



AUTISM  
HOME  
BASE  
DURHAM

## Community Impact Report

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## Autism Home Base Durham: Community Impact Report

Autism Home Base Durham (AHBD) was established in 2012 as a social club for adults with autism and their caregivers. AHBD provides social and recreational opportunities for adults with autism and their caregivers in order to promote social interactions and relationships. The four objectives of the present study are to assess:

- 1) The impact AHBD has had on the lives of caregivers with respect to supporting an adult with autism,
- 2) The impact AHBD has had on the adults with autism,
- 3) The ability of AHBD to address future concerns of caregivers, and
- 4) Changes in level of \*social provisions as a result of being a member of AHBD.

\*Social provisions assess the degree to which a respondent's social relationships provide various dimensions of social support (see methodology for more details).

### Methodology

#### Participants

Participants were randomly selected from the membership database of AHBD in the Durham region of Ontario, Canada. A total of 12 members were included and were placed in two main groups:

- 1) An interview group, which consisted of eight members and who received a structured interview via phone-call, and completed a social provisions scale after joining AHBD.
- 2) A before- and after- membership group, which consisted of four members and who completed a social provision scale before and after joining AHBD (age range: 29 – 55+).

The *interview group* was further divided in half and placed in:

- a) A long-term member subgroup (member for 12 or more months; age range: 52 – 61 years).
- b) A short-term member subgroup (member for less than 12 months; age range: 43 – 56 years).

Inclusion of the long-term and short-term member subgroups allowed us to evaluate if membership duration contributed to the level of impact in four areas:

- i) Assessment of impact (i.e., on quality of life, finances, social relations) on the lives of caregivers with respect to supporting an adult with autism,
- ii) Impact AHBD had on the adults with autism,
- iii) Ability of AHBD to address future concerns of caregivers, and
- iv) Changes in levels of social provisions as a result of being a member of AHBD.

The *before- and after-membership group* allowed the assessment of changes in social provisions as a result of membership with AHBD.

## Measures Used

**Structured impact interview.** A structured impact interview was administered via telephone to participants. This interview contained 20 items, which assessed the following areas:

- How supporting an adult with autism impacted a caregiver's life (i.e., economic security, quality of life, family)
- How AHBD impacted the caregiver's life in supporting the adult with autism (e.g., quality of life, economic security)
- How AHBD impacted the life of the adult with autism (e.g., social skills, social connectedness)
- How AHBD can address the concerns of its members in supporting an adult with autism
- If members found value in belonging to AHBD
- The benefits or drawbacks of being a member of AHBD.

In addition, the interview included a scale, which assessed the degree of impact felt by the caregiver and adult with autism. This scale ranged between 1 and 10, with 1 indicating very little impact and 10 indicating quite a lot of impact (see Appendix A for full interview).

**Social provisions scale.** The social provisions scale examines the degree to which a respondent's social relationships provide various dimensions of social support. The scale consists of 24 items, separated into six different social provisions:

- *Attachment* - The degree of emotional closeness one experiences with others (e.g., having close friendships or family relationships), which provides a sense of social and emotional security.
- *Social integration* - Sense of belongingness to a group that shares similar interests and concerns.
- *Reassurance of worth* - Recognition of one's competence, skills, and value by others.
- *Reliable alliance* - Assurance that others can be counted upon for aid.
- *Guidance* - Degree to which one is able to gather advice or information from others.
- *Nurturance* - Sense that others rely upon them for their well-being.

Respondents indicate on a 4-point Likert scale the degree to which each item describes their current social network. Scores for each social provision can range between 0 and 16 with high scores indicating a greater degree of perceived support (Cutrona & Russell, 1987).

## Results

### Interview Summary

The following section is a summary of key information gathered from the structured impact interview; this summary is listed by question number. All the questions and responses

from the interview can be found in Appendix B.

### **1. How supporting an adult with autism has impacted the caregiver's life.**

Within the long-term member subgroup, one member in this subgroup claimed the impact of supporting their adult son or daughter with autism to be “fulfilling and enriching”. The remaining responses included the following themes:

- A negative impact on finances
- Constant worrying
- A continuous lifelong battle

In the short-term member subgroup, one member declined to answer. The remaining responses included the following themes:

- Impacting every aspect of their life
- Stressful
- Isolating

Overall, there were not many differences in responses between long- and short-term member subgroups. The majority of members across both subgroups indicated the impact of supporting an adult with autism to be negative.

### **2. How AHBD impacted the caregiver's life in supporting the adult with autism.**

Similar to the previous question, the responses indicated similar themes in both subgroups, that is, AHBD had a positive impact with respect to supporting an adult with autism:

- A non-judgmental and supportive environment
- A place which provides activities and opportunities to engage in with a community
- Reduced isolation
- Fostering supportive relationships

### **3. How AHBD impacted the life of the adult with autism.**

It should be noted that caregivers provided responses on behalf of the adults with autism because the adults with autism were nonverbal. Caregiver responses to this question were positive in nature, with no difference in themes across short- and long-term members.

There was one member in the long-term group; however, that indicated that it was difficult for them to judge impact on their adult with autism's behalf and one member in the short-term group stated that the current impact of AHBD was minimal until they got more involved with the organization.

Responses from both groups included the following themes:

- Enhanced quality of life
- Enhanced mental health (e.g., less anxiety) and physical health (e.g., weight loss)
- Reduced isolation
- Fostering supportive relationships

#### **4. Caregivers' concerns for their future, and the future of their adult with autism.**

Responses to this question indicated a divide in the degree of concerns the caregivers had, both within and across groups. In regards to the long-term member group, two members claimed that they had minimal to no concerns for their future; however, all members in this group provides responses that included the following themes:

- Providing work and financial support
- Providing housing
- Being able to fight for their child's rights and best interests

All four members in the short-term member group indicated strong concerns for their future and the future of their adult with autism. Their responses included the following themes:

- Providing valuable and interesting opportunities everyday for the adult with autism
- Providing financial and social support
- Ensuring their son or daughter was happy
- Providing a positive community
- Supporting the adult with autism upon the caregiver's death

Thus, concerns for the caregiver and adult with autism's future appeared to be greater for the short-term member group.

#### **5. How AHBD addressed concerns for the caregiver and adult with autism's future.**

Once again, there was a clear divide in responses between short- and long-term members. In regards to the long-term subgroup, no comments were made regarding AHBD and concerns of providing work and financial support. Moreover, one member did not provide a response as they claimed to have no concerns for their future or the future of their adult with autism. The responses from the remaining three members indicated the following themes:

- AHBD has investigated the housing concerns shared by members
- AHBD is doing well in addressing concerns for supporting their child's rights and best interests upon a caregiver's death

As for the short-term member group, concerns regarding financial and social support, and ensuring the adult with autism is happy were not commented on. Of the four members in this group:

- Two indicated that AHBD could not address their concerns of supporting the adult with autism upon their death.
- The remaining two indicated that AHBD was a good start in providing valuable and interesting opportunities for their adult with autism, and that AHBD had addressed a concern of providing a positive community.

Thus, the long-term member group had greater faith in AHBD's ability to address their concerns compared to the short-term member group.

## Social Provisions and Membership Duration

Short-term and long-term members were compared on mean social provision levels (see Table 1). The findings indicated:

- *No differences* across the social provisions of guidance, reassurance of worth, social integration, and attachment.

**Table 1.** Mean social provision scores for short-term vs. long-term members.

Social Provisions	Short-Term Member (< 12 months)	Long-Term Member (> 12 months)
Guidance	12.50	13.00
Reassurance of Worth	12.25	12.00
Social Integration	12.50	12.50
Attachment	12.25	13.00
<b>Nurturance</b>	<b>14.25</b>	<b>12.75</b>
<b>Reliable Alliance</b>	<b>10.75</b>	<b>13.25</b>

*Note.* Scores range from 0 – 16. The higher the score, the greater the perceived support.

However,

- Nurturance was *higher* in short-term members ( $M = 14.25$ ) in comparison to long-term members ( $M = 12.75$ ).
- Reliable alliance was *lower* in short-term members ( $M = 10.75$ ) compared to long-term members ( $M = 13.25$ )

These findings indicate that compared to short-term members, the long-term members felt greater assurance that they could count on others for aid (i.e., reliable alliance), but felt less responsible for the well-being of others (i.e., nurturance), compared to short-term members.

## Social Provisions and Before-Membership and After-Membership

Mean scores on the social provisions scale were compared before- and after-membership in AHBD (see Table 2). Scores on items 1, 14, 15, and 22 were missing from the before-membership data and therefore, could not be used in the comparison analysis. These items are part of the reliable alliance, social integration, and nurturance scores. Implications of the removal of these items for these scores are discussed in the limitations section.

The comparison analysis showed:

- *An increase* in the levels of all six social provisions scores in the after-membership time point, in comparison to the before-membership time point.

These results suggest that the members' levels of guidance, reassurance of worth, social integration, attachment, nurturance, and reliable alliance, *all improved* as a result of being a member of AHBD.

**Table 2.** Mean social provision scores before- and after-membership

	Before-Membership	After-Membership
Guidance	11.75	14.00
Reassurance of Worth	9.25	14.50
Social Integration	4.75	6.50
Attachment	12.00	14.25
Nurturance	6.50	11.75
Reliable Alliance	9.75	10.50

*Note.* Scores range from 0 – 16. The higher the score, the greater the perceived support.

### Level of Impact and Member Duration

Mean ratings on life impact for both the caregiver and adult with autism across membership duration were compared (see Table 3). The results showed:

- *Minor differences* in the impact on the caregiver's life between
  - Short-term ( $M = 8.50$ ) and long-term ( $M = 8.00$ ) members
- *Large differences* in the impact on the adult with autism's life between
  - Short-term ( $M = 5.50$ ) and long-term ( $M = 7.75$ ) members

This suggests that membership to AHBD has less impact on the reported life impact of the caregiver compared to the reported life impact of the adult with autism, which was large.

**Table 3.** Mean ratings of life impact across membership duration.

Domain of Impact	Short-Term Member ( $< 12$ months)	Long-Term Member ( $> 12$ months)
Impact on Caregiver's Life	8.50	8.00
Impact on Adult with Autism's Life	<b>5.50</b>	<b>7.75</b>

*Note.* Scores range from 1 – 10 (1 = very little impact; 10 = quite a lot of impact).

## How AHBD Impacted the Lives of Their Members

### The Impact of AHBD on Caregivers Across Membership Duration

The results of the structured impact interview indicated that the majority of the members of AHBD, regardless of the duration of membership, found supporting an adult with autism to be a negative experience (e.g., negative impact on finances, constant worrying, a lifelong battle). This finding is not surprising and is consistent with the findings of last year's stakeholder survey study. Of greater interest, is our primary finding:

- That all caregivers, regardless of membership duration, reported that AHBD had a *positive impact* (e.g., supportive environment, reduced isolation) with supporting an adult with autism.

Moreover, mean ratings of impact on the caregiver's life (see Table 3) did not differ greatly between short-term ( $M = 8.50$ ) and long-term ( $M = 8.00$ ) members. This latter finding can be interpreted in two ways:

- 1) Regardless of membership duration, caregivers experience a great deal of positive impact in their lives as a result of being part of AHBD
- 2) That being a member for a longer duration does not necessarily increase the degree of impact experienced by caregivers.

Overall, this suggests that caregivers of adults with autism, who join AHBD, immediately experience a high level of positive impact in their lives with respect to supporting an adult with autism (e.g., fostering supportive relationships, reduced isolation, providing activities and opportunities to engage in with a community). This positive impact is also stable and consistent across short- and long-term members

### The Impact of AHBD on the Adults with Autism Across Membership Duration

In regards to the impact AHBD has had on the life of the adults with autism, the overall consensus was a positive one (e.g., enhanced quality of life, reduced isolation), regardless of membership duration. However, mean ratings of impact on the adult with autism's life did differ across membership duration (see Table 3):

- *Short-term members* reported a moderate degree of positive impact for their adult with autism ( $M = 5.50$ )
- *Long-term members* reported a high degree of positive impact for their adult with autism ( $M = 7.75$ ).

Thus, it seems that being a member of AHBD for a shorter duration (i.e., between 1 and 12 months) provides a moderate degree of positive impact to the adults with autism and being a member for a longer duration (i.e., 12 months or greater) enhances this level of impact.

## The Impact of AHBD on Caregivers Concerns for the Future

As for the caregivers' concerns for their future and the future of their adult with autism, there is a clear divide between group responses:

- *Long-term members* had fewer concerns for the future compared to short-term members
- *Long-term members* had greater faith in the ability of AHBD to address their concerns.

Moreover, there were notable differences across groups in the amount of concerns they held for the future and whether AHBD had addressed, or was in the process of addressing, these concerns:

- *Long-term members* indicated that AHBD had addressed, or was in the process of addressing, many of their concerns. More specifically, they identified three themes of concern for the future and indicated that AHBD had addressed two.
- *Short-term members* indicated that AHBD either could not address their concerns or could address very few of their concerns. More specifically, they identified five themes of concern for the future and indicated that AHBD had addressed two.

Thus, these findings indicate that the longer an individual is a member with AHBD, the fewer concerns they have and the greater the likelihood that the individual feels their concerns for the future can be addressed by AHBD.

## How Social Provisions Are Influenced by Membership to AHBD

Levels of social provisions were similar between short- and long-term members (see Table 1). Only two notable differences in social provisions were observed:

- The sense that others rely upon them for their well-being (i.e., nurturance) was lower in long-term members ( $M = 12.75$ ) compared to short-term members ( $M = 14.25$ )
- Feelings of assurance that others can be counted upon for aid (i.e., reliable alliance) were higher in long-term members ( $M = 13.25$ ) compared to short-term members ( $M = 10.75$ ).

The finding that nurturance was lower in long-term members was somewhat unexpected. Nurturance typically refers to the relationship between a caregiver and their offspring (Cutrona & Russell, 1987). A goal of AHBD is to provide a supportive community of people to rely on. The reduction in nurturance with greater membership duration may be the result of long-term members feeling that they are able to rely on other members, something that short-term members may not yet experience. As a result, long-term members may feel a shared sense of community when it comes to the relationship between them and their adult with autism.

Thus, the overall levels of social provisions were moderate to high, regardless of membership duration, which indicates that levels of social provision were relatively high in the short-term and long-term member group. Since we have no measure of social provisions prior to

membership in AHBD, it is difficult to ascertain whether levels of social provision were affected by membership in AHBD with these two subgroups.

## **Social Provisions and Before- and After-Membership**

A comparison of social provisions before and after joining AHBD allows us to examine whether membership in AHBD affected levels of social provision (see Table 2). It is important to note that this group consisted of members who have been part of AHBD for less than 12 months, and therefore, demonstrates findings representative of a short-term member. Analysis of scores showed that:

- Levels of social provisions *increase* after being a member of AHBD
- Increases in levels of social provisions *occur after a relatively short period of time* with AHBD (between 1 and 12 months)

Interestingly, levels of nurturance for this group were higher after-membership ( $M = 11.75$ ) than before-membership ( $M = 6.50$ ). This contradicts the previous finding in the interview group that membership with AHBD may reduce the reliance an adult with autism has on their caregiver, thereby reducing nurturance over time. However, as previously discussed, this group of participants contained incomplete data, which may explain this contrasting finding (see limitations section).

## **Limitations**

- It is important to acknowledge that the structured impact interview is subject to response bias and it is possible that participants might have been hesitant to provide negative feedback.
- Originally, 12 members were randomly selected for the interview; however, only eight answered the telephone calls and agreed to participate. It is possible that the addition of the other four members may change or modify the results.
- The social provisions scale data for the before- and after-membership group was incomplete. As mentioned above, participants skipped items 1, 14, 15, and 22 when completing the survey prior to membership and therefore a before- and after-membership comparison was not possible for these items. Scoring was adjusted to account for the missing items; however, this adjustment changes the composition of the reliable alliance, social integration, and nurturance social provisions scores, and may affect their validity.

## Conclusions

1. All members of AHBD, regardless of member duration, experienced a *positive impact* as a result of their membership.
  - Caregivers report experiencing a non-judgmental and supportive environment, reduced isolation, development of supportive relationships, and opportunities to engage in activities with a community.
  - The adults with autism experienced an enhanced quality of life, enhanced mental health (e.g., less anxiety) and physical health (e.g., weight loss), reduced isolation, and the development of supportive relationships.
2. As a whole, AHBD *addressed concerns* that caregivers have for their future and the future of their adult son or daughter with autism. However, members who have been involved with AHBD long-term reported that more of their concerns for the future had been addressed and greater faith in AHBD's ability to address these concerns, compared to short-term members.
3. Regardless of duration of membership with AHBD, members report levels of social provisions that are *moderate to high*.
4. Levels of social provisions *increase* as a result of joining AHBD and these increases appear to occur after a relatively short period of time with the organization (between 1 and 12 months).

## Directions for Enhancement of Members' Well-Being

Overall, AHBD appears to be making a strong and positive impact on its members. Nonetheless, this study also highlighted areas that might further enhance the well-being of caregivers and adults with autism:

- Short-term members indicated that they were not confident that AHBD could address their concerns for their future, and the future of their adult son or daughter with autism. This suggests a need to regularly survey new members to get a sense of areas of improvement in order to more actively address their concerns (e.g., providing new programs).
- High levels of impact and social provisions in caregivers of adults with autism were observed regardless of membership duration; however, it might be beneficial to identify ways to increase levels of impact and social provisions over time. Perhaps regular updates or "check-ups" on how AHBD is addressing the needs and concerns of members would be useful.
- Short-term and long-term members are similar in many respects, but the current study indicates that these two groups appear to have different concerns and needs. Identifying these differences (as has been done in the current study) would likely serve useful in future programming, thereby enhancing the well-being of all members.

## References

Cutrona, C. E., Russell, D. W. (1987). The provisions of social relationships and adaptation to stress. *Advances in Personal Relationships, 1*, 37-67.

## Appendix A

### **AHBD Structured Interview Questions**

1. *Is this (Insert Initials)? Are you the primary caregiver for (insert initials)?*
2. *Would you be willing to share your age?*
3. *How long have you been a member of AHBD?*
4. *How often does (insert initials) participate with Home Base Durham?*
5. *Tell me about how supporting (insert initials) has impacted your life? (ie. family, economic security/employment, quality of life)*
6. *Can you indicate on a scale of 1 – 10, with 1 being very little, and 10 being quite a lot, the extent to which being a part of AHBD has impacted your life with supporting (insert initials).*
7. *In what ways has being a part of AHBD change how supporting (insert initials) has impacted your life? (e.g., improve quality of life in any way)*
8. *How does being a member of Autism Home Base Durham make you feel, regardless of whether or not you participate in the programs we offer?*
9. *Again, on a scale of 1 – 10, with 1 being very little, and 10 being quite a lot, to what extent has being a part of AHBD impact the life of (insert initials)?*
10. *In what ways has being a part of AHBD impact the life of (insert initials)?*
11. *What long-term changes would you like to see as a result of you and (insert initials) being a part of AHBD? (e.g., for members, caregivers, community, economic security, quality of life)*
12. *What concerns do you have for your future, and the future of (insert initials)?*
13. *Has being a part of AHBD addressed these concerns? If so, how has it been addressed? If not, what could AHBD do to address them?*
14. *What do you think are the benefits of being part of AHBD?*
15. *Are there any drawbacks of being a part of AHBD?*
16. *Do you find value in simply belonging to Home Base Durham?*
17. *Does your participation in the programs we offer help enhance any sense of belonging to AHBD?*
18. *Would you be willing to complete a short online survey which will help us improve the programs we provide here at Home Base Durham? \*\*\*Social Interaction Survey*
19. *What email address could I reach you at to send you a link to the survey?*
20. *Is there anything else you would like to share?*

## Appendix B

### AHBD Interview Responses

#### 1. Can you tell me about how supporting (insert initials) has impacted your life?

##### Long-Term Members

Member 1:

“It’s a constant battle. He doesn’t say much, and it’s hard to get him to give eye contact, and even when he knows people he doesn’t give eye contact very well.”

Member 2:

“It’s huge, I’ve had to completely switch jobs, I was working full time in an office and when he finished high school I had to quit my job because I had nowhere to send him five days a week! I had to sell my place up north that I’ve had forever. I almost had to sell my house! its more than anyone could dream, imagine, or prepare for.”

Member 3:

“That’s a good question. It’s very fulfilling with him. Brett’s is a wonderful young man and with everything that has happened with him, it has enriched our lives and we’re very happy to have him with us.”

Member 4:

“Everything, Iain is the center at this point, the centre of my life. I am semi-retired, but he is the total centered focus of my life. Yes, it’s been a negative impact on my financial aspects, but in many other aspects he has been a positive aspect.”

##### Short-Term Members

Member 5:

“Oh greatly, dramatically, a lot, every inch of my life.”

Member 6:

“Some parents get to let go, I don’t. Sometimes its stressful. Sometimes it’s the most surprising and amazing thing ever. Its not easy.”

Member 7:

Declined to answer

Member 8:

Well you’re pretty tied down after they’re done school right? And it’s trying to balance work and he can’t be left alone. So, it’s kind of isolating.

#### 2. In what ways has being a part of AHBD change how supporting (insert initials) has impacted your life?

##### Long-Term Members

Member 1:

“I know if we didn’t have AHBD I would have been searching out trying to find other activities, and things for him to do. The more things we have the better it is for him, for his cognitive skills. It’s better for his social aspects too because he has a tendency, when he doesn’t know people well, to be quiet and reserved. So it’s good for him to be social, and to feel comfortable, where he will interact and he does very much so with everyone there. They’re very accommodating for him.”

Member 2:

“It’s that day of week where you get to go and nobody judges you, and when your kid freaks out nobody gives you the stink eye. Or when you go in and you’re grumpy or you’ve had a crappy week, everyone there understands, nobody judges. When you’re in there, everybody just really puts forth an effort to help each other. People cheer each other up. You get there, and within minutes of walking in the door you always feel better! You have to experience it too!”

Member 3:

“It helps us integrate, meet other parents, and socialize, and you realize that you’re not isolated and alone, and that there are other people out there.

Member 4:

“Well, it’s the interaction of other parents who have had their challenges with their son/daughter. But this is the first time in my life that I have been able to interact with those parents. I figured these battles the parents were fighting were on an individual basis, but now that I look back on it I think, oh my gosh these guys have been fighting similar battles as well.”

### **Short-Term Members**

Member 5:

“It’s a small part of my life, but it has impacted it greatly. Really, there’s only one area I struggle with that I find Autism Home Base Durham to have helped, that I can’t bring her anywhere for entertainment, I have to do it alone. I am now able to have some entertainment with my daughter!”

Member 6:

“It’s relieved some of the stress for me, in organizing things. It’s also help us connect with other people in the community.”

Member 7:

“There’s not a lot offered out there, especially at their ages. I found we were aging out of a lot of programs, and sometimes there’s really nowhere to turn when they’re done school. It’s been great, it’s been a really great transition (into Autism Home Base Durham).”

Member 8:

“There’s just the option, you know, the opportunities, so there’s a little hope there right? It’s nice to know there’s a community there, it’s just actually nice to see parents out there and not isolated from each other!”

### **3. How does being a member of Autism Home Base Durham make you feel, regardless of whether or not you participate in the programs we offer?**

#### **Long-Term Members**

Member 1:

“I feel good that he has activities, a group and activities that he is comfortable with, because that makes a big difference with them, that he feels comfortable and at home. He is much more social and interactive.”

Member 2:

“I stand behind it, even if there were no events or even if we stopped going, I would still promote it to people because I truly believe in it. It’s the type of place where people listen and every single

suggestion I've ever heard anyone make has been taken to heart and investigated. Many weeks, the parents will show up without the children, and to me that speaks huge volumes!"

Member 3:

"I enjoy it, I like it, it's very nice. It's a very accepting and good group, nobody judges anybody they're very open and friendly, it's a family feeling. It's a warm and welcoming atmosphere."

Member 4:

"Oh it's awesome. Right up there. It's a privilege because I get to meet these people (other members) and interact with them."

### **Short-Term Members**

Member 5:

"It makes you feel like there is a group out there that gets you, and they do."

Member 6:

"A little more secure, a little more supported in the world."

Member 7:

"We feel pretty good, she looks forward to it, and we enjoy ourselves. She (daughter with autism) kind of says it gives it a sense of like it feel like school but it's a happier place, because it's such a relaxed environment, you know what I mean?"

Member 8:

"A part of the community. Not so isolated in my own house, you know. A bit more brave and confident to be out and about."

## **4. In what ways has being a part of AHBD impact the life of (insert initials)?**

### **Long-Term Members**

Member 1:

"I think his quality of life, just because its offering him activities to do, you know. We do live out in the country, and there is not much to do out here, so I think it's made a big difference in his quality of life, even if its just getting him up and going in the morning"

"It makes a big difference because we tried various places and other resources, and we didn't have a lot of success."

Member 2:

"it's definitely helped his general health to be honest, because he gets to do some exercise. It's not just about being out with people and socializing; it really helps a lot of us you know."

"When the kids finish school there's no where to go, and the parents stay at home all day, and everyone starts gaining weight which isn't healthy. So it's not just mental health, it's about physical health too! "

Member 3:

"He gets to meet other people, makes friends, and gets to socialize and see other people. They get to go out to the community and do different events, trying to do things to see if he'll enjoy it, and just meeting with other families."

Member 4:

“it’s good for all these autistic dudes, so it’s good for everybody. But it’s hard to say. It’s affected the parents, but these autistic dudes, it’s difficult to judge their reactions. But in terms of the parents it’s amazing.”

### **Short-Term Members**

Member 5:

“Raising her tolerance levels for new and different activities. And also giving her kind of a friendship with other members”

Member 6:

“She’s met some new people. And she’s done a couple of things she wouldn’t have otherwise done. Like she’s done some art and some self-defence”

Member 7:

“I see her starting to connect more with people and she seems more relaxed in this group, where anxiety was really a huge thing before for her and I’m starting to see her relax finally and actually enjoy herself, and smile and look forward to seeing everybody. It’s nice to see her making friendships, which is quite important because its hard for them (people with autism).”

Member 8:

“I wouldn’t say too much right now until we get him more involved. But it gives him options instead of just wanting to stay home, and just to know there’s a group there for him, and a lot of them are high school friends so he still has that connection.”

### **5. What long-term changes would you like to see as a result of you and (insert initials) being a part of AHBD? (e.g., for members, caregivers, community, economic security, quality of life)**

#### **Long-Term Members**

Member 1:

“I know that we’d like to see him applying to work, a job, even if it was part time. Or even helping with a non-profit or something”

“Going down the future, housing and preparing him for being self-sufficient, or as efficient as he can be, is something that’s always on my mind.”

Member 2:

“I think it would be great to get funding for a work program. Seeing kids sitting at home all day when they could be out doing something constructive, it saddens me.”

Member 3:

“Well, the way the group is growing and expanding out from the Oshawa area, it’s beginning to have different aspects and avenues opening up for the young adults with different abilities, where they could try different things to see if it’s a good fit for them. It’s a good idea and a good program, something that’s very well needed for this area.”

Member 4:

“Oh, um, from my perspective the notion that we’re not alone. You know, you’re facing difficult parental challenges and we always have, but now I’m starting to realise I’m not alone, we’re not alone. These guys have faced their own challenges. There’s a comforting aspect of that.”

### **Short-Term Members**

Member 5:

“More activities, maybe more that she will enjoy, and maybe starting a friendship, maybe someone a little more similar to her. Yea I can see it definitely growing and they’re very interactive with us as parents, with the little time I’ve been with them I know it will grow into something that will benefit her even more.”

Member 6:

“I’m hoping that we get connected with some of the families and maybe have some friendships grow.”

Member 7:

“Can’t really think of anything, I’m not too sure.”

Member 8:

“To be more involved, the group to be bigger of course. It could be nice to have a place that if he wanted to be on the computer or his drums he could be there, just another spot to be.”

### **6. What concerns do you have for your future, and the future of (insert initials)?**

#### **Long-Term Members**

Member 1:

“Financially we’re fine, I think, and we have provided to some degree for him, whether its enough or not, nobody really knows. you don’t know what his needs or financial needs might be in the future”

“I don’t have too many concerns, like I said, I’d like to see him find something, work or something, that would give him something to get up for and work towards. Whether it be work, or contributing in some other way.”

Member 2:

“It gets pretty scary because eventually I’m going to have to retire, sell my home. And then its like where do you go, what do you do?”

“I honestly believe its housing, because its hard to manage a house when you’re sixty, and these guys can’t do the work. And if you go into an apartment you’re going to get so many sound complaints!”

Member 3:

“I don’t have too many concerns as of right now. Everything is good, and we have made plans for events later on as we get older, we have already taken care of a lot of that through family and friend supports. With Home Base Durham now we’re trying to help expand that and make it better for other people and individuals too right. We have a lot of support with family members.”

Member 4:

“Well, it’s all really about the long term, because, think about his parents are going to get older, and eventually we’re not going to be able to have the energy or vitality to fight for his (son with autism) rights and best interests.”

### **Short-Term Members**

Member 5:

“Once she’s out of school, keeping her busy is my biggest concern. Finding something valuable or interesting for her to do every single day, and that’s in 2 years, so. This could be part of it, who knows.”

Member 6:

“I have all kinds of concerns. I’m worried she won’t be able to take care of herself, have friends, or have a happy life without me constantly telling her how. I’m afraid of what will happen to her if I die. I’m afraid she’s never going to be able to work or do anything to take care of her life. I’m afraid there won’t be enough money to hire people to help.”

Member 7:

“Well I worry about what’s going to become of her, but it’s too hard to tell at this point. I’m not going to be here forever, so that’s my huge concern.”

Member 8:

“I think a biggest fear for all parents is what happens when we leave. We put as much as we can in place, but it would be nice to have that sense of community that someone is paying attention, or that someone is noticing him, or someone has got his back you know?”

### **7. Has being a part of AHBD addressed these concerns? If so, how has it been addressed? If not, what could AHBD do to address them?**

#### **Long-Term Members**

Member 1:

“A member of Home Base Durham was going to investigate as to whether we might be able to set up a resource center, it would be a respite type home. Something like that would probably be beneficial to me as well, as well as other people in the group. If it was a housing type project or opportunity, it’s possible that we might be interested in too. Because it’s something that, eventually, we’re going to want for (REDACTED NAME).”

Member 2:

“It’s hard to say. I don’t think it’s (housing) really become an issue yet, but it’s certainly something we’ve been discussing because most of the parents at Home Base Durham are in their 50/60s, and so it’s something that will come up, but hasn’t really come up yet.”

Member 3:

Not Applicable (They have no concerns)

Member 4:

“They’re doing good. Absolutely... it’s going to take time for individual parents and families to be comfortable and to be able to talk about the real deep rooted issues that have come from being a parent of these autistic children. It’s going to take time, but I believe that’s going to happen (ensuring there is someone to fight for the adult with autism’s rights and best interests)”

#### **Short-Term Members**

Member 5:

Yea I think it’s a good start. Maybe it could turn into a program that is more regular. I don’t need it regular right now, but that would be awesome when the time comes. That it became more of a routine or an everyday occurrence.

Member 6:

Well, I'm going to say no. I don't know if Durham Home Base is the place to address those kinds of questions (see previous responses from member 6 for details). You know what I think would be helpful? If people got opportunities to talk to each other, like the adults, to talk about these fears and what to do about them."

Member 7:

"I don't know if they can do anything, I think that's for the parent to worry about."

Member 8:

"They have addressed just being out in the community without those horrible glances or whatever, just to kind of be, not a sideshow, and be comfortable as a community. It has addressed that we have a place, even just renting out that room for once a week, we have a place!"

## **8. What do you think are the benefits of being part of AHBD?**

### **Long-Term Members**

Member 1:

"I think they are tremendous, If I had to leave or anything else for a few minutes I would have no issues at all with leaving (REDACTED NAME) with them. And I know they would watch, we all look out for each other"

Member 2:

"Emotional support, safe nonjudgmental place you can go to have fun. It's a stress reliever for the child and parent. Most affordable program I've ever come across in my entire life."

Member 3:

"The benefit is that you get to meet other families with autism, because after our children grow up and leave the school structure, Autism Home Base Durham gives them something to look forward to, to interact, and be a part of society and not isolated, where they can meet and hopefully make new friends and try new things."

Member 4:

"That you're not alone, you're not fighting some incredible battle on your own. There's other people with similar interests, and maybe fighting the same battles. So it's strength in numbers, and there is comfort in numbers. The more people that are in the group, the better you're going to feel."

### **Short-Term Members**

Member 5:

"I think that the majority or parents do feel that isolation, I think it (Autism Home Base Durham) does unite them!"

Member 6:

"I think a big one is just the community connection. It can be very isolating this life. When everyone is out there talking about how their kids are accomplishing things and going to university and this and that, sometimes it can feel alienating, so it allows for some very important social connections and feelings of belonging."

Member 7:

“Well, having friendships and being able to connect with other people that get it and understand that nobody is judging anybody. Its nice to be able to go somewhere and not feel embarrassed or have everybody staring, or having to explain to everyone what’s going on. It’s a very relaxing and easy atmosphere.”

Member 8:

“A sense of community, networking for sure with the parents because everyone is going through the same thing, and stress levels go down when we talk. Networking is important too! I think that we want to do this for our kids, but parents need it more than people realize.”

## **9. Are there any drawbacks of being a part of AHBD?**

### **Long-Term Members**

Member 1:

“I can’t think of any. I’m very happy we found it, and it’s nothing but positive for us.”

Member 2:

“None, honestly, not a single one. I could never say anything negative.”

Member 3:

“None as of right now, like I said, right from the day we started going it’s been a pleasant experience.”

Member 4:

“There are no drawbacks per se, my only drawback is that I wish it had happened sooner in time”

### **Short-Term Members**

Member 5:

“Not that I can think of, no.”

Member 6:

“Well, I can’t think of drawbacks necessarily, like I said, being that we’re both occupied during the day and I’m going to be a fulltime worker for years to come, it would be nice if there were some things that happened in the evenings more and stuff, like swimming, or bowling.”

Member 7:

“No, no it’s all good!”

Member 8:

“No, there’s no negative of being a part of it! No no!”

## **10. Do you find value in simply belonging to Home Base Durham?**

### **Long-Term Members**

Member 1:

“Definitely”

Member 2:

“Absolutely”

Member 3:

“Yea, I find the value is that there is a support group there with knowledge and resources, It’s a good way to get valuable information and for networking.”

Member 4:

“Absolutely. I wish this stuff had existed years ago when he was younger.”

**Short-Term Members**

Member 5:

“As long I’m joining them I do, yea. Just the belonging part doesn’t really matter because you can get that on Facebook or Instagram”

Member 6:

“Yea, for sure!”

Member 7:

“Yes, it’s nice to feel part of something, it’s nice for our kids to look forward to something, and feel like they matter!”

Member 8:

“Yes, sense of community, the support, and being a part of them and then having a routine.”

**11. Does your participation in the programs we offer help enhance any sense of belonging to AHBD?**

**Long-Term Members**

Member 1:

“I would say yes, that it does.”

Member 2:

“I think so. Everybody participates amazingly in their own way, and nobody looks at anybody like ‘oh, you didn’t help!’”

Member 3:

“Anybody that participates is valued for sure because its rewarding for them and their young children involved in it. It is rewarding, because you’re there and you have a sense of belonging.”

Member 4:

“Yes. Well mind you we haven’t been able to participate in all the programs because he’s got his own stuff going on. But overall yes, absolutely.”

**Short-Term Members:**

Member 5:

“A little bit, yea.”

Member 6:

“Yes”

Member 7:

“No, it would stay the same.”

Member 8:

“Well, it has, yes!”

## **12. Is there anything else you would like to share?**

### **Long-Term Members**

Member 1:

“I’m very glad I’ve found AHBD”

Member 2:

“Nope! But I think it’s great when you guys do these kinds of projects because you need to talk to the parents to really get an idea of what is going on! Thank you for taking us on as one of your projects.”

Member 3:

“No that’s about it”

Member 4:

“it’s been positive for me, as a parent, because I get to spend time with other parents.”

### **Short-Term Members:**

Member 5:

“I think it’s a hard, deep down I think that this is going to be a hard group to keep going due to the differences between low functioning and high functioning children, and the differences in things they can do together...”

Member 6:

“I don’t think so!”

Member 7:

“No!”

Member 8:

“I’m glad I found the group. So far it’s been a better fit than anything I’ve seen out there! We’ve tried other things so, right now, this is the better fit.”