

Research Article

Beyond Driving: Joy, Self-Assurance, Belonging and Success among Young Adults with Autism

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Abstract

Autistic individuals earn their driver's license at a significantly lower rate than their typical peers, limiting their engagement in development adult roles. There are limited options driving and community mobility interventions. Therefore, this qualitative phenomenology was conducted to explore the lived experiences of autistic young adults who participated in a driving and community mobility bootcamp from the perspectives of participants (n=67) and their parents (n=71). The bootcamp consisted of pre-driving, driving, and community mobility skills specifically designed for the unique needs and skills of autistic teens and young adults who attended the bootcamps each year. The results included themes of 1) Embracing a sense of joy, 2) Empowering competence and emerging self-assurance, 3) Building a sense of belonging, and 4) Experiencing success. The results highlight how an intervention targeting community mobility offers impactful and meaningful gains on improved quality of life for young adults with autism and the people that support them.

Keywords

- Driving
- Community mobility
- Competence
- Belonging

BACKGROUND AND INTRODUCTION

While an increasing number of teenagers are delaying obtaining a driver's license [1], the independence of driving is a major step towards adult roles of work, social participation, and leisure activities outside the home environment [2]. Although many young adults with autism do achieve licensure, it is significantly later than those individuals without autism. In fact, one in three autistic teens obtain licensure compared to 83.5% of their neurotypical peers [3]. Sheppard et al., [4], found autistic youth needed more lessons from the driving instructor and their driving difficulties were different from their neurotypical peers. Specifically, autistic drivers face challenges with executive function (attention, distraction, multi-tasking), understanding driving situations, and social interaction needed for driving.

Multiple studies have validated the need for the development of targeted support and specialized training for novice autistic driving [5-9]. This need has been clearly expressed from the viewpoint of autistic drivers and their parents. In an early study, 70% of parents interviewed indicated they believe autism moderately

or extremely affected their child's driving ability and identified multi-tasking, motor planning, generalizing information, and other related skills as barriers to learning to drive [10]. In a more recent qualitative study, autistic young adults saw driving as a way of becoming more self-determined and become less of a burden on others [2]. Using individual interviews and focus groups, Vindin and colleagues [6] uncovered specific challenges to learning to drive (e.g., anxiety, executive functioning issues, social communication), concerns about the reality of driving from the parents, and the need for specialized training. Unfortunately, few studies offer specific strategies to improve driving skills [7] or driving programs [11]. However, one such occupational therapy intervention for autistic teens and young adults was found to significantly improve driving capabilities, decrease anxiety about driving, and meet self-identified driving and community mobility objectives [12]. In a follow up study [13], perceptions of the efficacy of the intervention were compared in pre and post surveys from the perspectives of participants and parents with statistically significant differences in driving and community skills, knowledge, and abilities. Almost all participants and parents

responded that the intervention was positive and exceeded expectations. Nevertheless, both studies lack the richness obtained from an analysis of the qualitative data collected upon the conclusion of the driving and community mobility “bootcamp” for teens and young adults with autism. Thus, the aim of this study was to explore the lived experiences of autistic youth who participated in a bootcamp, as perceived by the participants and their parents.

METHODS

Design

A phenomenological qualitative study was conducted to analyze seven years of data obtained through in-depth open-ended questions of parents and autistic teens and young adults who participated in a five-day occupational therapy intervention to facilitate driving and community mobility. Performance-based outcomes and quantitative survey data are examined in prior publications [12] and [13] respectively. Qualitative analysis added an understanding of the lived experiences of these teens and young adults related to the driving and community mobility intervention to the literature, to extend understanding of the influence of the bootcamp on their perceived skills and achievements.

Participants

Participants of this study were autistic teens and young adults who completed the driving and community mobility bootcamp and their parents. They were asked to complete the surveys, to provide more comprehensive data which was described within a broader context of the person’s life. Since comprehensive perspectives are sometimes difficult for the individuals with autism to explain, resulting in answers that are brief and relatively concrete, the parents were also asked to answer open-ended questions to provide broader and potentially more insightful information.

Individuals attending the bootcamp had to be at least 14 years old, motivated to participate, and have a self-disclosed diagnosis of autism spectrum disorder (ASD). These individuals were recruited from pre-existing contacts in the community (e.g., autism support groups, medical providers), website information, and networks of previous participants. The study was approved by the University Institutional Review Board and all participants provided informed consent.

Approximately 67 participants and 70 parents provided data. Most parent respondents were mothers, although some parents did the questions together. In one instance, the caregiver was a grandparent. Each of the seven intervention groups (years) had a range of 7 to 14 autistic

teens and young adults for a total of 67 who completed the bootcamp. Of the group, 52 (80%) were male and 13 (20%) were female, with a mean age of 17.8 (SD = 3.03) years and a range from 14 to 30 years of age.

Instrument and Procedure

Using the online questionnaire *Qualtrics*TM platform, pre and post questionnaires were developed to collect young adult and parents’ perception of the intervention and change in the participants following the bootcamp. While Likert scales were used to determine objective opinions about the boot camp, open-ended questions were designed to elicit greater depth and richness of data regarding the outcomes, expectations, and perspectives of the attendees and their parents. Participant surveys included questions such as “What did you enjoy most about the bootcamp?” “What were the best outcomes for you because of participation in the bootcamp?” and “Do you think any of your skills improved as a result of the bootcamp (please describe).” Parent surveys included questions such as: “What has been the best outcome for your family member as a result of participating in the driving and community mobility bootcamp?”, “What did you family member enjoy the most about the bootcamp?”, “Do you have any special story about your family member as a result of the bootcamp?” and “Do you have anything you would like to share?”

Surveys were emailed to participants and parents and typically completed within a week of the completed intervention. If not answered within the week, reminders were sent regularly with a follow up phone call to capture all participants and parent feedback.

Intervention

The driving and community mobility bootcamp was established in 2015 and continued annually through 2023 (with exceptions of 2017 and 2020) with data for this analysis collected over all seven years of the intervention. Four to eight occupational therapy master’s level students assisted in evaluation of applicants to the program and implementation of the program under the leadership of the principal investigator, an occupational therapy faculty researcher with an extensive background in driving and community mobility. The intervention consisted of planned individual and group activities designed to introduce, build and/or improve driving and community mobility related skills. These include knowledge-based sessions related to pre-driving skills. It also included community mobility skills such as ridesharing services, riding a community bus, and navigating public transportation routes. Active learning strategies including scavenger hunts, mapping

games, interactive driving simulators, visual scanning boards and hazard identification software, were used to facilitate skill development in participants. Stationary vehicles facilitated orientation and demonstration of vehicle parts as well as an interactive visit with law enforcement officers while participants role played a driver during a traffic stop. A detailed description of the bootcamp, including the model of implementation fidelity, is described by Dickerson, Turbeville, and Wu.

Data Analysis

Responses to the open-ended sections of the questionnaires were analyzed following phenomenological methods, to understand the lived experiences of autistic teens and young adults who participated. Three rounds of coding were conducted by the research team.

For data gathered from parents, a novice researcher first organized all data according to question and year and identified repetition of phrases or words to group the data into descriptive codes. For data gathered from bootcamp participants, a team of novice researchers engaged in the first round of descriptive coding, after direction from a member of the research team who regularly engaged in qualitative analysis. As the participant responses were typically shorter than parent responses, this initial coding process was relatively efficient. Data from both sources, as well as the initial codes, were reviewed by a researcher with a background in qualitative analysis. This researcher facilitated second round pattern coding with each of those initial research groups. This assimilation of data into smaller, more meaningful units serves as a transition from purely descriptive ideas to constructs and patterns that forms the basis for emerging themes (Saldana, 2021). None of the members involved in the initial rounds of coding, including the experience qualitative researcher, were engaged in delivery of the driving and community mobility bootcamp, which reduced potential for bias.

The research team was then expanded to include the principal investigator of the driving and community mobility bootcamp from all years in which data was collected. This facilitated credibility of the data, due to prolonged engagement with the bootcamp attendees and observation of the events and interactions of the bootcamp. The subsequent meeting of all members of the research team allowed for discussion of the coding process to date, triangulation of perceived meaning, and peer debriefing regarding identification of meaning, ultimately resulting in the creation of themes [14]. An audit trail was created during the process to ensure dependability of analysis (Figure 1).

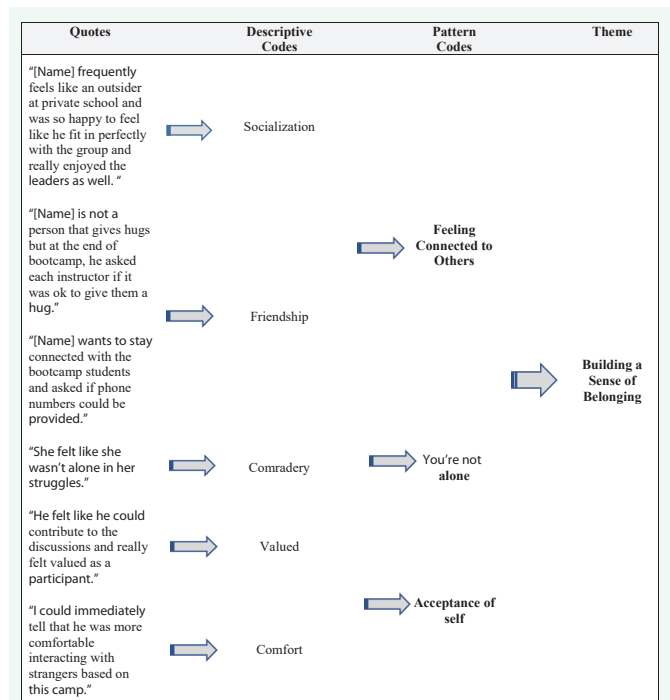


Figure 1 Audit Trail for Theme of Building a Sense of Belonging

QUALITATIVE THEMES

Through three rounds of coding the following themes were identified: 1) Embracing a sense of joy, 2) Empowering competence and emerging self-assurance, 3) Building a sense of belonging, and 4) Experiencing success.

Embracing a Sense of Joy

For all young adults, life is full of challenges which can elicit a variety of emotions and experiences. For autistic young adults, the negative emotions and challenges often outweigh the positive experiences in a society that promotes conformity and rewards high achievers in athletics, appearance, and social engagement. While the driving and community mobility bootcamp provided challenges, parents described those as experiences that facilitated learning, self-improvement, and accomplishment. These challenges differed significantly from the competitive nature most often experienced by individuals with autism in our society. The bootcamp was created and housed in a learning environment built specifically for their unique learning needs and facilitated by emerging health care providers.

The young adults were motivated by the positive and fun experiences of the bootcamp. They described enjoying the experiences of meeting new people and in particular, making new friends "who were like me," as stated by one participant. Other participants reported "I enjoyed the

social environment” and appreciated “getting out of my comfort zone.” An additional participant reported enjoying “The fun of it all! Just hanging out with all these people made me happy!” To describe the impact of the positive experience, one person recounted, “Early in the camp, a fellow student said ‘Alright, no pressure, let’s get excited!!’ Shortly after, I started using that quote in my head before starting something I was scared of, and it helped some.”

One parent explained, “[Name] looked forward to attending the camp each day. She usually encouraged us to get her there on time because she didn’t want to miss anything.” Another stated “He was excited to get up every morning and attend the camp. This is out of the ordinary as he would normally want to spend his summer days sleeping or playing video games.”

Those positive emotions were almost universal during the driving and community mobility bootcamp, which was a novel experience for some of the attendees. A parent stated “Before the bootcamp, I thought my daughter’s anxiety levels would increase.... instead of anxiety, she experienced excitement. She looked forward to returning to the bootcamp each day.”

Empowering Competence and Emerging Self-Assurance

A primary objective of the driving and community mobility bootcamp was to facilitate community access for autistic young adults, either through learning the skills of driving or using public transportation. The overwhelming benefits of the bootcamp described by the participants was gaining these new skills, and how it increased their confidence in related skills. They identified learning specific driving skills, such as understanding the controls of the car, steering, lane management, and using a driving simulator to identify hazards and improve driving skills. Specifically, one participant reported an outcome of “not having me freak out as much and having the ability to at least have a start to driving.” Confidence was expressed as a meaningful outcome by many of the participants. One participant stated that they had gained “confidence behind the wheel, improved hand eye coordination, and great advice from professionals. I love driving more than ever now!”

The process of learning driving and community skills was described by parents as being profound. Almost universally, parents described new and growing confidence and a sense of accomplishment in their children as a result of the bootcamp. Instead of being held to low expectations typically set for them, these young adults experienced learning that created comfort in the often-uncomfortable task of learning. A parent explained,

He is very confident in his ability to drive. He understands more about the rules of the road and how to navigate in his environment. Most of all, he feels that he has the ability to drive now, which is something he was fearful about in the past.

Another parent stated, “I am so proud of [name] for attending the boot camp. His skill set has broadened substantially regarding better driving by overcoming some of the attributes of Autism / Asperger’s.”

While this confidence was related to the specific skills addressed in the bootcamp, it was often expressed in other areas of life as well. A parent described the best outcome of the bootcamp for her child, stating that he had “more confidence, not only regarding driving, but in his ability to succeed in life.” Another parent also described this distinctly as “She is now desiring even greater involvement in life and has returned to logical goal setting and impassioned pursuit of her own dreams.” Clearly, this experience of success created a self-assurance that extended beyond the specific activities and skills included in this interactive intervention.

Building a Sense of Belonging

Friendships and relationships bloomed during the bootcamp fulfilling a distinct need for many of these autistic young adults. The carefully planned activities were offered for participants in small groups or teams, facilitated by graduate students as bootcamp leaders. This encouraged teamwork with typical peers and with others on the autism spectrum. For individuals who may struggle with relationships, this held particular significance and meaning. One participant stated, “The people at the bootcamp are amazing and I would love to meet them all again one day, teachers and other participants attending the bootcamp.” Another stated “I enjoyed being in the company of friends the most.” One parent described, “[Name] frequently feels like an outsider at private school and was so happy to feel like he fit in perfectly with the group and really enjoyed the leaders as well.” Additionally, a parent explained “[Name] is not a person that gives hugs but at the end of bootcamp, he asked each instructor if it was ok to give them a hug.” Socialization is important not just in the moment that it is occurring, but in building a sense of belonging and self-assurance that allows a person to embrace new challenges and tolerate discomfort inherent in personal growth.

Experiencing Success

Finally, the experience of success had a profound impact on driving and community mobility bootcamp participants. Parents described feelings of hope, motivation, and self-

advocacy in their children that were built on a foundation of safety and enjoyment. The knowledge, confidence, and relationships all contributed to the sense that these young adults could thrive, contributing to a sense of empowerment that is rarely experienced by autistic young adults, especially regarding the challenging and complex task of learning to drive. Participants described “I enjoyed the sense of accomplishment that comes with increasing my driving skills.” Another summarized, “I learned a lot from the teachers and made myself and family proud (mom, godmother, aunts, brothers, sisters, uncles and cousins).” A parent summarized the deeply felt impact of success in this way:

For me, the compassion and excitement of [leader] and her students before and during the boot camp was unparalleled. I cried a few happy tears each day because of something [my daughter] learned each day that I had not considered she would need to successfully navigate her world. This experience has been so much more than driving. The relationships formed, the confidence built, and the excitement as she works toward getting her permit and license are priceless.

DISCUSSION AND CONCLUSIONS

This driving and community mobility bootcamp was designed to facilitate greater independence in accessing the community for youth and young adults on the autism spectrum. Feedback provided by parents over seven years allowed for a deeper understanding of the meaning of this intervention to the people who participated. Quantitative analysis of skills related to the tasks and activities of the bootcamp has determined that driving skills have improved [12,13]. Equally important, however, are the experiences described by the participants as observed by their parents and the insights afforded by this qualitative analysis.

These young adults are often limited by the expectations of society as well as the judgments and constraints placed upon them by others, including parents [15]. Through this experience, however, parents have described positive outcomes related to joy, self-assurance, and a sense of belonging, and participants described the satisfaction of building a competent skill set in this important adult role. Ultimately, this sense of success has continued to move these young adults toward personal growth and success that influences their experience of living, not only in driving but in feeling empowered to tackle other areas of successful living. In many ways, this has allowed these individuals to break the mold of low expectations and limited skill performance, revealing opportunities that

were otherwise not considered achievable [15]. The sense of success of the bootcamp intervention is supported by research evidence that found it is essential for autistic young adults to develop a balanced self-perception for high quality of life and well-being [16]. Emphasizing the strengths and unique characteristics of our bootcamp participants contributed to their sense of well-being.

While the bootcamp intervention was provided through group sessions designed to emphasize socialization skills and improving communication, the importance and depth of these relationships was unexpected by the parents, participants and facilitators. For example, one mother was outside the classroom, observing her son in a solitary activity. When another participant approached and joined the activity with her son, the parent stated in amazement “Look! I have never seen any other child speak to my son!” In a related study [12], new friends and the social environment were the most frequently reported favorite components of the bootcamp, which is significant, as Orsmond and colleagues [17] found high rates of social isolation for young adults with ASD. Specifically, they found autistic young adult rates have significantly higher odds of friends not calling and being socially isolated compared to young adults with intellectual or physical disabilities, even after adjusting for other factors. With social interaction difficulty being a defining feature of autism, the opportunities and support in the protective and secure environment were unique. One parent adeptly described:

The combination of appropriate learning environment and structured scientific delivery of the course created a perfect storm of opportunity for her that does not exist anywhere else we’ve ever found (and we have looked for many years)! The peer learning aspect cannot be understated during the targeted and planned activities.

Limitations

The primary limitation of this study was the manner in which data was elicited. Although many parents were robust in their articulation of the changes they observed in their children, the open-ended questionnaires did not allow for deeper exploration by researchers. Therefore, future iterations of the driving and community mobility bootcamp will include a more rigorous qualitative process based on semi-structured interviews. Hopefully, additional data can build on this preliminary analysis to deepen the understanding of the impact on the lives of these young adults. Additionally, this data was gathered immediately after the bootcamp was completed. Future study will include follow-up data to learn more about the effects of this program months after it is concluded.

Application to Practice

What is clearly understood from this qualitative study is that this driving and community mobility program meets the distinct learning needs of autistic young adults. The benefits not only include building the skills, knowledge, and abilities to improve success for driving and community mobility but also facilitate personal growth and development that may influence other life areas. This model program may be useful in developing other types of programs to address the needs of autistic young adults, which might include employment, transitional, or interpersonal skills. One parent summarized these benefits as:

[My daughter] experienced a sizeable gain in confidence, driving interest, and understanding of rules of the road and driving ability ... However, there is more to it. She also experienced so much more joy as a result of being fully engaged in a structured and safe learning environment with true peers.

This study highlights the critical role structured group interventions can play in addressing the service gap of this population as they transition into adulthood. Specifically, occupational therapists have the skills, abilities, and knowledge to provide these essential services in an inclusive and supportive environment unique to the needs of autistic community. Evidence has identified that existing services are not adequate or designed to meet the distinct needs of autistic young adults [18]; autistic young adults have poorer outcomes than other young adults with other disabilities [19]; and healthcare providers do not feel prepared to assist with driver readiness [20]. Occupational therapists are well-suited to address these gaps through interventions that build foundational skills of social engagement and skill development, through innovative programs like a driving and community mobility bootcamp which blend success, belonging and self-assurance with community access necessary for full role performance and fulfillment.

Approval: This study was approved by the University and Medical Center IRB.

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