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# The Use of TYZE.com to Enhance Social Inclusion for Individuals with Intellectual/ Developmental Disabilities

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**ABSTRACT/EXECUTIVE SUMMARY**

The use of the TYZE.com website by families who had teens and young adults with intellectual/developmental disabilities was evaluated for its usefulness in connecting and enhance the social network of the young people. Arc Greater Twin Cities (Minneapolis-St. Paul area, Minnesota) sent surveys to 22 families who had been introduced to the site. Nine families responded, in either focus groups, phone interviews, or email surveys. Most families found the technical aspects and site interface too challenging, especially after site ownership and design changed. There were also issues of insufficient technical assistance and training, and confusion about the site administrator role. For those who were using TYZE, the site was useful for the young person to stay in more frequent contact and communication with their friends and family members about what was happening in their lives but did not assist in expanding their social network.

## **INTRODUCTION**

Formal social services support systems for persons with disabilities are constantly faced with funding challenges, and as need increases into the future, will continue to be. Given these challenges, other models are needed for support for individuals with intellectual and/or developmental disabilities (IDD) and their families. Most individuals with IDD live with their families (Larson et al., 2018) and have some types of supports from their families and friends, but oftentimes these are insufficient for all types of needed support, and families look to formal systems for additional needed assistance. One alternate model to the formal support system is the “Network Model of Care,” which emerged from the earliest versions of Person-Centered Planning and is representative of the types of “natural supports” envisaged in the Medicaid Home and Community Based Services program. Besides providing an alternative to the funding challenges of the formal system, network models of care reflect the values of community inclusion and natural supports. However, the benefits and challenges of such informal networks of support have not been rigorously studied, especially for individuals with IDD.

One avenue of supporting informal networks of care is the use of social networking tools. One such tool is the TYZE website ([www.tyze.com](http://www.tyze.com)), a tool for identifying, establishing, and expanding a personal support network. Developed by PLAN (Planned Lifetime Advocacy Networks) Institute of Canada, the site aims at creating personal, private, secure, online networks that strengthen relationships and address isolation. The TYZE system is family and person centered, facilitating choice and decision-making. It supports not only the person with a disability, but also caregivers, helping the family access needed services and supports

(Cammack & Byrne, 2012). One distinction between TYZE and other social networking sites such as Facebook or Caring Bridge, is the security of the site. For example, secure networks can be established on TYZE that will allow individuals who receive formal support to share private and confidential information such as medical information or care plans.

Most previous research about the use of TYZE has been focused on use with persons who are elderly (Cammack & Byrne, 2012). Little is known about the application of TYZE for the IDD population apart from anecdotal reports.

Arc Greater Twin Cities (Arc GTC), an advocacy agency for persons with disabilities in the Minneapolis-St. Paul area of Minnesota, has been offering the use of TYZE to families they support, and especially as part of two of their projects. First, the Arc offers comprehensive person-centered planning in a format called FutureLife Options, formerly called Lifetime Assistance Planning, and has offered TYZE to families who use that form of planning. Secondly, TYZE was offered to families in a specific project called Bridges to Employment; this project was first offered in Ramsey County (in metropolitan Minneapolis-St. Paul area) and was aimed at youth graduating from high school to assist them in transitioning to community jobs. The plan was to have the employment service provider, the case manager, and any other support people use TYZE as a way to assist the student across services. Circles of Support were established around each student, and circle members could use TYZE to connect with each other. In some cases, staff from agencies that were providing residential or in-home support were also included in the circles. In the second year, the project was expanded to an additional metropolitan area county (Dakota), and service providers in both counties were trained in providing the role of community connector. The connector role was intended to help families engage in using TYZE, assist them in connecting existing circle members to the site, and expand

the circle through assisting family members to invite other people to be part of the circle and to use the site.

The Arc GTC asked us to evaluate TYZE for the purposes of their continuing use of the site, especially regarding whether the site was useful for expanding a participant's social network. The aim of this study was to understand the varied uses and challenges related to individuals with IDD and their families using the TYZE program, to better understand the innovative uses of the site as well as practical barriers, and to understand its impact on social inclusion. There were four specific research questions that were addressed during the study:

1. What are the experiences, benefits, and challenges of families with a member with IDD living at home who use TYZE to strengthen support networks?
2. What are the experiences for transition-age students compared to older adults?
3. What are the reasons some families stop using TYZE?
4. To what extent and how does the use of TYZE have an impact on the social inclusion of family members with IDD? Is there a difference in impact for transition-age participants versus older adults?

## **METHODOLOGY**

### **Population and Sample**

The study intended to understand how different user groups of families and people with IDD implemented and experienced using the TYZE site. The study was aimed at 3 groups of families with members with IDD: 1) those who were using TYZE when the project began; 2) those who had used TYZE in the past but had stopped before this evaluation project began; and 3) those who initiated use of TYZE during the course of the project. Arc GTC contacted all the families which had a record of using the site up to that point (March, 2016), whose child was at

least 18 years old. Families receiving support from Arc GTC and/or Ramsey County that had a child that was at least 18 years old, that began to use TYZE during the project were also offered the opportunity to participate.

### **Research Design**

The original design of the study was to use multiple descriptive case studies (Gerring, 2006; Yin, 2003) regarding the varied uses and challenges related to the TYZE program to better understand its uses, barriers, and usefulness for social inclusion of persons with IDD. The original intent was to develop at least five in-depth case studies that reflected the diversity of the three types of user groups.

Based on the inclusion criteria, 22 families were initially contacted via email asking if they would be interested in being a part of a focus group about their use of the TYZE website. Of the 22 families, two responded that they were available to attend the scheduled focus group meeting (held April 19, 2016). Three participants attended this meeting: two parents and one young person. Four additional parents responded stating that they could not attend the focus group but would be willing to be interviewed by phone. Three of these had phone interviews with an independent evaluator. During one additional phone interview, the participant reported that she wanted to send her responses to the questions asked via email; this person's responses have been categorized with the phone interviews. One person stated they were not interested in participating at all. Due to the limited number of responses and/or availability for the focus group and phone interviews, one additional method was utilized to gain information; an online survey was sent out to the remaining 16 families that met the inclusion criteria. Of the 16 emails sent in February 2017, two emails came back as undeliverable and three people completed the online survey. Compiling the three different formats of responses -- 2 from the focus group, 4

interviews over the phone, and 3 on-line surveys, this was a total of 9 families of the 22 contacted, for a 41% response rate overall. Respondents' family members with IDD ranged from age 13 to age 33 with one participant stating that their child was of "adult age." (Appendix A, Question 1).

Because of the limited number of families responding from whom more in-depth information could be gathered, the original research design of case studies was changed to reporting the results from the interview protocol. The interview protocol of 19 questions (Appendix A) was developed to address the research questions and other areas of information which Arc GTC staff requested. The same nineteen questions were asked of the participants in the focus group, phone interview, and the online survey, and addressed respondents' use of the site, benefits and challenges, and support from Arc GTC.

## **RESULTS**

Results are reported here in two sections: responses to general questions about the use of the TYZE site, and responses to the four research questions as well as the two additional areas of questions concerning the relationship with Arc GTC programs.

### **Use of TYZE site**

Arc GTC had made TYZE available to families starting in 2010. Most respondents reported that they had started use of the site between 2012-2015. Most responses to the question, "When did you start using the TYZE website?" ranged between 2003 and 2015 with two participants stating that they couldn't remember the dates but that it was "several years ago." One participant reported they had starting using the site in 2003 and one in 2007; it is unclear whether these participants had access to the site through some avenue other than through Arc

GTC, prior to the Arc's program, or whether their memory was unclear of when they started using the program.

Length of Time Using the Site. (Appendix A, Question 2) Participants were asked if they are currently using the TYZE website. Of the 9 respondents, only one of the participants was currently using the TYZE program. Participants were also asked approximately how long they have/had used the site. Four of the participants stated that they had used TYZE for less than one year and two participants stated that they had used TYZE for 3-4 years (including the one who was currently using the site). Three participants stated they could not remember how long they used TYZE.

Why People Started Using the Site. (Appendix A, Question 3) Participants began using the TYZE website for various reasons including four people stating it was part of a job coaching program or Arc's Bridges to Employment program, two participants were invited to use the free trial when it was available, two participants were encouraged to use it as a way to build their circle of supports, and one participant stated they were encouraged to use it when working with the Lifetime Assistance Program.

Changes in Site Design. (Appendix A, Question 7) In June 2014, the TYZE site had been purchased by another company, which undertook updates and design changes that significantly altered the website and interface. Parents were asked to report on how they felt the changes to the website impacted their utilization of the site. Specifically, participants were asked, "What do you like about the changes to the website? What do you dislike?" "What functionality, if any do you miss, and with the new TYZE website, is there any training you would like to improve how you use the program?" The responses related to more training on how to use the

program can be found in the “Recommendations for Arc and TYZE” section at the end of this paper. Of the 9 respondents, two people responded to the questions related to the TYZE updates:

*“There was no notification about the update happening. We had no idea that TYZE was going to have such a big update. It made it difficult to use and understand right after it happened, but we are used to it now.”*

*“The changes to the site did not improve accessibility for me. It was difficult to understand and navigate.”*

## **Research Questions**

The qualitative data that was collected in response to the 19 interview questions was organized to address the study’s four research questions. After reviewing the data from the three methods of collection (online survey, phone interview, and focus group interview), it appeared that one person responded to both the online survey and the phone interview, since responses were worded virtually the same. Since the on-line survey was anonymous, it was impossible to determine if this suggested duplication actually occurred. The results reported here reflect information from nine respondents, but it is possible that these responses reflect the experiences of only 8 families.

### **1. What are the experiences, benefits, and challenges of families with a member with IDD living at home who use TYZE to strengthen support networks?**

Participants were asked several questions related to their experience using TYZE including: “What are your experiences overall with using TYZE? What have been some of the challenges and benefits? What has worked well and what has not worked well?” (Appendix A, Questions 4, 5, 6). There were several areas of challenges reported, primarily about the use of the site

itself. Overall, when it came to using the site, respondents reported more challenges and things that did not work well than benefits and things that worked well. The challenges and things that did not work well reported, are listed below under Research Question # 3.

When participants were asked what were their overall experiences with using the TYZE website, (Appendix A, Question 4) all 9 participants answered. Five of the 9 respondents reported that they did not feel it was a good use of time or provided any benefit. Responses included:

*“A waste of time.”*

*“We did not feel it helped.”*

*“I felt the program was confusing with a lack of focus, direction, and support.”*

*“It did not feel like a good fit for us.”*

*“We didn’t really feel this was helping with getting a job. There didn’t seem to be any tools or strategies we were given to use this and look for jobs. It also is not a really good match for the way we do things. We do better in making connections face-to-face, knocking on doors.”*

Two participants reported an indifference to using the program. Their responses include:

*“It might work better with younger or older children. No different than Facebook but costs money.”*

*“We did invite people to join, people from what we call his ‘circle of strength,’ the network of people who support him and us, and some of them did, but all they ever really did was reply to things. We never used it to request help or support.”*

Two participants reported that overall, they enjoyed TYZE and found benefit from it. Their responses include:

*“We liked the website and used it to post with my son.”*

*“My son really likes TYZE and uses it each week to send updates, check messages, reply to comments.”*

These two participants who stated that they enjoyed using the website with their family member also stated that there has been significant technical difficulty with the website and an overall lack of technical support.

During the Bridges to Employment program, there were difficulties reported regarding the site “administrator” function and the community connector roles. When agency staff were set up as the site administrator, there was a challenge when the staff who had been the administrator left without transferring knowledge of the site to the next staff, who had never used the site. It appeared that no one knew how to transfer the site administration back to the mother. One father got locked out as the site administrator and did not know how to get back in.

These two families both stated that the biggest benefit they get out of using the site was communication with the person’s support network, including posting updates and replying to other people’s comments. These connections have meant being able to stay in contact with family members, previous teachers, and staff, among others. Two other participants also felt that although they didn’t use the website and it wasn’t right for their family, they could see other families having a need for it or enjoying utilizing it to build up a support network.

*“It gives you a format to share a story with your network and it gives you a format if you needed to reach out for support.”*

*“The biggest benefit is the acknowledgement that informal supports are badly needed for those with IDD.”*

## **2. What are the experiences for transition-age students compared to older adults?**

In this study, transition age was defined as someone who is between the ages of 18 and 21.

Of the 9 respondents, identification of transition age compared to older adults was not possible due to participants not remembering when they started or stopped using TYZE, and thus they were not able to identify the age of their child at the time they started using the site. Two respondents stated that they thought it would be easier to use TYZE with the younger school aged population to grow their child’s network before transition and then those supports would be in place after graduation, when school supports are gone and then more support is needed. These comments included:

*“It was difficult to find supports as our child aged out of transition.”*

*“I think waiting until adulthood to try to establish circle of support is too late, it creates stress and grief.”*

## **3. What are the reasons some families’ stop using TYZE?**

Participants were asked, if they stopped using TYZE, why? “Were there problems, issues or challenges?” (Appendix A, Question 14). Many of the families reported that TYZE was not user-friendly, and that additional training and support was needed to use it. Because some participants, family and/or support staff were unable to get comfortable enough with the technology, it would often require more effort than they were getting back in reward. There was

confusion about who should have the role of site administrator. The technical issues involved in being the site administrator were also confusing; one parent disconnected from the site because residential staff were assigned the role of site administrator.

*“I think it works if the person who is the administrator, usually the mom, is a little more tech oriented. That’s not me. I think the network needs monitoring and maintaining, and I didn’t do that.”*

*“Not into social media, uncomfortable asking people for help, effort to keep the site going was too much.”*

*“I found it was cumbersome. I didn’t think it was very user friendly.”*

Two family members commented that their residential agency, which had staff that were supposed to be using the site and assisting with its use, had high staff turn-over. This turn-over resulted in difficulties in keeping new staff up to date with the website.

Other participants reported that they felt that there were more efficient ways to build a support network, including face-to-face interactions and other social media platforms such as Facebook. A few respondents also remarked on the difficulty of getting people to join their family member’s TYZE network, due to either not having people to ask or not feeling comfortable asking. Because of the lack of technical support for using the site and lack of support for expanding the social network, some participants stated that it wasn’t worth the time to continue.

*“I found TYZE wasn’t user friendly or intuitive. After several attempts, I quit using it.”*

*“I never understood why not use something like Facebook or email.”*

*“For our family, we see a lot of people face to face. So, I don’t need an email kind of relationship.”*

*“There are no supports to add for an adult child, it would have worked better with younger school age children.”*

**4. To what extent and how does the use of TYZE have an impact on the social inclusion of family members with IDD? Is there a difference in impact for transition-age participants vs. older adults?**

When participants were asked how many people were in their son’s or daughter’s network, 6 people responded to the question (Appendix A, Question 8). Five of the six respondents reported between two and twelve people in their child’s TYZE network, and one response was that there were a number of people in their child’s network but did not provide a specific number. The other 3 people either did not answer or marked N/A. When asked what their experience was when adding new friends to their child’s network (Appendix A, Question 9), only two participants responded. One stated that they had sent out several invitations but only received two responses back. The other participant stated that when they invited people to their child’s network, everyone joined that was invited but nobody knew what to do or how to use the site.

Participants also were asked “Are there people in your child’s social network that are not in the TYZE network?” (Question 10). Two participants reported that there is a social network outside of using TYZE. Their responses to the question include:

*“People in his social network (not on TYZE) participate with him with different frequency, some daily, some weekly, and some less often. But especially through school he has a lot of daily and weekly contact and activities with friends.”*

*“He has a large and strong network of people that includes relatives, friends, neighbors, social worker, personal trainer at the gym, snowboard instructor, and so forth. We have a huge network. It just happens that his network is not in internet space. “*

Participants were also asked “What are the challenges in asking friends, family members and others to join the TYZE site?” (Question 10). Some of the challenges listed include friends and family not using the site, not knowing other people’s emails, and not explaining it well to other users. Their responses include:

*“A number of people in his network accepted the invitation to join the site. But it never went anywhere beyond that, again, because I think it needs someone to keep it up, and that’s not me. And, also, because that’s not how we would ask for support or make connections. We would do that face to face. When we were trying the site, people did reply to things, but that was all.”*

*“Friends and family don’t go on it much. There is a lot of competition with other social media sites.”*

*“Maybe I didn’t do a good job of explaining that it would be a support network for the whole family.”*

*“I don’t know or want to know the email for most of the people in the network. We see people at the cabin, or I go talk to people, or (name) sees them at the gym. So, I don’t need an email kind of relationship.”*

*“Our circle tends to change year to year, or sometimes more often, based on different volunteer activities, maybe a new personal trainer, so it felt complicated trying to add and delete people from the network.”*

Participants were also asked “What types of things do these people (the ones in the TYZE personal network) do with your son/daughter or for your son/daughter?” (Appendix A, Question 11). Two participants directly answered the question and reported that they use it as a communication tool for providers or as a social media tool with teachers. They were also asked if

there are things that people not in the TYZE Personal Network do with your son or daughter?

(Question 11) No participants responded to this question directly. When participants were asked how often do friends and family participate on the site (Question 12) and how often do they participate directly (in person) with your son or daughter? (Question 13), it was unclear if they were reporting participation on the site or in person. Some of the responses to these two questions include:

*“People in our network participate with my son in different ways. Some every week, or a few times a week, and some not as frequently, or some more sporadically, like his snowboard instructor.”*

*“About 15 people were invited to join my son’s personal network but only about 10 accepted. This included teachers, friends, group home staff, and siblings. Teachers used the site to comment on my son’s updates.”*

*“We do not use TYZE as a social media site, only for communication with providers.”*

Based on the responses of the participants, the majority of study respondents found the TYZE website to be cumbersome and difficult to use when trying to build a social network for their family member with IDD. Two of the participants felt there was benefit to using the program for social networking, but both had or were currently experiencing technical issues with the website or the administrative login and were not sure how to resolve the issue. The benefit for one family was that exposure to the site resulted in their having ideas regarding building their social network, and they have done so independently of the site:

*“TYZE did not help us create a bigger network or even a more effective one. TYZE did give us the idea about formalizing our network and tying people together. So, we have*

*done that, but not online. We call it his ‘circle of strength,’ and we have an annual picnic and gathering to bring people together and celebrate that network.”*

There appeared to be no difference in the age of the participant with regard to the impact the TYZE site had on social inclusion. However, as noted above, two families thought it would be useful to start building the circle of support at a younger age in anticipation of losing supports after transition or not having any supports to add in adulthood.

**5. What support have you received from Arc staff about using the TYZE site? Do you feel that support has been useful? What could Arc staff do that would be more useful?**

Besides the principal research questions, respondents were also asked their impressions of Arc staff participation and support when using the TYZE site (Appendix A, Question 15). Of the 9 participants, three did not respond to the question. One participant felt that the Arc staff offered a lot of support when using the site. They reported:

*“Arc staff was really great. They helped me with many technical questions and things. They gave a workshop to our circle about TYZE and use of it. I don’t think there is any other support they could have given that would have changed in using it, as that is just not us.”*

Two of the responses reflected a lack of support, that the Arc staff did not support them while using the site and made judgements about how families were using the site. However, based on responses to additional questions, it is possible that these responses were coming from the same person, that appeared to have completed both an online survey and a phone interview.

*“I felt we were judged by the group that was implementing this. Our family has two staff who are with my son. They are the ones who would be implementing this with him. So, I sent them to*

*the training. They (Arc staff) asked, “Why aren’t the parents involved?” Of course, we are involved. So that felt like they were questioning us.”*

*“ARC staff were part of the problem. The director accused parents of not being involved if they sent someone else to be with their son or daughter for the meetings.”*

Of the 9 respondents, three people included recommendations about how Arc staff and the TYZE site could be utilized more effectively. One participant suggested that using the site at a younger age would be more effective. The participant reported this to Arc staff but felt the Arc staff did not embrace the recommendation. Two participants reported that training new in-home or group home staff to use the program was confusing and that training provided by Arc or the TYZE site would be beneficial. The responses from these family members include:

*(wording in parentheses added) “ARC’s role with TZYE and the (son’s) transition to (one residential agency) from (another residential agency) was very confusing. There was a lot of confusion about supporting families using the program and who is responsible for training new caregivers. It was thought that ARC was going to be a community connector. Trainings and workshop would be helpful and having a TYZE rep at the meeting or having a quarterly meeting/webinar, or phone call with a rep for technical support would be great. There was no communication around web updates.”*

*“Reminder calls from the Arc were useful but it would have been nice to have more of them. More training for group home staff would have been helpful.”*

*“Using the program during transition seems to work a little better as there are still several supports in place, but my thought was to try using TYZE with parents of much younger kids. I think this would have a better chance of being successful as there seems to be more natural supports around families when kids are younger and keeping the*

*support around as the kids age seems easier and less stressful in general. Arc disagreed with this idea.”*

## **6. Experiences with the FutureLife Options program**

One of the avenues through which TYZE had been made available to families was through Arc GTC’s program called FutureLife Options, an in-depth life planning process which was formerly called the Lifetime Assistance Program. At Arc’s request, study participants were also asked about their interactions with the FutureLife Options and their experience with the program. The specific questions that were asked included: “Have you participated in FutureLife Options (formerly the Lifetime Assistance Program)? What have been your experiences with FutureLife Options (formerly the Lifetime Assistance Program)?” (Appendix A, Questions 16, 17).

Two of the 9 respondents either mentioned the program or responded to the questions about the program. One of these reported that she had been in the process of using the Lifetime Assistance Program in 2007, that is when she first heard about the TYZE program and had then been encouraged through the program to utilize the TYZE website. As mentioned in an earlier section of the paper, the TYZE site was not introduced to Arc participants until 2010 so it is unclear whether this respondent was recalling the date of first information about TYZE correctly, or whether she was offered TYZE at the later date than her first introduction to Future Life Options. No further information was provided about the use of FutureLife Options or Lifetime Assistance Program by this respondent, only that this was the avenue through which she had first heard about TYZE.

A second participant reported that they are actively using the FutureLife Options program. The participant reported that they like this program because it covers social aspects of

life, it helps families to think about setting up a trust for their child, allows families to explore what makes for a good life such as traditions and values, etc. This respondent reported that the planning process is paid for by the county, includes a lot of paperwork, that it is a good planning service, and that it is person centered planning.

## **DISCUSSION**

Overall, study respondents utilized the TYZE website for different lengths of time and for some, it was many years ago. One respondent reported that it had been about 13 years (2003) since they had used the website and they had difficulty remembering some of the answers to the questions. As discussed earlier, if this family had used the site that long ago, it was not through Arc GTC. Because of the time lapse for many of the participants between the time they had used the site and the time of this study, many struggled to answer some of the questions. The information gathered through this study may also be limited by the fact that not all people contacted who had used the site responded; however, it is probable that those who did not respond were no longer using the site.

While many parents reported technical challenges with the site, the Arc staff also reported several challenges in their experiences. The Arc's contact person at TYZE changed several times over the course of their implementation of the TYZE program. The Arc staff often relied on hearing back from TYZE staff to solve technical challenges and reported a delay in the support they received. When the TYZE platform was sold to a new entity, as well as the subsequent significant design changes to the site, Arc staff were not given much notice. These delays and lack of information and support directly impacted their ability to keep users such as these families well-informed.

Many study respondents stated issues with website technology and user interface as the main reasons why they did not continue to use the site. In addition to technical concerns, training and time needed to train staff or participate as the site administrator was also a barrier for some.

As technology continues to advance, social media is becoming more and more user friendly and popular for maintaining social connections. For participants that began using the site several years ago (even as recently as 5 years ago), the use of social media might not have been as engaging or appealing to users at that time. It may be that newer users introduced to the site more recently may find it easier to use or more appealing, or may now be more experienced or comfortable with more complicated site features.

A few participants felt that the concept of a support network such as TYZE was a great idea and that it should be started with families when their child was at a younger age. For the few families that did continue to use the site, it was primarily a way to keep members of the existing social network updated with news about the young person's activities and life, rather than a mechanism to add new members to the social network or to expand social activities with existing network members.

### **RECOMMENDATIONS FOR ARC AND TYZE**

Participants were asked about their feelings toward the support provided by Arc when using the TYZE site and recommendations regarding what would be more helpful to assist them in the use of TYZE to build their child's network. The two recommendations made most frequently were to provide additional training for the program and to provide more on-going technical support. Many of the families reported struggles with using the program at the beginning, causing them to lose interest. The benefits of using the site to either engage the

existing social network or to expand it were not greater than the time and energy which family members were putting into using and understanding the program. There seemed to be some confusion as to who was supporting the families to use the program, whether it was up to the family member as the TYZE administrator, the Arc staff, or the group home staff. Providing additional trainings and workshops either in a face to face format or as a webinar on a regular basis will assist the families when transitioning with new staff and/or when feeling stuck using the program. Also providing access and introduction to a TYZE representative to assist with technical problems would allow for timely trouble shooting when questions arise.

A third recommendation for both TYZE and Arc was more frequent communication. Parents stated that Arc GTC was sending out reminder emails and phone calls to utilize the program. One parent found these to be very useful and wished there were more reminders sent out. The two families that used the TYZE program for the longest period of time (3-4 years) felt that communications from TYZE was missing when it came to system updates. Both participants felt they did not receive communication when TYZE made significant changes to the program. Sending out regular updates on changes that were occurring to the program and timelines for the changes would have allowed the parents to feel more supported and reduce potential anxieties when logging in after a system update.

Direct recommendations from participants:

Initial training:

- Onboarding program, user manuals, and training videos to use with new staff, formalized online training program
- User manual and/or helpful tips cheat sheet
- Mentoring on social media use for parents and teaching for child on internet use

- Private workshops for person and their network
- Ongoing training for staff at group home and home care providers

On-going support:

- More reminder emails from Arc to use the site
- More notifications from TYZE when the site changes
- Announce updates and explain changes in features as updates occur
- Webinars and phone support with TYZE representative
- Helpful hints on how to maintain and how to talk with others (the network) about using it
- Group homes need a point person, someone who is going to push the program

Technical issue with site design:

- Integrate with Gmail-When a post is added to the “care board,” it’s hard to start a private conversation from the original thread

Social inclusion:

- ARC to become a community connector
- Have someone co-create the network to assist in getting started

## **CONCLUSION**

In conclusion, families felt they needed more support in becoming comfortable with the technical aspects of the site in order to use it effectively, especially after the site changed ownership and there were changes in many features. For those who were using TYZE, the site was useful for the young person to stay in more frequent contact and communication with their friends and family members about what was happening in their lives. For expansion of the individual’s social network, a more active role for the community connector would be needed, including more support for adding new people to the site.

## REFERENCES

- Cammack, V. & Byrne, K. (2012) Accelerating a network model of care: Taking a social innovation to scale. *Technical Innovations Management Review*, July.
- Gerring, J. (2006). *Case study research: Principles and practices*. Cambridge, UK: Cambridge University Press.
- Larson, S.A., Eschenbacher, H.J., Anderson, L.L., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Bourne, M.L. (2018). *In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2016*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- Yin, R. K. (2003). *Applications of case study research (2<sup>nd</sup> ed)*. Thousand Oaks, CA: SAGE Publications.

**APPENDIX A****FOCUS GROUP, INTERVIEW AND SURVEY QUESTIONS**

Note: these questions were asked in all three forms of participation.

1. How old is your son or daughter?
2. When did you start using TYZE?
3. Why did you start using it? What did you hope to accomplish with TYZE?
4. What are your experiences overall?
5. What has worked well with TYZE? What has not worked well with TYZE?
6. What have been the benefits? What have been the challenges?
7. The site recently changed format and features, what do you like about the changes? What do you dislike about the changes? What functionality do you miss that the previous TYZE site had?

Is there any training about the new TYZE site that is needed to improve how you use TYZE?

8. How many people are in your son's or daughter's TYZE Personal Network?
9. What have been your experiences with adding more friends and family to the network?  
Has the TYZE site helped to create a bigger personal network? If yes, how? If no, why not?
10. Are there people in your child's social network that are not in the TYZE network? What are the challenges in asking friends, family members and others to join the TYZE site?

11. What types of things do these people (the ones in the TYZE personal network) do with your son/daughter or for your son/daughter? (If applicable) Are there things that people not in the TYZE Personal Network do with your son or daughter?
12. How often do friends and family participate on the site?
13. How often do they participate directly (in person) with your son or daughter?
14. If you have stopped using it, when was that? (Or: how long did you use it?) If you stopped using it, why? Were there problems, issues or challenges?
15. What support have you received from Arc staff about using the TYZE site? Do you feel that support has been useful? What could Arc staff do that would be more useful?
16. Have you participated in FutureLife Options (formerly the Lifetime Assistance Program)?
17. What have been your experiences with FutureLife Options (formerly the Lifetime Assistance Program)?
18. Would you be willing to be interviewed individually by phone about your experiences using TYZE? (If so, please provide contact information).
19. Would you be willing to participate in monthly or semi-monthly meetings about what is working or not working with TYZE.... a community of practice? (Please collect names and preferred way to contact)