is because the parents have a lot of difficulties and concerns regarding their caregiving. The transitioning of their children before and after guaranteed public education until the age of 21 is very hard to navigate. The parents are often worried about the future guardianship after they can no longer care for their children with IDDs. Some of these results coincide with the existing
literature that there is a lack of support from the community and hardships experienced by the parents. Furthermore, people with IDDs can have melt down in the middle of a store, throw tantrum, and knock over the shelf when the parents are with them. It is also mentioned that there have been cases when the police are called because of the meltdown and other behavioral issues mentioned above, but the police sometimes do not know how to deal with such a situation. The parents of children with IDDs can receive a lot of odd looks and comments because of these behaviors of their children in public. The staff also reported that their client shared a story that a nonverbal teenager with autism was in a car accident, and the teenager was not able to follow the direction of police officers. The staff acknowledge that there is a lack of understanding and ignorance about challenges of people with IDDs and their families face. The two staff members indicated that police, restaurants, and other services can make efforts to better accommodate people with IDDs and their families. One example provided by the interviewees is to accommodate their light sensitivity needs by having lights dimmed after certain time. To address the validity issue for the interview, it is likely to collect information biased towards being negative due to the interview questions formed to specifically understand issues, constraints, and needs of parents of people with IDDs.

**Document Review Results**

During the second stage of data collection, a municipal document, the City of Ames Programs and Facilities Guide for Fall 2019 and Winter 2020, was analyzed. This analysis was done in order to understand the level of accommodation offered by the City of Ames for people with IDDs and their families so that they are able to utilize facilities
and activities. This review of a municipal document is specifically aimed to address the study’s third research question (3) “How can communities and local governments accommodate and support the families of people with intellectual and developmental disabilities?” in the context of City of Ames. This review helped shape some of the questions that appeared on the survey questionnaire. Two questions were asked as part of this document review:

1. What recreational facilities and activities are offered by the City of Ames?
2. Do the facilities and activities provide services and accommodation to serve people with IDDs and their families?

There are many facilities, programs, and events are offered by the City of Ames. Parks, municipal pool, Ames/ISU Ice Arena, sports and fitness classes, school programs, special events, and many more are provided for Ames residents. Even though there are a lot of recreational services provided, there is no information to indicate the accessibility of facilities and programs in the document. The city states in the document that:

The Americans with Disabilities Act (ADA) prohibits discrimination on the basis of disability. In addition, the ADA requires that all citizens be given the opportunity to recreate in the “most integrated setting.” Individuals with disabilities are encouraged to recreate with their peers by registering for any activity offered by the Ames Parks and Recreation Department. Reasonable accommodations are provided to enable an individual’s successful participation in a program (City of Ames Parks and Recreation, n.d., p. 48).

However, despite acknowledgement of a need to provide accommodations for people with disabilities, the City of Ames does not appear to offer programs or classes designed specifically for people with (ID) disabilities and no information as to how they will accommodate a service user with a disability. It is very crucial to encourage all people to participate, but it is also important to have a prepared and safe environment for all people
to participate in services provided by the city. Furthermore, the Programs and Facilities Guide does provide recreation facilities tables for people to know about the availability of various amenities in woodlands, community, neighborhood, and specialized parks. Nonetheless, the tables do not indicate accessibility provided in these parks and woodlands like availability of multi-purpose restrooms.

**Survey Results**

This section will discuss the findings from the survey detailed in chapter 3. A total of 122 surveys were distributed, 114 online and 8 paper form surveys. On the Qualtrics system, 32 responses were recorded, however six respondents did not fill out more than half required questions. As a result, a total of 26 survey responses were analyzed to ensure the consistency of the results. Therefore, the responses rate is 21 percent. All the online surveys were recorded directly to Qualtrics - an online survey system. There were no paper form surveys returned to the primary investigator. It was presented at the beginning of the survey that the respondents had a choice to skip answering questions if they feel any discomfort answering them. The results show that some places and activities in the community are difficult to access due to the facility’s accessibility, unwelcomeness, and the characteristics and ability of individuals with intellectual and developmental disabilities. However, because of the nature of the survey questions to collect the experience and reasons why the parents choose not to go to certain places or activities, it contains possible bias due to the question asking specifically about the challenges they experienced. In addition, some of the multiple-choice answers intended to provide the respondents with comprehensive choice to choose from to make it
easier for answering questions. Nevertheless, the multiple-choice responses might have limited the possible answers from the survey participants even though an open-ended choice was provided with each question. Furthermore, these survey results cannot be generalized outside of this pilot case study.

**Characteristics of Respondents**

The survey results show that 82 percent of the respondents are parents who are between 50 to 79 years old (see Figure 2). The remaining 18 percent of the respondents were age 20 to 49 years old. There were three respondents who said they are between 20 and 39 years old which suggests that these respondents might be the guardian who are the siblings or other family members of the adults with the disabilities, rather than parents of the disabled individual. The surveys were asked to be sent to the parents of adult with intellectual and developmental disabilities, however, the distribution might have included respondents other than the parents of people with intellectual and developmental disabilities. Four respondents did not provide their age.

![Figure 2. Age of respondents](image)
In addition, 73 percent of the respondents who completed the survey were female, and 27 percent, were male.

When asked, 40 percent of the respondents reported to be the primary caregiver for their adult children with intellectual and developmental disabilities. The rest of the respondents, 60 percent, said they are not the primary caregiver. This seems likely that respondents who aren’t the primary caregiver might include siblings or other family members who filled out the survey, as 3 respondents identified their age between 20 to 39 years old (see Figure 2). It could also mean that the parents are getting daily assistance outside their house or by service providers more than half of a day as reported by 8 respondents (see Figure 5). It could also mean that the respondents simply did not identify themselves as a primary caregiver because someone else in their family are the primary caregiver. One person did not provide an answer for this question.

![Figure 3. Respondents' Employment Status](image-url)
Are you employed or working beyond the role as caregiver to your family member with IDDs? (Q. 17 in survey form)

As shown in Figure 3, 24 percent of respondents were not employed or did not work outside of the caregiving role and an additional 32 percent indicated that they are retired (see Figure 3). 44 percent of the respondents (11 respondents) reported that they work or are employed outside of caregiving. Those who worked outside of caregiving for their children with intellectual and developmental disabilities work either full-time or part-time. One reported volunteering 20 hours a week outside of caregiving. The number of responses were equal for full-time working for more than 40 hours a week, part-time working for 20 to 30 hours a week, and part-time working for 10 to 20 hours a week by 27 percent (see Figure 4).
How many hours of care or assistance per week does your family member with IDs receive outside of your house or by other care and service providers? (see Q. 19 in Appendix A)

The next question focused on the amount of assistance that was received in order to care for the individual with IDD. The assistance includes residential, vocational, skill building, recreational services, occupational therapy or any other daily assistance they receive from local organizations to fulfill their needs for independent and inclusive community living. All respondents reported that some assistance is provided, although the amount of assistance varies widely. For instance, 35 percent of 23 respondents whose children receive assistance from service providers reported more than 12 hours of assistance provided per day, which indicates either they live in a family home or live in a shared residence getting daily assistance through an agency (see Figure 5). Another 35 percent of respondents reported that their children receive less than 10 hours of assistance a week. This implies that the respondents might be required to provide assistance to their adult children more often than ones who receive assistance more than 10 hours a week. 17 percent of the survey participants said they receive assistance between 24 hours to 70 hours a week. The rest of 13 percent reported receiving assistance between 10 hours to 20 hours a week. One did not provide an answer and one reported “all”, and it was not able to get a numerical value.
Characteristics of Adult Children with IDDs

The age of respondents’ adult children with intellectual and developmental disabilities vary widely, ranging in age from 20 years old to 59 years old (see Figure 6). The survey respondents identified 72 percent of their adult children were 20 years old to 39 years old. The rest, consisting of 28 percent, were reported to be between 40 years old to 59 years old. Five respondents did not provide the age of their adult children.
The gender of adult children of respondents were almost equal by one count of answer. 11 respondents, 48 percent, reported their adult children were female, and 12 respondents, 52 percent, reported that their children with the disabilities were male. Three respondents did not provide gender of their adult children.

Please select the type of disabilities the other family member with IDDs have. Please select all that apply. (see Q. 23 in Appendix A)

Respondents were asked to identify more than one type of disabilities if applicable for this question. Percentages are calculated out of all 24 responses. 88 percent of respondents’ adult children have intellectual disability, the second most reported disability they have is speech and language impairment (See Figure 7). Autism spectrum disorder was the third highest disability to have among respondents’ adult children. Vision impairment was the fourth highest disability reported by 21 percent of the respondents. Fifth highest responses were ADHD, cerebral palsy, epilepsy by 17 percent. Hearing loss had the smallest response by 13 percent. Other disabilities reported
that were not included in the list of choices were low muscle tone, learning disability, Angelman Syndrome, some physical disabilities, and medical disability. There are other comments seen in the adult children “don’t have a good balance when walking in new places” and have “some autistic traits but not diagnosed”. Two respondents did not provide the answer to this question.

As shown in Figure 8 below, 20 percent of 25 responses (5 respondents) reported that the respondents have more than one adult children with intellectual and developmental disabilities in their families. Out of the five responses, two adult children are between 20 to 24 years old, three other adult children are between 25 to 29 years old, 45 to 49 years old, and 65 years old and above respectively. Furthermore, each of intellectual disability, autism spectrum disorder, ADHD, speech and language impairment had two people reported their children have these conditions, as shown in Figure 9. On the other hand, there was one respondent each who reported that the other child in their families had
cerebral palsy or epilepsy. Only three respondents out of five reported their adult children’s gender, one female and two males.

Figure 8. Other adult children with IDDs in a family

Figure 9. Disability type of other adult children with IDDs
Meaning and Experience at Public Places and Community Events

Do you go to public places and community events and activities in Ames with your adult children with IDDs? (see Q. 1 in Appendix A)

77 percent out of 26 respondents (20 respondents) said yes that they go to public places and attend community events in Ames with their adult children with IDD (see Figure 10). 15 percent of the respondents (4 respondents) reported that they “sometimes” go to public places and community events and activities in Ames with their adult children with intellectual and developmental disabilities. Only 8 percent of the survey participants (2 respondents) said they do not go to public places or community events and activities in Ames. The reasons for not going to public places and community events and activities were not provided by the respondents who answered no to the question. These two respondents who answered “no” to this question were not inquired for all the questions presented below in this chapter.

![Use of Ames Public Facilities and Events](image)

*Figure 10. Facility and activity visited in Ames*
Based on your own experience, what are the positive aspects of going to public places and community events with your adult children with IDDs in Ames? (see Q. 4 in Appendix A) (respondents choose all choices that apply)

The top two positive aspects were “We can have a good time with our adult children with IDDs (intellectual and developmental disabilities)” by 79 percent and “We can have a good time with our family as a whole” by 75 percent (see Figure 11). The third and fourth most reported positive aspects of community activities were “Socializing opportunity for my adult child with IDDs” by 58 percent and 54 percent of respondents chose community events and activities are “Inexpensive and affordable”. The least three positive aspects of were “Health benefits for my adult child with IDDs” by 33 percent, “Stress reliever for my adult child with IDDs” also by 33 percent, and “Meeting new people in my community” by 25 percent. These results correspond with the literature reviewed in chapter 2. Social interaction and participation in community activities gives people with IDDs opportunities to build relationships, improve their skills, emotional and physical functions (Schleien, Rynders & Green, 1994), and how the family recreation are considered positive for both individuals within family and family as a whole (Mactavish & Schleien, 2004).
Based upon your own experience, what are the negative aspects of going out to public places and community events in Ames with your adult child with IDDs? (see Q. 5 in Appendix A) (respondents choose all choices that apply)

Along with positive aspects, parents were asked to identify negative aspects associated with going to public facilities and community activities and events (see Figure 12). The most selected choice of negative aspect of utilizing public spaces and participating in community activities are “Where we can go is limited” by 38 percent. One respondent commented that “We have to be somewhat selective where we go due to her behavior”. 25 percent of the respondents reported that “It is very stressful”. Each of “It is time-consuming”, “Difficult to coordinate because of my adult child's disability” and “It takes extensive planning” had 21 percent out of all 24 responses. The adult children’s ability can cause some limitations in terms of where they chose to go and what they chose to do. It was mentioned that the child’s inappropriate public behavior, short attention span, and difficulty with waiting for a table in restaurants are some of the
negative aspects associated with going out to public spaces and community activities. The extensive planning and challenges with spontaneity and accessibility of enjoying community events and amenities were also reported by Mactavish and Schleien (2004). There were 13 percent of survey participants who said “We don’t feel welcomed” at the public places, community events and activities in Ames. It is commented that “Sometimes we don't feel welcomed or people stare or they don't try to understand my son's speech, but mostly people are very accepting”. In addition, the facility environment such as unavailability of adult changing table is also reported as one of the negative aspects. This shows that not only the adult children’s ability and behavior but also their surroundings and physical environment to accommodate individuals’ needs are the key elements for deciding places they go. Overall results coincide with the results of the interview and document review, as well as the literature review. Especially people don’t feel welcomed receiving some odd look and comments, shared by interviewees, and the community facilities and activities such as programs, fitness classes, and events are not integrated and accessible for people with IDDs as it is observed in municipal document. These findings are connected to respondents feeling where they can go is limited. Furthermore, these limitations also link to their extensive, stressful, exhausting, and time-consuming planning of leisure activities. On the other hand, one reported that “We're fortunate; we have not had negative aspects.”
The responses for questions asking positive and negative aspects of community activities answers the two sub-questions for the first research question asked in this study. The two sub-questions are:

a. What does it mean to attend community events and engage in activities in public spaces for parents of adult children with intellectual and developmental disabilities?

b. What are the thoughts, attitudes, feelings, concerns associated with community events and public activities?

The survey results show that participating in community activities is regarded as both positive and negative for these caregivers. On one hand participating in community activities provides an opportunity for the individuals with IDDs and their family to have a great time and socialize inexpensively. However, at the same time, this can be very stressful and time-consuming because of the extensive planning and limited public activities they can participate in. In addition, they don’t feel welcome at the events.
because they are stared at or they receive negative responses from others in public due to behaviors of their adult children with IDDs. These findings correspond with research literature discussed in chapter 2 that community activities can be both beneficial and stressful, requiring extensive planning, to go attend community activities. Besides, there is still a disconnect among the meaning, thoughts, attitudes, feelings, and concerns that parents of adults with IDDs have in regard to community activities under this study. The two sub-questions could be addressed better by enhancing the research methodology, such as utilizing focus groups or interviews with the parents of adults with IDDs for further understanding of their thoughts and feelings when interacting with the public out in the community.

Please identify public places and events you have visited/used in the past year with your adult children with IDDs. (see Q. 6 in Appendix A) (respondents choose all choices that apply)

The next question asked the respondents to “identify public places and events you have visited/used in the past year with your adult children with IDDs”. In Ames, Reiman Gardens and Ames Public Library were the most common places that 55 percent of the respondents visited in the past year (see Figure 13). Furthermore, CyRide, Downtown Ames Farmer’s Market, 4th of July Parade, and Furman Aquatic Center were utilized or visited more than other places on the list. In addition, the North Grand Farmer’s Market was visited by 27 percent of the respondents. Parks in Ames such as Brookside Park (2 responses), Ada Hayden (4 responses), Park on Oakwood Street (1 response) were visited by 23 percent of the respondents. The same percentage of participants, 23 percent, also
visited Durham Bandshell Municipal Band Concert and the Ames City Auditorium.

Outside of the list of choices, Jack Trice Stadium, Hilton Coliseum (2 response), Special Olympics cycling, ISU campus (2 response), ISU CY Stephens Auditorium. Two respondents who were inquired for this question did not identify the places, activities, and events they visited in the past year.

Please identify places you would like to go/ use with your adult children with IDDs but choose not to go/ use. (see Q. 7 in Appendix A) (respondents choose all choices that apply)

In addition to identifying the places and events they have visited, the respondents were asked to identify places they would like to go/ use with their adult children with IDDs but choose not to go/ use. The most reported place they would like to go but choose
not to go was Durham Bandshell Municipal Band Concert by 29 percent (see Figure 14).
Including Durham Bandshell Municipal Band Concert, Rock Creek State Park, North
Grand Farmer’s Market, Municipal Pool, Big Creek State Park, CyRide, Furman Aquatic
Center, Community Center are the top 8 choices of public places and events that
respondents would like to go but choose not to go. The Municipal Pool has “Limited
open hours” for persons with special needs, and one reported “The locker rooms are dirty,
the water is cold and there is no instruction for her ability”. Whereas Furman Aquatic
Center is too crowded and noisy which is overwhelming for the adult children with the
disabilities. Some respondents said their adult children with the disabilities can swim but
need light supervision. The Downtown Ames Farmer’s Market was also reported as being
crowded and noisy and overwhelming for some adult children with the disabilities. There
are some that are interested in City Fitness Classes and Wellness Programs, but because
of their individual child’s ability, it is said that suitable classes for these individuals are
difficult to find or not available, and there are no integrated activities for them. In
reviewing the Programs and Facilities Guide, there was no information of integrated
classes or programs for people with IDDs. Besides the situation with facilities and events,
public transportation is also a key element to consider as a limitation. In terms of CyRide,
a respondent mentioned the ability of the adult child and said “physically able but can’t
read”. This indicates that the adult child needs assistance with transferring from place to
place.

Aside from limitations due to ability, physical environment, and the
characteristics of the place and events, some parents mentioned reaction and attitude of
others in public. For example, at the Reiman Gardens, “some of the activities for kids
would interest her. But she is an adult and would be out of place.” Another respondent said that they “Don't want to inconvenience other golfers with the extended time it would take and potential need to chase lots of errant hit golf balls” at Homewood Golf Course, even though they would like to utilize the facility. The respondents’ worries might come from their experiences of receiving odd looks and/or comments. These results align with the lack of understanding and ignorance mentioned by service providers during their interview. Across the survey results, it seemed that the supervision of the activities is something to do with the limitation or hesitation to go to some public places and activities in the community. This includes the Municipal Pool, Furman Aquatic Center, Ames/ISU Ice Arena needing to provide some degree of supervision or assistance in order to be utilized by this population. One respondent wasn’t sure of the current availability of assistance at Ames/ISU Ice Arena that they have received in the past.

![Figure 14. Public places, community events and activities that parents would like to use but chose not to](image-url)
What would make it easier or possible for you to go to places you would like to go (with your child) but choose not to go? Identify the type of support/changes needed. (see Q. 9 in Appendix A)

The top three answers were “Quiet place is available”, “Welcoming atmosphere”, and “Flexible use (multi-purpose) bathroom is available” (see Figure 15). The ease of finding things they want to do and having access to navigation with readable and accessible signage were chosen by 40 percent of the respondents in total. 20 percent of respondents supported having people to give direction and assistance needed at the site of the event. These results are associated with accessibility of the place they visit. However, only 13 percent of respondents chose “Public places and venue for community events are accessible”. This matter of accessibility indicates not only eliminating physical environmental barriers such as having no steps and curbs and installing flexible use/multi-purpose bathrooms but also eliminating invisible barriers such as having assistance such as navigation, supervision, and accommodated instruction and guidance available and a welcoming atmosphere.
Both the positive and negative aspects of going to public places and community events shared by survey respondents had common results with the existing literature. Many respondents think community activities are positive experiences that bring the family opportunities to have a good time, socialize, relieve stress, stay healthy, build relationships, and improve their skills (Schleien, Rynders & Green, 1994: Mactavish & Schleien, 2004). Even though the negative aspects were reported relatively less than positive aspects, many reported that community activities they can do is limited, very stressful, and time-consuming. It is also reported that it requires extensive planning, and it is difficult to coordinate because of the disability. Sometimes they do not feel welcomed. It was also reported by Mactavish and Schleien (2004) that extensive planning and challenges with spontaneity and accessibility of enjoying community events and amenities limited the ability of families with children with IDD to take advantage of these
opportunities. Furthermore, the results from the interview and review of municipal document also showed that limited accessibility to facilities and programs and a lack of understanding and ignorance from the public can result in limitations and negative aspects as to participating in community activities. Overall, there are some issues for people with IDDs and their families to access some facilities and activities in the community due to the lack of accessibility such as flexible use restrooms, accommodation to meet the needs of people with IDDs to participate in programs and activities, and the lack of a welcoming environment.
Chapter 5. Discussion and Recommendation

The results in chapter 4 show that even though there are a lot of recreational and leisure facilities, activities, and events available in the city of Ames, there are many considerations that the city and planners can make to improve physical and social accessibility of facilities, activities, and events to better accommodate people with intellectual and developmental disabilities (IDDs) and their families. Chapter 5, will discuss what the City of Ames, city planners, and the Ames community can do to better serve people with IDDs and their families. This chapter will also make convergent recommendations based on the results from the interview, analysis of municipal program and facility guide, and survey discussed in the last chapter. This chapter will focus on answering the third research question:

3. How can communities and local government accommodate and support the families of people with intellectual and developmental disabilities?

In detail, it will consider recommendations and possible improvements on how to make the public and social environment and activities in the city more accessible and accommodating for people with intellectual and developmental disabilities (IDDs) and their parents. Lastly, it will consider what specific steps and detailed strategies planners and the city can make to better serve people with IDDs and their families. Planners play a significant role to engender attention and action by conducting research to plan for all and generate positive community change. Therefore, this research should be shared and used to influence and shape public policy. The results and recommendations which are
discussed in this chapter will be shared with the City and service providers in a form of an executive summary.

In the interview portion of this study, the staff from a service provider for people with IDDs presented their understanding of issues and needs the parents of children with IDDs face. They reported that the parents often feel overwhelmed with caregiving for their adult children with IDDs. Navigating through residential, vocational, and other services available for individuals with intellectual and developmental disabilities is not easy, and the parents have concerns thinking about the future such as guardianship for their children with the disabilities. In addition, the parents can face challenges when they go out in communities with their children with IDDs because of lack of understanding and ignorance from others. For example, the parents received odd looks and comments from others due to a meltdown or some other behavioral challenges displayed by their children with IDDs when in public. In addition to the results from the interview, the review of a municipal document shows that there is no information provided in the document as to public facilities, programs, events that are accommodated or prepared for people with IDDs and their families. There is no indication of accessibility in terms of ADA compliance of facilities, such as parks, municipal pool or community center where some fitness and youth class are held, in the document either. The results from both the interview and municipal document review, as well as the survey results indicates why parents limit themselves to going to some facilities or participating some programs and events with their children with IDDs in the City of Ames.

The results from the survey show how the respondents have felt and experienced activities both in a positive and negative manner outside of their house in public places
and the community. 38 percent of the survey respondents (see Figure 12) said that where they can go is limited, and this is mostly because of the behavioral and other challenges respondents’ children have. Furthermore, going to community facilities, activities, and events can be stressful and time-consuming due to the extensive planning required for the outing. 13 percent of respondents identified that they do not feel welcome at the community activities (see Figure 12). It is also reported that the inaccessibility of facilities is also a negative aspect of participating in activities outside of the house. However, the majority of the respondents also said community activities have a positive implication on their adult children with intellectual and developmental disabilities and on the whole family. This outcome is similar to the finding that family recreation is perceived as “a positive means for promoting overall quality of family life” (Mactavish & Schleien, 2004, p. 133). 54 percent of respondents said that these community activities are inexpensive and affordable and have a good socializing and health benefit for the respondents’ children with the disabilities.

Half of the respondents said they visited Reiman Gardens and Ames Public Library at least once during the past year (so between December 2018 and December 2019), when the survey was conducted. CyRide, Downtown Ames Farmer’s Market, 4th of July Parade, Furman Aquatic Center were identified as the most visited places other than Reiman Garden and Ames Public Library. However, because of the need for assistance with some of the activities, such as sports or using public transportation, the respondents are reluctant to use the services such as supervising aquatics and baseball, especially when they cannot provide that assistance or supervision themselves. Furthermore, 29 percent of respondents said that they choose not to go to Durham
Bandshell Municipal Concerts even though they would like to (see Figure 14). This might be due to the high level of noise that the adult children might not be able to cope well with due to the sensory challenges. Finally, the respondents commented that Fitness Classes and Wellness Programs offered by the city does not have suitable and integrated classes for individuals with the disabilities. This lack of accommodation with classes and programs for people with IDDs were also observed in review of Programs and Facilities Guide (City of Ames Parks and Recreation, n.d.).

In addition to the constraints with the nature of disabilities and facilities’ inaccessibility, there are some social constraints as well. It is mentioned that the parents are reluctant to go to places, events and activities in the community because they don’t want to trouble others who also engage in the activities/events. Besides, many respondents said that they have limitations with where they can go. For instance, one of the respondents said that “One time, our adult child wet his pants because he was nervous because he was in someone's wedding (…) that was kind of challenging...”. The experience both parents and the adult children have can also contribute to limiting the places they go. Furthermore, one respondent said that they get stared at by other people, and they don’t try to understand the speech of their adult child with the disability. This specific limitation was mentioned in the interview with the service providers to the people with IDDs as the parents can receive “odd look and comments” because of behavior of their children in public. Considering the responses from the survey participants, the next section will discuss what could be improved and how a community can become more inclusive to people with intellectual and developmental disabilities and their families so that they can go to public places and engage in community activities.
Recommendations and Possible Improvements

The survey results indicate that many respondents value accessibility to the places they visit. Having access to a quiet place and/or a flexible use bathroom and having welcoming atmosphere where they go is important to making a particular public place accessible to this population. The ease of finding things they want to do and having access to navigation with readable and accessible signage are also important to accessing facilities and activities in the community. This means that the city can arrange so that people can get direction and assistance needed at the site of the event. To better serve the people with IDDs and their families, eradicating physical environment barriers such as having no steps and curbs and installing flexible use/ multi-purpose bathrooms but also getting rid of invisible barriers by having navigation, supervision, and accommodated instruction and guidance available and creating welcoming atmosphere would be positive measures the city could take in order to improve access to this population. One respondent reported that restroom facilities are the major issue, as well as wheelchair-accessible walkways in parks in Ames. This information can be used to advocate for people with IDDs and their families by social service providers (see Appendix C for executive summary for local service providers).

Accessible and Accommodated Environment and Activities

In the comments received from the survey respondents, many mentioned wanting activities that specifically accommodated the needs of people with intellectual and developmental disabilities. For instance, Special Olympics was mentioned by some respondents because it accommodates an individual’s ability for swimming, cycling, and
the like. I believe these activities for people with and without disabilities should be integrated when it can ensure to be done safely. It is said that when the participant’s adult child was younger, there were no opportunities for sports, and the participants would have loved involvement with sports activities from elementary to the end of middle school age. In terms of sports, special needs baseball in Boone, Iowa was mentioned by a respondent saying it was a fun experience. Sports and exercise seemed to be commonly desired activities by the caregivers for their children with IDDs. One wished for inside spaces such as “open place to go exercise or ride a bike, indoor pool, etc.” during the winter due to the weather. Winter weather in Iowa makes it hard for everyone to do things outside of the house in terms of leisure activity. Because of the limitation with ability of the adult child and environmental constraints at facilities, the combination of weather and these two factors can make it even harder for individuals with intellectual and developmental disabilities and their families to identify a place where they could enjoy their leisure activities. One said “It helps so much to get out and do some kind of activity to blow off some steam” especially when the winter weather brings more constraints. In addition to sports activities, music, dance, and other social activities were also mentioned to be good programs for people with intellectual and developmental disabilities. One respondent stated that the parents and families of people with IDDs formed an Active Lifestyles Program which “holds holiday parties and dances and organizes Special Olympic teams and activities” because of lack of activities for individuals with the disabilities by the city. This Active Lifestyle Program helps engage people with IDDs with sports, social, and recreational events with their peers and the
community (The Arc of Story County, n.d.-a). For the City of Ames, the Active Lifestyle Program is coordinated by The Arc of Story Country.

For some facilities in Ames, there were some comments about having more flexible open hours and space for people with the disabilities. For example, respondents reported that the Municipal Pool has limited hours and Ames Public Library has “limited space” for special needs persons such as people with intellectual and development disabilities. This comment needs to be clarified in terms of what is meant by “limited space” for people with IDDs and merits a further investigation. According to Programs and Facilities Guide (City of Ames Parks and Recreation, n.d.), Ames Municipal Pool is open to the public from 7pm to 8pm on Fridays and from 1pm to 3pm on Saturdays and Sundays at the time of investigation, for Fall and Winter of 2019 to 2020. Ames Public Library mainly consists of spacious and open reading or studying spaces across the facility. This might be difficult to freely utilize the spaces when the parents are with their children with behavioral challenges or sensory sensitivity. Moreover, transportation was also discussed in terms of needing “more options/ times to use” specifically for Heart of Iowa Regional Transit Agency (HIRTA) bus system. HIRTA, door-to-door rides service provided in Ames and Story County, generally has to be scheduled one day in advance. It is also said on its website that reservations may be made between 7am to 3pm. The hours of operation for the rides are from 6:30pm to 8pm on weekdays and 7:30am to 6pm on weekends within Ames area. It also provides rides in Story County but only on weekdays until 5:30pm (Story County Transportation Brochure, 2019). The safety of pedestrians with intellectual and developmental disabilities was also mentioned, such as lower speed limits, safer street crossings, and no turn on red at intersections. Walkability within the
city needs to be improved along with considering the safety and connectivity of the sidewalks. This matter needs to be further studied to identify the specific areas needed to improve overall walkability and pedestrian safety, especially for people in a wheelchair and pedestrians with some physical challenges, including balance issues.

Additionally, to accommodate the needs of the Ames residents with intellectual and developmental disabilities and their families, there are few things that can be considered for a better access to facilities, events and services. Because there is a mismatch in time when the individuals can use some facilities, flexibility in hours can make a difference. In addition to the flexibility regarding hours of operation, another solution can be to have a set day and time that can specifically set aside to accommodate the population with the disabilities due to their difficulties coping with large noise and crowds. This is not intended to segregate the population with IDDs from ones without IDDs, but rather prepare the environment so that people with IDDs and their family can enjoy the activities with others. It might be a good solution to have a space available where these individuals and their family members can rest or have quiet place in case they have psychological meltdown. Furthermore, for a better access for people with the disabilities to CyRide, providing training for drivers to be able to accommodate or guide the passengers with intellectual and developmental disabilities to utilize the transportation easier and more safely. The Arc of Story County provides transportation training for CyRide (The Arc of Story County, n.d.-b). This training for CyRide drivers enables them to assist individuals with IDDs which can enhance mobility, safety, accessibility to transportation of people with IDDs.

**Recommendations for the City of Ames**
Even though parents of people with intellectual and developmental disabilities see community activities as positive and beneficial, there are limitations on the things they can do out in the community due to a lack of accessibility. Based on the results from the survey, there are places and activities in Ames that are not considered accessible for people with intellectual and developmental disabilities and their families. It is important for the City of Ames to be willing to serve all members of the community including individuals with intellectual and developmental disabilities. There are aspects that the city planners and the City of Ames can do to improve the physical and social environment and promote greater accessibility. This study’s results and recommendations will be shared with the City of Ames and are provided in the Executive Summary for the City of Ames.

The essential recommendation is for the city to conduct ADA (Americans with Disabilities Act) assessment on parks, facilities, and equipment and other things within those public facilities, programs, and events. This can simply mean complying the ADA requirements of building and facilities for all the public use. Complying with the ADA requirement can include putting in wheelchair accessible and gently sloped walkways at public facilities, putting multi-purpose use restrooms in place in all the public facilities, repairing and maintaining paved paths and walkways for better mobility, having accessible signage with appropriate height and readable fonts (Osterberg, 2010). In addition, it is crucial to go beyond the ADA requirements and be more inclusive by providing a welcoming environment and atmosphere, providing a quiet resting space as part of public facilities, having flexibility in facility services, and so on. For instance, providing training or sessions to a variety of city staff so that they understand the
challenges and needs the people with IDDs have and learn how they can better assist this population for police, all staff who work in public facilities and people who deal with park and recreation classes, programs, and events can improve the overall inclusivity. Specifically, providing training for CyRide drivers to be able to assist with the transportation of people with IDDs, the training session can be collaborated with The Arc of Story County to provide their knowledge and experience as to giving transportation training to the individuals with IDDs. In public places that can experience large crowds, that can cause sensory overload to people with IDDs, the public facilities can have a separate room with “noise-canceling headphones, bouncy balls, color-changing floor mats, bean bag chairs and weighted blankets” that can help them feel less overwhelmed (Williams, 2018). Based upon the comments received there appears to be a strong desire to have some inclusive and integrated activities available for people with IDDs to be able to participate, such as City Fitness Classes and Wellness Programs and sports programs such as baseball.

Other than the public facilities and activities, preparing safe sidewalks and improving CyRide accessibility with appropriate assistance that the riders with the disabilities can receive every time they ride are also important. The city should be encouraged to create an ADA committee to make sure the city and the public facilities, activities and infrastructures in the community are not potentially exclusive to those who have people with any kind of disabilities. The city and planners have the (legal and moral) responsibility to accommodate and be responsive to the needs of people with disabilities. This is to pursue to improve the community to be better and better by
promoting an inclusive and supportive environment that includes the participation of people with intellectual and developmental disabilities and their families.

In Ames’ Land Use Policy Plan (City of Ames, 2018), the greater connectivity of neighborhoods and amenities with a healthy, safe, and attractive environment is mentioned as an objective. This addresses how the connectivity of sidewalks, neighborhoods, and amenities is realized with a consideration of safety and accessibility for people with disabilities, both physically and psychologically. It is also present as a goal that “Ames seeks to establish a comprehensive and integrated transportation system that includes automotive, public transit, pedestrian, bicycle and ride-sharing modes” (City of Ames, 2018, p. 24). It is important to have a various means of transportation that are comprehensive and integrated to meet the needs and to be accessible for people with intellectual and developmental disabilities. In the City of Indianapolis, (see in figure 16) there are markings for the trail which is designed to be accessible for all means of transportation including users of wheelchairs and people with disabilities. This 8-mile trail runs through the city connecting six cultural districts in the city (Indianapolis Cultural Trail, n.d.). “Indianapolis/ Marion County Pedestrian Plan” addresses the connectivity and existing challenges for individuals with disabilities (2016). This is a good example for the City of Ames to have an accessibility lens to assess the conditions of walkways.
The city’s ADA committee can also inform the assessment of social accessibility. Recognizing the experiences that parents and their adult children with IDDs have had in the community can influence facilities, activities, and events they go to, it is crucial for planners to consider how to mitigate the existing limitations, both physical and social, as much as possible. To be able to provide proper assistance to people with IDDs, it is important to train police, facility staff, bus drivers and others with knowledge and understanding regarding the challenges and needs of people with IDDs and their families. These sessions can also be done with the ADA committee to be able to better understand the situation and challenges these families face. It is important to encourage other businesses and stakeholders in the community to attend such sessions. Besides, the ease of finding things they want to do and having access to navigation with readable and accessible signage are also important to access facilities and activities in the community. This means that the city can arrange it so that people can get direction and assistance needed at the site of an event.
What does it mean to create an inclusive and integrated community? I believe it means that the city planner and the city make the best effort to serve all persons who live and reside in the community the ability to thrive. The population with disabilities like the intellectually and developmentally challenged, are overlooked in terms of community facilities and activities in the City of Ames. All the recommendations presented in this chapter might seem romanticized, yet as the findings from this study indicate it is important and achievable. Specifically for recreational and leisure programs, such as Fitness Classes and Wellness Programs, sports programs, and other educational programs, it is very important to have staff, coaches, and instructors who are knowledgeable about needs of participants with IDDs. There are, of course, things that are difficult to accommodate such as making Durham Bandshell Municipal Band Concert accessible in terms of loud noise when people with IDDs are sensitive to sounds. Preparing and accommodating every aspect now might be infeasible, however, effort has to be made to gradually accommodate the population with disabilities and their families to be able to enjoy community interactions and activities without feeling limited to do so. Furthermore, the knowledge obtained and discussions from this report can be also useful to many other cities who are interested in tackling issues related to accessibility for people with IDDs in their communities. Ideally, city planners in neighboring cities can collaborate and work with local organizations who provide services to people with IDDs to better serve the population and their families with not only recreational and leisure activities but also other services as well. Moreover, there are some results that need more details to better understand the context or needs such as for the question regarding places they would like to go but chose not to go (see Figure 14). Findings from this pilot case
study suggest that future studies are needed in order to understand and make better recommendation as to what other detailed actions cities and planners can make to better include those with IDDs and their families to participate in community activities.

**Next Step**

This research study involved a single-case pilot study. Generally, a pilot case study is a first step of a multiple-case study. In the future a next step would be to conduct a multiple-case study to better understand the experiences and circumstances of parents of adults with IDDs when they engage in community activities in multiple cities with different demographic and sizes. It is recommended that this multiple-case study be conducted utilizing qualitative methods such as interviews and focus groups with the parents of adult children with IDDs. These qualitative methods can be strengthened by survey of the parents and interviews with local service providers to people with IDDs, as these methods were conducted in this study. This would assist in filling the disconnect and provide a better understanding of the meaning, thoughts, attitudes, feelings, and concerns parents of adults with IDDs experience in regard to community activities. Furthermore, this research will hopefully help spur efforts to mitigate the limitations that the parents and their children with IDDs experience when they go out to community activities. Communities and Planners should be engaged and committed to further study this topic to better serve for people with IDDs and other disabilities and their families to pursue an inclusive community.
References


APPENDIX A: SURVEY FORM
Dear Survey Participants:

As a part of Community and Regional Planning’s Creative Component at Iowa State University, I, Aya Higuchi, am conducting a survey in order to help the Ames Community to understand and better serve people with intellectual and developmental disabilities and their families.

The purpose of this research study is to understand the experience of parents of adult children with intellectual and developmental disabilities (IDDs) and how the experience influences decision-making and range of actions related to going to public places and events in Ames. The report produced based on the survey results will be shared with the City of Ames and other organizations throughout Ames to use for their advocacy to better serve the community with IDDs. The personal information will be securely kept confidential and de-identified when written in the report.

In this survey, you will be asked to provide your community experience, both positive and negative, with your family members with IDDs mainly in Ames, Iowa. You are invited to participate in this research study and your participation with this survey is voluntary. Please proceed to start the survey ONLY IF you agree to participate in this research study by the survey. If you feel any discomfort or distress by answering the questions, you may choose to skip or leave the survey. If you have a partner who also takes care of your adult children with IDDs, please refer them the survey.

Please take 20 minutes to complete this survey. We need your help and your input to understand experience and situation of you and your children with IDDs so that we can improve existing services and amenities in Ames. If you have any questions please contact Primary Investigator Aya Higuchi, ahiguchi@iastate.edu or Supervising Investigator Dr. Susan Bradbury, bradbury@iastate.edu.

Thank you so much for your time and participation.

Aya Higuchi
Community and Regional Planning
Iowa State University
Community Accessibility Survey

Q.1 Do you go to public places and community events and activities in Ames with your adult children with IDDs?
☐ Yes → skip to Q.4  ☐ Sometimes → skip to Q.4  ☐ No Q.2 & Q.3

Q.2 Why do you not go to public places and community events and activities in Ames with your adult children with IDDs?

Q.3 What changes/factors/improvements would make it possible for your family to go to public places and community events and activities in Ames?

If you selected “No” on Q.1 and proceeded to Q.2 and Q.3 then skip to Q.11 and continue
Please continue to Q.4 if you answered “Yes” or “Sometimes” on Q.1

Q.4 Based on your own experience, what are the positive aspects of going to public places and community events with your adult children with IDDs in Ames? Please identify all responses that apply to your situation.

☐ We can have a good time with our adult child with IDDs  ☐ Socializing opportunity for my adult child with IDDs
☐ We can have a good time with our family as a whole  ☐ Health benefits for my adult child with IDDs
☐ Inexpensive and affordable  ☐ Meeting new people in my community
☐ Stress reliever for my adult child with IDDs  ☐ Others _____________________________________________________

Q.5 Based upon your own experience, what are the negative aspects of going out to public places and community events in Ames with your adult child with IDDs? Please identify all that express your situation.

☐ It takes extensive planning  ☐ It is exhausting
☐ We don't feel welcomed  ☐ Difficult to coordinate because of my adult child's disability
☐ It is very stressful  ☐ Where we can go is limited
☐ It is time-consuming  ☐ Others _____________________________________________________
Q.6 Please identify public places and events you have visited/used in the past year with your adult children with IDDs.

- Ames City Auditorium
- Ames/ISU Ice Arena
- Brookside Park Pool
- Carroll Marty Disc Golf Course
- Community Center
- Durham Bandshell Park
- Durham Bandshell Municipal Band Concert
- Durham Bandshell Free Movie Night
- Furman Aquatic Center
- Georgie Tsushima Memorial Skate Park
- Homewood Golf Course
- Municipal Pool
- Parks in Ames (please specify the parks)

- Ames Public Library
- Downtown Ames Farmer's Market
- North Grand Farmer's Market
- Reiman Gardens
- CyRide
- 4th of July Parade
- Annual Fire Station Open House
- Ames Community Pancake Breakfast
- City Fitness Classes and Wellness Programs
- Ledges State Park in Boone
- Pine Lake State Park in Hardin
- Rock Creek State Park in Jasper
- Big Creek State Park in Polk
- Walnut Woods State Park in Polk
- Others __________________________________________

Q.7 Please identify places you would like to go/use with your adult children with IDDs but choose not to go/use.

- Ames City Auditorium
- Ames/ISU Ice Arena
- Brookside Park Pool
- Carroll Marty Disc Golf Course
- Community Center
- Durham Bandshell Park
- Durham Bandshell Municipal Band Concert
- Durham Bandshell Free Movie Night
- Furman Aquatic Center
- Georgie Tsushima Memorial Skate Park
- Homewood Golf Course
- Municipal Pool
- Parks in Ames (please specify the parks)

- Ames Public Library
- Downtown Ames Farmer's Market
- North Grand Farmer's Market
- Reiman Gardens
- CyRide
- 4th of July Parade
- Annual Fire Station Open House
- Ames Community Pancake Breakfast
- City Fitness Classes and Wellness Programs
- Ledges State Park in Boone
- Pine Lake State Park in Hardin
- Rock Creek State Park in Jasper
- Big Creek State Park in Polk
- Walnut Woods State Park in Polk
- Others __________________________________________

- Not Applicable/None --> Skip to Q. 10 & proceed
Q.8 If you check places you choose not to go, why do you choose not to go/use to those places? Please select the same choices and describe your experience that have influenced your decision not to go to those places.

- [ ] Ames City Auditorium
- [ ] Ames/ISU Ice Arena
- [ ] Brookside Park Pool
- [ ] Carroll Marty Disc Golf Course
- [ ] Community Center
- [ ] Durham Bandshell Park
- [ ] Durham Bandshell Municipal Band Concert
- [ ] Durham Bandshell Free Movie Night
- [ ] Furman Aquatic Center
- [ ] Ames Public Library
- [ ] Downtown Ames Farmer's Market
- [ ] North Grand Farmer's Market
- [ ] Reiman Gardens
- [ ] CyRide
- [ ] 4th of July Parade
- [ ] Annual Fire Station Open House
- [ ] Ames Community Pancake Breakfast
- [ ] City Fitness Classes and Wellness Programs

List continues to the next page ----->
Q.9 What would make it easier or possible for you to go to places you would like to go (with your child) but choose not to go? Identify the type of support/changes needed. Please provide in "Others" if your preference of support/changes is not expressed on the list.

- Public places and venue for community events are accessible
- Signage is easy to read and navigate
- Flexible use (multi-purpose) bathroom is available
- What we want to do is easy to find
- People are available to give directions and assistance needed
- Welcoming atmosphere
- Place to sit and rest is available
- Quiet place is available
- Others_______________________________

Q.10 Are there any supports or programs in other cities that you wish Ames had? Please be specific as possible as to the city/program. If there aren't any, what ideas do you have to help the Ames community better serve you and your family?
Q.11 What is your age? Please select the age range that is applicable to you.

- □ 20 - 29 years old
- □ 30 - 39 years old
- □ 40 - 49 years old
- □ 50 - 59 years old
- □ 60 - 69 years old
- □ 70 - 79 years old
- □ 80 years and above

Q.12 What is the age of the family member with the disability?

- □ 20 - 24 years old
- □ 25 - 29 years old
- □ 30 - 34 years old
- □ 35 - 39 years old
- □ 40 - 44 years old
- □ 45 - 49 years old
- □ 50 - 54 years old
- □ 55 - 59 years old
- □ 60 - 64 years old
- □ 65 years and above

Q.13 Which gender do you identify with?

- □ Female
- □ Male
- □ Prefer not to answer

Q.14 What is the gender of your family member with the disability?

- □ Female
- □ Male
- □ Prefer not to answer

Q.15 Please select the type of disabilities your family member with IDDs have. Please select all that apply.

- □ Intellectual Disability
- □ Autism Spectrum Disorder
- □ ADHD
- □ Cerebral palsy
- □ Epilepsy
- □ Vision impairment
- □ Hearing loss
- □ Speech and language impairment
- □ Other (please specify) ____________________________

Q.16 Are you the primary caregiver to your family member with IDDs?

- □ Yes
- □ No

Q.17 Are you employed or working beyond the role as caregiver to your family member with IDDs?

- □ Yes
- □ No → Skip to Q.19
- □ I am retired → Skip to Q.19

Q.18 If you answered "Yes" in previous question, are you employed:

- □ full-time (40+ hours/ week)
- □ part-time (30 to 40 hours/ week)
- □ part-time (20 to 30 hours/ week)
- □ part-time (10 to 20 hours/ week)
- □ other ____________________________
Q.19 How many hours of care or assistance per week does your family member with IDDs receive outside of your house or by other care and service providers? Please fill the number of hours in the blank.

[ ] hours/week

Q.20 Do you have more than one adult children with IDDs?

[ ] Yes Q.21 Q.22 & Q.23
[ ] No --> This is the end of the survey if you selected “No”

Q.21 What is the age of the other family member with the disability?

[ ] 20 - 24 years old
[ ] 25 - 29 years old
[ ] 30 - 34 years old
[ ] 35 - 39 years old
[ ] 40 - 44 years old
[ ] 45 - 49 years old
[ ] 50 - 54 years old
[ ] 55 - 59 years old
[ ] 60 - 64 years old
[ ] 65 years and above

Q.22 What is the gender of the other family member with the disability?

[ ] Female
[ ] Male
[ ] Prefer not to answer

Q.23 Please select the type of disabilities the other family member with IDDs have. Please select all that apply.

[ ] Intellectual Disability
[ ] Autism Spectrum Disorder
[ ] ADHD
[ ] Cerebral palsy
[ ] Epilepsy
[ ] Vision impairment
[ ] Hearing loss
[ ] Speech and language impairment
[ ] Other (please specify)

[ ]
[ ]
APPENDIX B:
EXECUTIVE SUMMARY FOR THE CITY OF AMES
Executive Summary

Aya Higuchi (Community and Regional Planning, Iowa State University)

INCLUSIVE COMMUNITY: What can Planners do to better serve adult children with intellectual and developmental disabilities and their parents with community recreational activities?

Overview

People with intellectual and developmental disabilities (IDDs) face a multitude of different challenges. IDDs include various different disabilities, such as autism, intellectual disability, and cerebral palsy. The challenges for individuals with IDDs involve activities of daily living such as dressing, eating, toileting, challenging behavior (meltdown/tantrum/self-injury), sensory sensitivity and insensitivity (sensitivity to loud noise or lights) and socializing skills. Due to daily challenges, people with these disabilities often require significant assistance from caregivers, especially from their parents. Typically, community awareness and support is inadequate, and this results in lack of friendship and inclusive community experience for people with IDDs.

The purpose of this study is to understand what kind of factors could influence the experience, decision-making, and range of actions of parents of adults with IDDs to participate in community events and activities. An interview with service providers, document review* and a survey of parents of adult with IDDs were conducted.

Highlighted Findings

Results show that despite many recreational facilities, activities, and events available in the City of Ames, there’s room to improve the physical and social accessibility of facilities, activities, and events for people with IDDs and their families. It is crucial for planners and the City to consider how to mitigate the existing limitations, both physical and social, as much as possible. Findings show that:

1) Where the parents and their adult children with IDDs can go and do is limited because of behavioral issues and other challenges their children have.
2) Parents of adult children with IDDs do not feel welcomed at community activities because of how others in public stare or they don't try to understand their child’s limitations, but they also reported people are mostly very accepting.
3) Many public facilities (parks, municipal pool, sports and fitness classes, and social events) are inaccessible due to a lack of adult changing tables, multi-purpose bathrooms, and limited time of operation.
4) There is a lack of accommodation throughout Fitness Classes and Wellness Programs for people with IDDs.

Recommendations

The City should, in partnership with the service providers to people with IDDs, form an Americans with Disabilities Act Committee to assess the physical and social accessibility of all city public facilities, programs, and events and equipment. The Committee could assist with the following efforts:

1) Eliminating physical barriers, such as having no steps, curbs, steep slopes, and installing flexible use/multipurpose bathrooms. Also eliminating invisible barriers by providing assistance such as signage to improve navigation, supervision, accommodated instruction and guidance and a welcoming atmosphere at the site of the event. Also provide a quiet resting place on site.
2) Provide flexible hours of operation for municipal pool, Heart of Iowa Regional Transit Agency (HIRTA)
3) Enhance the safety of pedestrians with IDDs by ensuring the quality and connectivity of sidewalks
4) Encourage and provide training for a variety of city staff so that they understand the challenges and needs of people with IDD and how they can better assist this population. The training should be available for police, CyRide drivers, all staff who work in public facilities, recreation classes, programs, and events to improve the overall inclusivity.
5) At public places that can experience large crowds, that can cause sensory overload to people with IDDs, provide a separate room with “noise-canceling headphones, bouncy balls, color-changing floor mats, bean bag chairs and weighted blankets” that can help them feel less overwhelmed. (This kind of room is referred to as an Autism break room)
6) Provide inclusive and integrated activities that can accommodate people with IDDs, such as City Fitness Classes and Wellness Programs and sports programs such as baseball.

*It was a review of municipal brochure, Programs and Facilities Guide Fall and Winter 2019/ 2020
APPENDIX C:
EXECUTIVE SUMMARY FOR SERVICE PROVIDERS IN AMES
Overview
People with intellectual and developmental disabilities (IDDs) can have multitude of different challenges. IDDs include various different disabilities, such as autism, intellectual disability, and cerebral palsy. The challenges for individuals with IDDs involve activities of daily living (bathing, dressing, eating, toileting, challenging behavior, sensory sensitivity and insensitivity and so on). Because of these daily challenges, people with these disabilities often require significant assistance from caregivers, especially from their parents. Typically, community awareness and support is inadequate, and this results in lack of friendship and inclusive community experience for people with IDDs. The purpose of this study is to understand and describe parents’ experiences with activities and community events outside of their home with their adult children with IDDs in Ames. It aims to understand what kind of factors could influence the experience, decision-making, and range of actions to participate in community events and activities. An interview with service providers, document review* and a survey of parents of adult with IDDs were conducted.

Highlighted Findings
Results show that despite many recreational facilities, activities, and events available in the City of Ames, there’s room to improve the physical and social accessibility of facilities, activities, and events for people with IDDs and their families. It is crucial for planners and the City to consider how to mitigate the existing limitations, both physical and social, as much as possible. Findings show that:
1) Where the parents and their adult children with IDDs can go and do is limited because of behavioral issues and other challenges their children have.
2) Parents of adult children with IDDs do not feel welcomed at community activities because of how others in public stare or they don't try to understand their child’s limitations, but they also reported people are mostly very accepting. Results of interview with service provider also shows how things can be challenging when people with IDDs have meltdown or behavioral issue in public places such as restaurants and grocery stores.
3) Many public facilities (parks, municipal pool, sports and fitness classes, and social events) are inaccessible due to a lack of adult changing tables, multi-purpose bathrooms, and limited time of operation.
4) There is a lack of accommodation throughout Fitness Classes and Wellness Programs for people with IDDs.

Recommendations
Partner with the City of Ames to form an Americans with Disabilities Act Committee to assess the physical and social accessibility of all public facilities, programs, and events and equipment at the places where community activities occur in Ames. Advocate for physical and social accessibility and equity throughout the city (in terms of public infrastructure, facilities and amenities).

The Committee can assist with following efforts:
1) Assist the city with eliminating physical barriers, such as having no steps, curbs, steep slopes, and installing flexible use/ multipurpose bathrooms. Also eliminating invisible barriers by providing assistance such as signage to improve navigation, supervision, accommodated instruction and guidance and a welcoming atmosphere at the site of the event. Also provide a quiet resting place on site.
2) Help coordinate flexible hours of operation for municipal pool, and Heart of Iowa Regional Transit Agency (HIRTA) based on needs and accommodation can be made for users with special needs.
3) Enhance the safety of pedestrians with IDDs by ensuring the quality and connectivity of sidewalks.
4) Encourage and provide training for a variety of city staff, such as police, CyRide drivers, and other city staff, so that they understand the challenges and needs of people with IDD and how they can better assist this population.
5) Help design and identify community facilities needing (Autism break) rooms with “noise-canceling headphones, bouncy balls, color-changing floor mats, bean bag chairs and weighted blankets at public places that can experience large crowds or noise.
6) Assist cities with providing inclusive and integrated activities that can accommodate people with IDDs, such as City Fitness Classes and Wellness Programs and sports programs such as baseball.

*It was a review of municipal brochure, Programs and Facilities Guide Fall and Winter 2019/ 2020