The Impact of Family Autism Camp on Families and Individuals with ASD

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Abstract
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Keywords
Autism Spectrum Disorders, Disability, Families, Family Camp, Support, Mixed-Method Design

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The Impact of Family Autism Camp on Families and Individuals with ASD

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Families of children with disabilities, such as Autism Spectrum Disorders (ASD), often search for opportunities to acquire information about and receive emotional support from others who may have or had similar experiences. An evaluation of the Dakota Black Goose Family Autism Camp sought to determine the impact of the family camp experience. Pre- and Post-Camp surveys were administered upon families’ arrival at Camp and prior to their departure (n=17) to evaluate the overall quality of the program as well as the level of informational and emotional support anticipated and received. Follow-up interviews were completed six months post Camp to determine how and if families incorporated the information provided at Camp into their daily lives. Overall, participants in Dakota Black Goose Family Autism Camp found a great deal of benefit from participation, especially as it related to information gathering, networking and emotional support, and opportunities for family members with ASD to be able to engage with others in a safe and accepting environment. Keywords: Autism Spectrum Disorders, Disability, Families, Family Camp, Support, Mixed-Method Design

Families of children with Autism Spectrum Disorders (ASD) make up an increasing portion of the American population (Centers for Disease Control and Prevention, 2014). As ASD rates increase, so does the need for informational and emotional supports to families. Karst and Van Hecke (2012) found families of children with ASD experienced lower levels of parental self-efficacy, increased stress, and generally reported a decreased sense of emotional well being and physical health. One area that proved relatively healthy was in the family’s relationship with the family member with ASD. For most families, the impact of ASD on caregivers and other family members seemed related to the type and quality of informational and emotional support available.

Typical mechanisms utilized to provide informational and emotional supports to families have been support groups, day-long workshops, special evening programs, or sometimes multi-day events such as conferences (SD Parent Connection, 2013). However, many of these programs are for parents only and do not always include a childcare or respite care option (for other children in the family or for the individual with ASD). Families sometimes struggle to participate in such events because of a lack of childcare and/or respite care. Alternatively, individuals with ASD often have opportunities to participate in special programs or camps developed especially to meet their needs, but it is usually without the participation of other members of the family (Neff, 2009).

The Value of a Family Camp

Summer camps for children and adults with disabilities have been around since the late 1960s (Neff, 2009). However, very few opportunities exist for individuals with disabilities and their families to participate in the summer camp experience. Camp is defined as a residential experience for individuals and/or their families that includes activities and programming developed for the benefit of its participants. Camp Yofi, located in rural, north
Georgia, is one of the few family Autism camp models that provide an overnight camping experience for individuals with ASD and their families (Kabot, 2009). Drawing families from as far away as California, Camp Yofi provides families with all the activities that one would expect at a summer camp, but with an emphasis on the needs of individuals with ASD. Camp Yofi, like other similarly focused camps, takes into consideration the special needs of the individuals who might participate and provide programming specializing in serving campers with disabilities or exclusively serve campers with disabilities.

A search of the American Camp Association (2015) website, an accrediting association for camps and camp professionals including recreational, rehabilitative, and disability-related, showed that approximately 10 percent of its accredited camps had programs that specialized in including both the individual with a disability and his or her family. States like South Dakota had no affiliated camps in the state. Independent, grassroots efforts (like the Dakota Black Goose Camp) appeared to be the only opportunities available to families.

Although there has been a resurgence in the popularity of family camps as represented in mainstream media contexts such as books, newspapers, and television news reports; and even in academic journals relevant to the field of recreation (Garst, Baughman, Franz, & Seidel, 2013), few mention options for families who have a member with a disability. Furthermore, the value of the family camp experience for families of individuals with disabilities has not been widely published in the academic context in any discipline. Of the known articles, only the Day and Kleinschmidt (2005) article attempted to determine the efficacy of the family camp experience.

Day and Kleinschmidt (2005) looked to determine the efficacy of the family camp experience for families who had children with visual impairments and participated in the Utah Schools for the Deaf and the Blind Parent Infant Program. The camp focused on providing families with informational support and opportunities to network and develop relationships with other families with similar experiences. The camp also planned specific children’s activities and family focused activities so that families could play, learn, and work together.

**Dakota Black Goose Family Autism Camp**

The Dakota Black Goose Family Autism Camp began in the summer of 1998 on the farm of Ron and Ranae Larsen in Lake Preston, South Dakota. The Larsens established Camp as an opportunity for families of children with ASD to meet one another and share their experiences in an environment that included and welcomed the entire family—especially family members with ASD. Ron and Ranae were especially sensitive to the needs of families of children with ASD because their youngest son, Rusty, had been diagnosed with ASD just a few short years prior to the first Camp (personal communication, July 19, 2007).

Camp began with five families and about 15 total participants. By 2009, Camp had grown to more than 25 families (with a couple of group homes participating as well) and over 100 participants and volunteers. Not only had the numbers of participants grown, but so had the vision and scope of the Camp experience. The Larsens opened up their home to allow families to meet one another and share experiences, and they also began bringing in relevant local, state, and nationally recognized speakers to address issues and topics that were beneficial to the participating families. Some of the topics included advocacy, behavioral analysis, transition planning, and post-secondary opportunities. Parent-led informational sessions were also incorporated so that families could hear the voices of experienced families who may have traversed similar paths before. In addition to the sessions, some of the family activities included fishing, horseback riding, visits to the animal barns/stables, arts and crafts,
and community meals. These activities are consistent with the offerings many recreational camps might offer participants, in general, yet for individuals with ASD, these activities may even be therapeutic as well. This study sought to determine the benefit of the family camp experience for families of individuals who have a member on the Autism spectrum.

I first learned of the Dakota Black Goose Family Autism Camp as a doctoral student in the Beach Center on Disability at the University of Kansas. My area of interest was the impact of law and policy on individuals with disabilities and their families—in particular, the impact of the Home and Community Based Services Medicaid waivers. The Beach Center on Disability is a nationally recognized “multidisciplinary research and training center committed to making a significant and sustainable positive difference in the quality of life of individuals and families affected by disability and the professionals who support them” (Beach Center, 2015). As such, our directors were often invited to provide keynote addresses or speak in a wide variety of disability-related contexts. The Larsens requested a speaker from the Beach Center who could discuss participant direction of supports and services using the HCBS Medicaid waiver (Gross, Wallace, Blue-Banning, Summers, & Turnbull, 2012). Because of my involvement on the participant direction research team, I was invited to be the Beach Center representative. My family and I attended the camp for three consecutive summers and it was in my final summer at camp, because I was graduating from my program that I learned of the Day and Kleinschmidt (2005) research and wanted to determine if similar outcomes could be found among the families who participated in Family Autism Camp.

Method

The experiences described by Day and Kleinschmidt (2005) proved very similar to the experiences found at the Dakota Black Goose Family Autism Camp and proved a suitable model for a replication study. This study had a mixed-method research design characterized by Creswell (2003) as sequential explanatory. The surveys allowed for the collection and analysis of the quantifiable experience of participating families, while the interviews helped to further explain the phenomenon they experienced. The participants in the current study were families who participated in the 2009 Dakota Black Goose Family Autism Camp, and the methodology, including survey instruments, were adapted from those presented by Day and Kleinschmidt (2005). Pre- and Post-Camp surveys were administered upon families’ arrival at Camp and prior to their departure. The surveys sought to determine family expectations of the Camp experience initially and then to also determine if their goals for participation were met.

Follow-up telephone or email interviews were arranged based upon families’ completion of the follow-up interview interest cards that were also given out on the last day of camp. Similar to the purpose of the follow-up interviews in the Day and Kleinschmidt study, the follow-up interviews focused on a review of the family camp experience and its impact on outcomes at home. Overall, this mixed-method study sought to better understand the benefit of the family camp experience as families reflected generally on camp as a whole and specifically on experiences related to the provision of emotional and informational support.

Participants

All families who attended the Dakota Black Goose Family Autism Camp (Camp) were eligible to participate in this study (n=17). Camp welcomes families who have at least one member with ASD to this three-day, weekend long event. For the most part, parent/guardian family members participated in all sessions and subsequent family activities.
There were no fees associated with Camp, although pre-registration was recommended. Most families camped out on the Dakota Black Goose Farm. Participants were all from the state of South Dakota and of European-American descent.

**Procedure**

Consistent with the method used by Day and Kleinschmidt (2005), participating families completed a pre-/post-camp survey and a six-month follow-up telephone or email interview. The method used for the follow-up interviews was determined by the availability of the families; however, efforts were made to complete telephone interviews to the greatest extent possible. Families were asked to complete only one survey per family, with the goal of every family being represented. The survey and interview questions derived from the overall goals of Camp (see Tables 1 and 2). The pre-/post-surveys were one page in length and took approximately 5 minutes to complete.

The study was introduced by the Camp hosts to the participants during the opening session of Camp. During the introduction, families received consent information and a full description of the study. The pre-survey was distributed at that time with a request that all pre-surveys, completed or not, be returned to a survey return area. Parents were also encouraged to consider completing the post-survey and participation in the follow-up interviews. A passive consent process was used so that families wishing to participate submitted their completed surveys, those opting not to participate submitted incomplete surveys, and full anonymity was maintained. Approval from the Western Michigan University Human Subjects Institutional Review Board was obtained to conduct this study.

Immediately following the final session, each family received a post-Camp survey and was asked to complete it. The researcher followed-up with a reminder about the six-month follow-up interview cards that were available at the post-survey return area. Families had an option to complete both the post-survey and sign-up for the interviews, they could opt to complete either, or neither.

**Subject Recruitment.** Families were eligible to be included in this study if they had a family member with ASD and participated in Camp at Dakota Black Goose Farm in Lake Preston, SD. Participants attended the last camp in July 2009. Families were invited to participate in the pre-survey during the opening session upon their arrival on Friday night. Participation was optional and in no way impacted their participation in Camp. During the closing session, families were also asked to complete a post-survey to function as a program evaluation and a point of comparison for family perceptions of the benefit of Camp. A separate card was also passed out if families wished to participate in the interview portion of the study. Families were asked to provide name and contact information (e.g., telephone number and email address).

**Consent Process.** Passive consent was accepted for the anonymous pre and post surveys. Families were instructed that by completing the survey and turning it in, they were consenting to their responses being used in the study. Following families expressing interest to participate in the interview portion of the study, the principal investigator sent a follow-up email 6 months after Camp to confirm the family’s interest in participating. Upon confirmation of participation, an electronic copy of the informed consent form was sent. Families had two options: (a) sign the form and email a scanned copy or fax it to the principal investigator or (b) reply to the email and state an affirmation of receipt of the informed consent and their understanding of it. The affirmation line read, “I have read and consent to participation in the Family Camp effectiveness study. I understand that I can withdraw from the study at any time. Sincerely, <state your name>.” None of the family members who replied to the email fell into a category considered vulnerable for the purpose of this study.
Following the receipt of the statement of interest to participate, the families were sent a copy of the consent form via email. They were instructed about their options to provide consent, and after they determined their continued willingness to participate, they were asked to submit a copy of their consent. Families were also asked to include a preferred date, time, and telephone number in their response so that a telephone interview could occur at their convenience. This contact information was obtained from the family to facilitate the telephone call. Each family was asked to participate in one telephone interview lasting approximately one hour. All contact information, audio files, and subsequent transcripts were managed using TruCrypt to ensure the confidentiality and protection of all participants.

Instrumentation. Camp surveys derived from the goals of previous Camps, taking into consideration questions that were commonly included on Camp evaluation forms, as well as from the surveys developed by Day and Kleinschmidt (2005). The Camp surveys were piloted to determine ease of use and response time. The questions included in the Camp survey were appropriate for the purposes of this study. The pre-survey had eight questions on a five-point Likert scale and also included two open-ended questions (see Table 1). The post-surveys included 12 questions on a five-point Likert scale with four open-ended questions (see Table 2). The additional questions included on the post-survey sought to summarize the entire event and also included specific questions of interest to the coordinators of Camp, such as (a) describing the best feature of camp, (b) areas in need of improvement, (c) recommendations for future presentation topics, and (d) respondent willingness to engage in conversations with the local and state leaders about issues relevant to individuals with disabilities and their families. Both surveys provided a comments section. The follow-up interview cards simply asked for family contact information such as name, telephone number, and email address. The follow-up interview questions were based on the eight overlapping questions found on both the pre-/post-surveys, served as a semi-structured interview guide for the telephone interviews, and were open-ended in nature (Maxwell, 2005). Participants who responded via email were asked to use the questions as a starting point, and were free to share additional information as they saw fit.

Data Analysis

This study utilized a mixed-method research design characterized by Creswell (2003) as sequential explanatory. The surveys allowed for the collection and analysis of the quantifiable experience of participating families, and the interviews helped to further explain the phenomenon they experienced. Mixed-method inquiry was the methodology chosen by Day and Kleinschmidt (2005) and allowed for a deeper examination of the experiences of families using pre-/post-surveys and individual interviews. The sequential explanatory design allowed for quantitative results to inform the qualitative inquiry, leading to a richer understanding of the camp experience (Tashakkori & Teddlie, 2003). For example, in instances where there was overwhelming agreement concerning the acquisition of informational support, probes where included in the follow-up interview to explain in more detail the specific and types of information acquired and how it was used. Descriptive statistics were used to describe and summarize the quantitative data.

The interviews were transcribed verbatim and analyzed for common themes. First, the transcripts were read “to obtain a general sense” of the content (Creswell, 2003, p. 191). Following the initial readings, emergent topics were documented and used to guide the open coding process. Open coding allowed for specific categories to be identified across interviews and subsequently grouped into common themes. Themes were grouped according to frequency found across transcripts, uniqueness of the topics addressed as they related to the scope of the research, and outliers. The themes subsequently informed the manner in which
family experiences are described, represented, and interpreted in the results. As the individual stories of the families were reviewed, note was also made of key quotes that might add value to the retelling of their experiences (Maxwell, 2005).

Results

Pre- and Post-Camp Surveys

Of the 17 families present at the opening session on Friday night, 17 families completed the pre-survey with a 100% response rate and 12 out of 17 families completed the post-survey (71%). A parent or responsible adult completed the surveys on the behalf of their family unit. Of the 8 families completing the follow-up interview cards, 4 out of 8 families were able to participate in the follow-up interview six months later either by telephone or by email. The interviews were with either the mother or the father of the individual with ASD. Only one family was unavailable for a telephone interview and opted to complete the interview protocol via email.

Summaries of the pre- and post-survey results are described in this section. Table 1 describes the questions presented on the pre-survey and the subsequent responses. Fourteen of 17 families present during the opening session either agreed or strongly agreed with the overall goals of Camp. It appears that family expectations were aligned with the goals of Camp, as indicated by the survey responses.

Table 1
PRE-Survey (percentage) and Response Summary

<table>
<thead>
<tr>
<th>Question</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Undecided</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
<th>No Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>I hope this camp provides me with opportunities to talk or share with other parents/families.</td>
<td>59</td>
<td>29</td>
<td>12</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I hope this camp provides me with opportunities to exchange addresses, phone numbers, or e-mail information with other parents.</td>
<td>35</td>
<td>41</td>
<td>24</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I hope this camp provides me with new information about my child.</td>
<td>65</td>
<td>29</td>
<td>6</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I hope this camp provides me with new information about community resources.</td>
<td>47</td>
<td>41</td>
<td>12</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
I hope this camp provides me with new information about advocacy.

<table>
<thead>
<tr>
<th>Question</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Undecided</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
<th>No Response</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>29</td>
<td>65</td>
<td>6</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

I hope this camp provides my child/children with opportunities to interact with other children who have Autism Spectrum Disorders (ASD).

<table>
<thead>
<tr>
<th>Question</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Undecided</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
<th>No Response</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>47</td>
<td>35</td>
<td>6</td>
<td>6</td>
<td>6</td>
<td>6</td>
</tr>
</tbody>
</table>

I hope this camp provides my children with opportunities to interact with brothers and sisters of children who have ASD.

<table>
<thead>
<tr>
<th>Question</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Undecided</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
<th>No Response</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>35</td>
<td>41</td>
<td>12</td>
<td>6</td>
<td>6</td>
<td>6</td>
</tr>
</tbody>
</table>

I view this camp as an opportunity to have a family outing.

<table>
<thead>
<tr>
<th>Question</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Undecided</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
<th>No Response</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>41</td>
<td>29</td>
<td>24</td>
<td>6</td>
<td>6</td>
<td>6</td>
</tr>
</tbody>
</table>

Table 2 describes the questions presented on the post-survey and those subsequent responses. Again, 10 of 12 of families either agreed or strongly agreed that the overall goals of camp were met. Of the families who completed the post-survey, all families either expressed satisfaction or strong satisfaction with Camp as a whole. Approximately 80% of families on both the pre- and post-surveys agreed or strongly agreed that seven of the eight Camp goals were important to them. The only Camp goal that was not consistently noted as important was the opportunity to exchange contact information for future contact with other participating families.

Table 2
POST-Survey (percentage) and Response Summary

<table>
<thead>
<tr>
<th>Question</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Undecided</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
<th>No Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>I talked or shared with other parents.</td>
<td>42</td>
<td>50</td>
<td>8</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I exchanged addresses, phone numbers, or e-mail information with other parents.</td>
<td>8</td>
<td>42</td>
<td>8</td>
<td>8</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Undecided</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
<td>No Response</td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>----------------</td>
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<td>-----------</td>
<td>----------</td>
<td>-------------------</td>
<td>-------------</td>
</tr>
<tr>
<td>I received new information about my child.</td>
<td>42</td>
<td>42</td>
<td>8</td>
<td>8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I received new information about community resources.</td>
<td>42</td>
<td>50</td>
<td>8</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The community resource information I received was adequate.</td>
<td>34</td>
<td>58</td>
<td>8</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I received new information about advocacy.</td>
<td>50</td>
<td>34</td>
<td>8</td>
<td>8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>My child/children had opportunities to interact with other children who have Autism Spectrum Disorders (ASD).</td>
<td>58</td>
<td>34</td>
<td>8</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My child/children had opportunities to interact with brothers and sisters of children with ASD.</td>
<td>42</td>
<td>42</td>
<td>16</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Camp was an opportunity for a family outing.</td>
<td>50</td>
<td>42</td>
<td>8</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>There was just the right number of families to participate in Camp.</td>
<td>16</td>
<td>68</td>
<td>16</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The presenters were knowledgeable and open to questions.</td>
<td>42</td>
<td>58</td>
<td>58</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Undecided</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
<td>No Response</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>---------------</td>
<td>-------</td>
<td>-----------</td>
<td>----------</td>
<td>-------------------</td>
<td>-------------</td>
</tr>
<tr>
<td>On a scale of 1 to 5 with 5 being very satisfied and 1 being very unsatisfied, how would you rate your overall satisfaction with Family Autism Camp?</td>
<td>50</td>
<td>50</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Families also had the option to provide written responses on both surveys. All of the families responding to the pre-survey opted to provide written responses to the open ended questions. The two questions asked about previous participation in Camp and how families learned about the Camp opportunity. Approximately 53% of the participants were first-time participants. Of the returning participants, the average number of previous Camps attended was four with the range being one to eight Camps. Most frequently, families reported learning about Camp from their children’s schools.

On the post-survey, 11 of 12 responding families opted to respond to the open ended questions. Most often, families responded to the question asking them about the best part of the Camp weekend. Families reported to most appreciate the ability “to meet other families with shared experiences.” Additionally, families also mentioned the presentations and information shared as being another highlight of the weekend. Few families had suggestions of how Camp could be improved, additional Camp agenda items, or expressed interest in state-level advocacy. Most additional comments provided expressed positive statements about the Camp experience overall such as: “great,” “keep up the good work,” and “this camp is awesome.”

The pre- and post-camp surveys allowed families to rate their expectations for and evaluate their experiences at Camp. Overall, the goals established for Camp and the outcomes families expected upon registration were consistent. Families indicated Camp was beneficial for obtaining informational support and for providing social and recreational support.

**Follow-up Interviews**

Even though only four families were able to participate in the six-month follow-up interviews, they provided some additional helpful information. Each of the respondents during the follow-up interview also participated in the pre-post surveys. During the follow-up interviews respondents were asked to give a general update on how things had gone over the six months since Camp and to also articulate whether or not any of the information shared at Camp had a direct impact on their lives or the life of their son or daughter with ASD. Only one family was unavailable for a telephone interview and opted to complete the interview protocol via email. Interviews were recorded and transcribed verbatim. The transcripts were analyzed and coded to determine the common themes. The responses fell into three primary categories: (a) the impact of information learned at Camp, (b) the impact of the family-focused atmosphere, and (c) recommendations for future camps.
Impact of Information

Overall, the families interviewed found the information shared at Camp to be quite useful. For some, the information shared acted as an impetus for future planning. For others, the information shared was immediately applicable. Families even mentioned that even if they’d heard some of the information shared before, it was still helpful to get a refresher. Families especially seemed to appreciate the information learned from other families through both formal presentations prepared by the parents or by simply being able to network and talk throughout the weekend.

When thinking about future planning, one parent shared, “I looked over [the information provided] pretty well and it was some good information to read and such but I still I need to get in contact with some people.” As a result, this parent found, “I need to start thinking about what [my son’s going] to do when he’s out of school you know and start preparing for that so that’s got me thinking.”

In terms of having a refresher or hearing some information again, some parents shared, “I view the information as beneficial to me, as there are constantly changes not only in services available but also in what is going on with [my son] and which services might be helpful.” Specifically, families mentioned that information provided on individualized education plans (IEPs), response to the diagnosis, assistive technology, dietary considerations, and services available all proved to be extremely helpful.

The one area that seemed to have the greatest impact on the respondents was the opportunities to hear from other families. From one parent’s perspective a benefit of the parent-led presentations was “it’s not from quote ‘the expert’ it’s from somebody that is exactly where you’ve been or where you’re going, that the ability for the audience to go ‘well gee, they learned about it, they can do that as well, it’s not such and such who gets paid forty hours a week to do that’ it helps them see that it is possible and they can really have an impact themselves.” Another parent followed up with the benefit of the networking opportunities. “I think the network building, to know that parent connections are out there, that advocacy is out there, to know that there are other parents out there that you are not alone, there are people to talk to and that is extremely valuable.”

Impact of Family-Focused Atmosphere

Another area in which respondents found extremely helpful related the family-focused atmosphere found at Camp. Parents described the impact in three ways: (a) the impact on their child with ASD, (b) the impact on their children without a diagnosis, and (c) the impact on them.

Impact on their Child with ASD. One parent described the atmosphere for their child in these terms, “Being able to go to Camp, let your kids disappear to wherever, and go and know they’ll be okay cause they are just like everybody else’s kids for once, and listen to something is wonderful.” Another parent stated it this way, “For [my son], it is the opportunity to have the freedom to be himself and to roam the farm and explore.”

Impact on Children without a Diagnosis. Parents also described the impact on their children who do not have a diagnosis. One parent shared, “my daughter got some friends, too, so she definitely wants to come back and so she really enjoyed it.”

Impact on Parents. When parents described the impact of the family-focused atmosphere for themselves, one of the most common responses was, “it is the opportunity to network with other families and the professionals who are presenting information.” And also mentioned, “The rest of our family benefits from any information that is obtained.”
As in many other family camp experiences, respondents also mentioned the overall impact of Camp on the family as a whole. For most, “[Camp] provided a chance for us to get away.” Camp was characterized as “The opportunity to get away to the peaceful environment of the farm with the added benefit of knowing someone is watching [my son] while I listen to the speakers makes this camp a win-win for everyone!”

**Recommendations for Future Camps**

Respondents were also asked to provide recommendations for future camps. Recommendations came in two forms: suggestions for improvement and suggestions related to future Camp content. The two primary areas noted in need of improvement were to have a clearly articulated schedule available beforehand and to consider an alternative menu for those who may have special dietary needs. Respondents had a few more suggestions to make about future Camp content to be presented. Some of the recommendations reflected presentations that may have been offered previously, but because of the nature of new families being added each year would be worth repeating. Ideas included highlighting options for life after school, transitions (large and small), handling anger and aggressive behaviors, guiding an individual with ASD through grief and loss, presentations on general nutrition, and supporting the siblings of children with ASD or other disabilities.

The sequential explanatory design allowed for the quantitative results to inform the qualitative inquiry of this study. Although the Likert-scale portion of the surveys provided a starting point for understanding family satisfaction with Camp, the open-ended questions and subsequent interviews allowed families to explain their experiences in their own words. The interviews built on the total analysis of the surveys and facilitated a conversation between the family being interviewed and the principal investigator. As a result, some of the recommendations for future Camps emerged out of those conversations, thus leading to a richer understanding of the camp experience.

**Discussion**

Overall, Family Autism Camp was a beneficial resource for the families who participated and served as an opportunity for families to have fun, work, and play together in an emotionally and physically safe environment. The findings here are significant for schools, community organizations, social services agencies, and anyone else looking to identify ways to provide families with both the emotional and informational support needed to be an effective parent, advocate, and community member for and with individuals with ASD. In more traditional settings, professionals often present a great deal of valuable information, but families articulated that they need the opportunity to be able to process the information, ask follow-up questions, and discuss it with others. The Camp experience allows for that to happen.

As the Camp experience benefitted the participants in many ways, it serves as a template for others planning such events and activities to follow. In fact, following the experiences at Camp, the author introduced a modified, day-long Camp experience to participants in the local area. The positive response was overwhelming and participants traveled from across the region to participate. The long-term goal for the author is to host an overnight camp experience for families similar to the Dakota Black Goose Family Autism Camp.

There continues to be a need for camps that strive to provide emotional and informational support to families of children with disabilities. In particular, families of children with ASD, make up an increasing proportion of the disability community. Family
camps are filling a much-needed void in the overall provision of the continuum of services that addresses not only the needs of the individual with ASD, but the needs of all members of the family unit.

Agate and Covey (2007) found the reason most families participated in family camps fit into three categories: (a) therapeutic or interventional, (b) prevention, enrichment, or maintenance, and (c) vacation. This study found similar experiences among families who participated in the Dakota Black Goose Family Autism Camp. In general, families looked forward to the recreational benefits of Camp, the enrichment offered by the diverse activities provided, and the vast amounts of information provided through the presentations offered and through networking with other parents.

This study was a replication of the Day and Kleinschmidt (2005) study that focused on the family camp experience for families who had children with visual impairments. Therefore, this study represents the evaluation of one family autism camp and provides a snapshot of families’ participation in the Camp weekend as well as a 6-month follow-up. Dakota Black Goose Family Autism Camp is unique in its design and execution. It allows families the freedom and flexibility to learn, network, and do whatever needs to be done for and with their family member with ASD.

This study sought to determine the benefit of the camp experience and to see if the camp experience provided a level of informational and emotional support to those families who participated. Overall, families reported that Camp did provide both informational and emotional support. Families not only found value in the Camp experience, but all who responded looked forward to future participation.

Although this study is a small sample representing the family camp experience for participants in the Dakota Black Goose Family Autism Camp, it confirms the need for additional opportunities for families to be able to come together to learn, network, and have some fun in the process. It is duly noted, however, that many communities do not have programs and opportunities such as the Dakota Black Goose Family Autism Camp. It would be recommended to examine the benefits of a Camp experience on families from more diverse backgrounds, attending to both ethnic diversity as well as locality. Future research should continue to examine the efficacy of other models and opportunities that might be used to provide emotional and informational support to families who have children not only on the Autism spectrum, but other disabilities as well.

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