

Assessing Impact and Outcomes of Respite Services

For Children with Intellectual Disabilities
in Pictou County



Chase Cameron and his dad, Gary Cameron

Northern Region Respite Services
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Introduction

Respite care is the short-term or temporary relief provided to those caring for a family member or loved one with special needs (Respite Care in Canada, Canadian Healthcare Association, 2012). Respite services provide care, interaction and supervision for clients with special needs to allow their full-time caregivers time for themselves and with other family members, friends, and activities. In other words, respite care meets the immediate needs of an individual but provides support for the whole family (Nova Scotia Respite Guide, Mental Health Foundation of Nova Scotia, 2014).

Northern Region Respite Services (NRRS) delivers respite services throughout northern Nova Scotia: specifically Cumberland, Colchester, Pictou, Antigonish and Guysborough counties. NRRS is a non – profit, community based service operated by Highland Community Residential Services (HCRS) through a contract funded by the Nova Scotia Department of Community Services. HCRS exists to foster personal growth, independent living and a high quality of life for persons dealing with an intellectual disability and/or a mental health issue. Since its establishment in 1999, NRRS has facilitated respite opportunities and programs to more than 200 families. It has also recruited, screened and matched more than 200 respite caregivers. However, during this 15-year period there has not been a systematic assessment of outcomes beyond a statistical summary of referrals for service. As resources and opportunities for individuals living with a disability continue to change, it is important that support programs adapt accordingly. In 2015, NRRS applied for and received a grant from the Aberdeen Health Foundation Children’s Aid Society of Pictou County Endowment Fund. The purpose of the grant was to conduct a survey measuring the outcomes of the various programs and resources offered by NRRS. Following are the methodology, initial findings, and recommendations for further research gained from the completion of this survey project.

Methodology

The goal of this survey was to assess how NRRS services and programs are meeting the needs of families in the service area, which due to funding restraints was limited to families and consumers in Pictou County. Within this goal were three specific objectives:

1. Obtain structured and comprehensive feedback from the families and consumers currently using respite services.
2. Assess how NRRS services and programs are meeting the needs of the families.
3. Obtain feedback from families whose children have aged out.

In Pictou County, NRRS provides both traditional and extended respite care services. Traditional respite services include:

- Assisting families in assessing, planning and accessing respite care for a child who has a disability
- Finding high quality respite workers able to meet their child's respite care needs. Respite care workers include both paid workers and volunteers.
- Extended respite programs currently include a Summer Recreation program, Fun Friday events, March break respite events and Christmas respite events. In previous years, NRRS has facilitated a Circle of Friends program. These extended programs are funded through a variety of grants from local community philanthropy and Federal program resources.



Carolling at the Annual Fun Friday Christmas event

Survey data was collected in two ways:

1. A 21-item questionnaire in five sections, administered in person. This face-to-face survey recorded program impact, level of satisfaction, and suggestions for program improvement. The complete questionnaire is presented in Appendix A. Fourteen (14) past and present caregivers of clients of NRRS were selected for interviews, representing 12% of the NRRS Pictou County database. Clients were selected from the NRRS database based on varying levels of usage and current age to provide a sample that reflects the demographics of the organization.

The demographics of the survey were:

- Five females and nine males
- Eight clients under age 19, and six clients aged 19 years and older
- Eight individuals living with Autism Spectrum Disorder, two living with Cerebral Palsy, two living with Down Syndrome, one living with an Intellectual Disability not otherwise specified and one living with a brain injury.

2. A 28-item online questionnaire administered via Survey Monkey. This questionnaire was made available to all families registered with NRRS in Pictou County, and also assessed usage and outcomes of traditional respite and extended respite programs. The complete online questionnaire is presented in Appendix B.

Twenty-seven (27) families responded to the online questionnaire, with 85% of respondents representing children under age 19. The sample consisted of 17 male and 10 female children. The diagnostic categories of the sample include:

- five(5) individuals living with Down Syndrome
- twelve (12) living with Autism Spectrum Disorder
- two (2) living with Cerebral Palsy
- four(4) living with an Intellectual Disability not otherwise specified
- four (4) individuals selected the “other” category

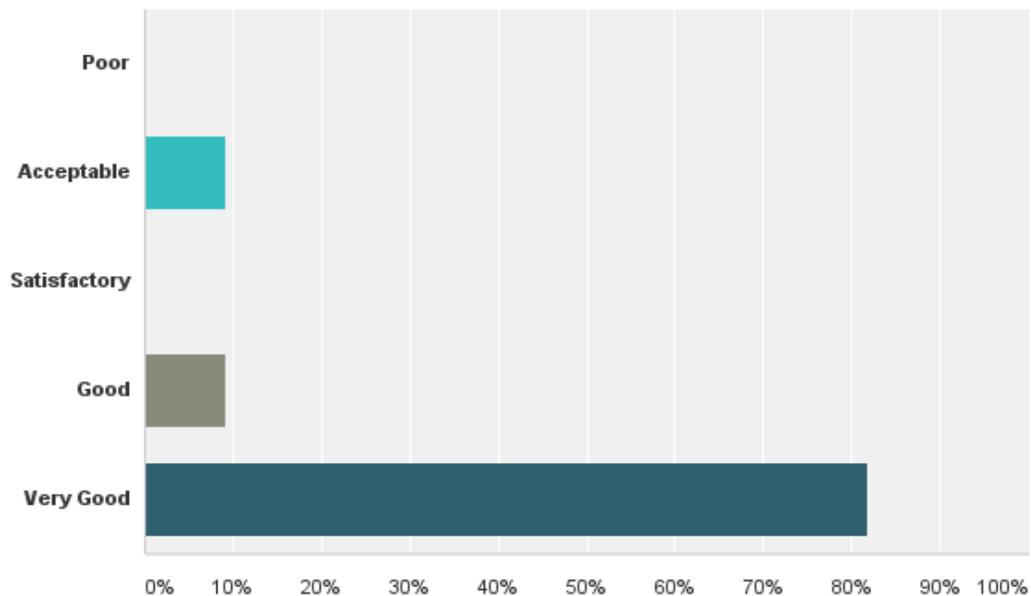
Fourteen per cent (14%) of respondents that completed the survey indicated their child had a physical disability. Eighty five per cent (85%) of respondents who completed the survey have been with the program for three (3) or more years.

Findings

The surveys yielded both quantitative and qualitative data. From that data, the following themes emerged:

A) **Traditional respite services are well-received and appreciated.**

A total of 88% of individuals who used the assistance of NRRS to match their child with a respite worker indicated that they felt supported by NRRS. Similarly, caregivers were asked to rate their satisfaction of their experience with Northern Region Respite Services. Overall, caregivers indicated that they were satisfied with the services provided (Please refer to figure 1.)



**Figure 1: Responses to survey question:
“Please rate your experience with NRRS on Traditional Respite.”**

B) Respite offers benefits to families who use it.

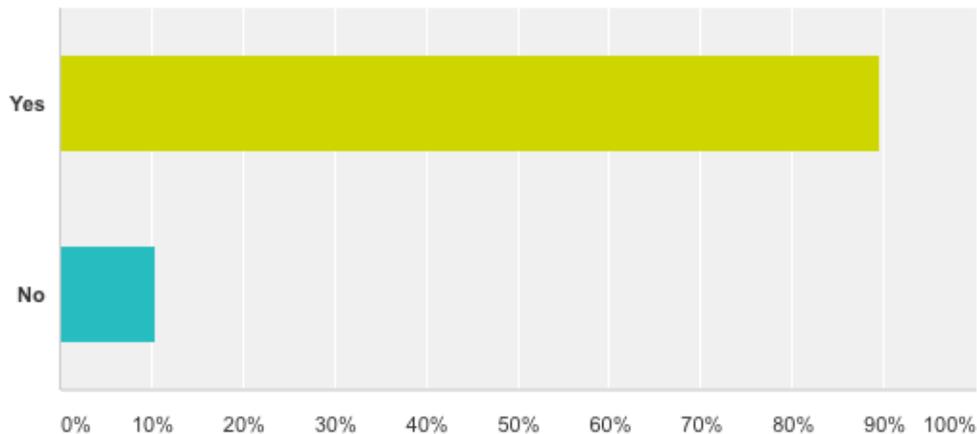
Respite care reduces stress, social isolation, improves caregivers' attitudes towards their child with a disability and thereby increases long term functioning (Canadian Healthcare Association, 2012). Similarly, significant outcomes have

“Because I’m busy, [networks created with other parents] helps me stay in contact with families we may not see otherwise.”
Face-to-face survey participant

been identified in consideration of mothers raising children with severe developmental disabilities. In such circumstances, respite care has been shown to improve the mother’s feeling of well-being and increases mood. Furthermore, the mother continues to experience the benefits extending well beyond the duration of respite

care (Canadian Healthcare Association, 2012). The results of the current survey are consistent with the previous research.

Nearly 90% of respondents in the on-line survey indicated that respite services improved their family life (Please refer to figure 2.)



**Figure 2: Responses to survey question:
“Have respite services improved your family life?”**

Responses from several families indicated that respite services reduced stress in the home and improved family functioning by:

- enabling the child to remain at home in their care for longer periods
- reducing the need to find alternative care
- supporting networks between families with similar experiences to share
- maintaining social and support systems for children and their families

In the face-to-face survey, 91% of families stated that the Fun Friday events allowed parents and siblings to create support networks with other families. One parent indicated that the Fun Friday events had a great impact on their family. It allowed them to learn more about the community and having a child with special needs. She said the other families provided insight for what their own family had ahead of them. Another family indicated that Fun Friday events were important as they were able to associate with families who were going through similar experiences. Similarly, one family indicated that because they lead a busy lifestyle, Fun Friday events allowed them to stay in touch and maintain the support networks they have created with other families.



The Ferris Family poses in the photo booth at the Halloween Fun Friday event

C) **Extended programs are used and appreciated.**

“It gave [my child] something to look forward to every day ... [the programs] keep [my child] on schedule.”
Face-to-face survey participant

In the face-to-face survey, 100% of individuals indicated that the extended respite programs increased their child’s opportunity to have social interactions. The current programs (Fun Friday events, Summer Recreation Program and the Respite events) averaged an interest rate of 89%, with Summer Recreation program being the most significant at 100% interest (Please refer to figure 3.)

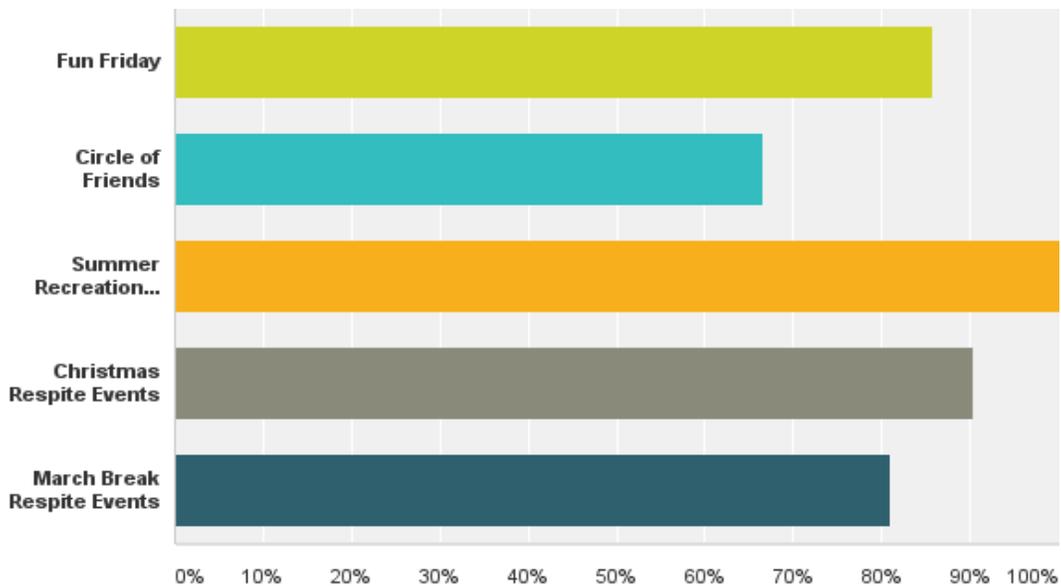


Figure 3 – Responses to Survey Question:
“Which extended respite programs were of interest to your child? Select all that apply.”

Similarly, parents were asked which programs provided the greatest benefit to their child. Significantly, 100% indicated that the summer recreation program provided great benefit to their child and 76% indicated that the Fun Friday events provided great benefit to their child. Although the other programs yielded lower

results, several parents did indicate the other programs were also beneficial to their children. One parent credits the Summer Recreation Program with providing his/her child with “awesome social skills” and the opportunity to meet “more people like themselves,” encouraging the child to try “a lot of new things with peers.” Circle of Friends was given credit by some respondents for helping children make long-term friendships.



The children pose showing their painted faces at the carnival-themed Fun Friday event

D) Respite programs provide opportunities for a child’s growth and expansion.

Children with intellectual disabilities and other needs often require more caregiver support to complete various activities of daily living. Many caregivers who completed this survey indicated that respite services were important not only for

“I see a big change in [my child.] Respite has opened [my child] up to be sociable.”

Face-to-face survey participant

care of the high-needs child, but to enable care and attention for other children in the family. The respite programs were credited with providing families with support and opportunities for their children to be with peers, have social interactions, have fun and gain new experiences. One parent indicated that the

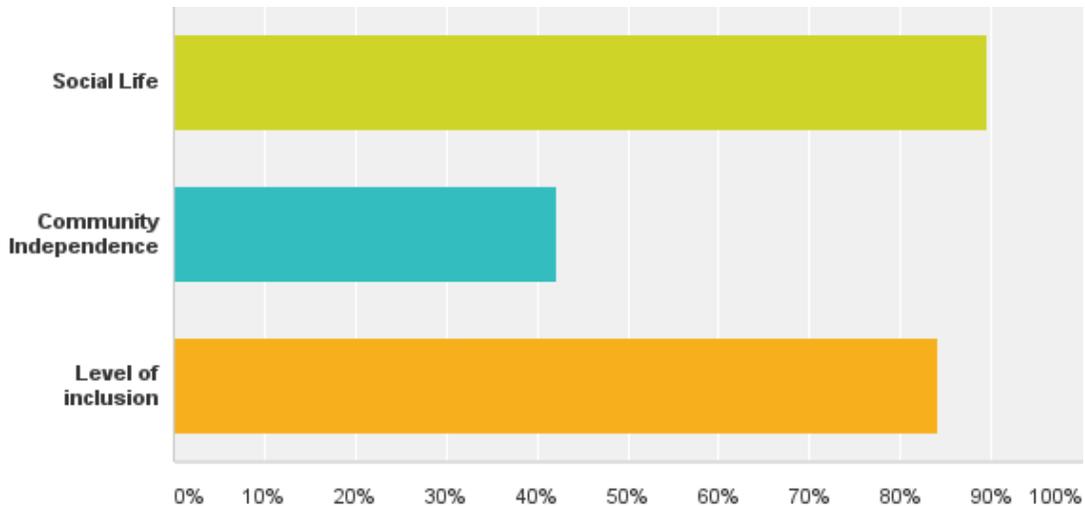
extended respite program provided her child with the opportunity to have experiences that would not otherwise have been possible.

“[My child] likes [Summer Recreation] because Mom is not there.”

Face-to-face survey participant

In the face-to-face survey, 93% of individuals indicated that the extended respite programs increased their child’s level of community involvement and sense of inclusion. The online questionnaire established similar findings, as

84% of individuals indicated the extended respite program increased their child’s level of inclusion and 42% indicated that it expanded their child’s community independence (please refer to figure 4.) Two parents indicated that the summer recreation program enabled their children to make friends, try new experiences with their peers, become more independent, have more community experiences, and feel included in social settings.



**Figure 4 – Results from survey question:
“Have respite services helped expand your child’s: Please select all that apply.”**

Conclusion

To review, the goal of this survey was to assess how NRRS services and programs are meeting the needs of families and consumers in Pictou County.

The qualitative survey results establish that generally, families in Pictou County registered with NRRS rely on and are satisfied with the variety of services and programs offered to meet the needs of their family. In the words of one survey participant:

“NRRS has provided my entire family with much needed support from the moment we first heard of the program. It was been a source of respite, fun, support and education. I can’t imagine where we would have turned without the support of this organization.”

Quantitative results show:

- 88% of individuals for whom NRRS matched their child with a respite worker indicated that they felt supported by NRRS
- Nearly 90% of respondents indicated that NRRS respite services improved their family life
- 91% of families stated that NRRS Fun Friday events allowed parents and siblings to create support networks with other families
- 100% of individuals indicated that NRRS extended respite programs increased their child's opportunity to have social interactions
- 93% of individuals indicated that the extended respite programs increased their child's level of community involvement and sense of inclusion

Satisfaction reports were high among respondents in both the face-to-face and on-line surveys. There are clear examples of improved social interactions, community involvement and level of inclusion for clients, as well as development and nurturing of support networks and quality of life for families. These results indicate that NRRS services are meeting the needs of clients and consumers in Pictou County.



NRRS families enjoy a fun game of prize bingo

However, there were some areas that would benefit from further study:

A) Efficacy and Needs of Transition Programs for 19-plus

Many respite services and extended respite programs are geared primarily towards children under the age of 19. Therefore, once individuals turn 19, the ability of NRRS to provide resources, support and opportunities declines. NRRS proposes a future project that would focus upon the progress, and needs of these individuals who are in their “transition period.”

B) Barriers to Accessing Traditional Respite Services

A total of 48% of the children represented in the online questionnaire receive traditional respite services. For respondents not qualifying for Department of Community Service funding, all reported a family income over the DCS threshold as the reason. Diagnosis can also prevent families from accessing traditional services. Some of these families rely upon extended services to fill their respite needs. From the surveys, 59% of individuals using extended respite programs indicated that they do so in place of traditional respite programs.



Summer Recreation 2015 staff and participants

A closer examination of these issues could help families access programs in line with their specific needs, and assist NRRS in enhancing the reach and quality of its services to clients and their families. This could in turn result in enhanced quality of life for clients and their families and a community at large that would benefit from the increased engagement and health of all of its citizens, including NRRS clients and families.

Appendix A

Face-to-Face Survey

Child's Name: _____

Child's Current Age: _____

Number of years with program: _____

Child's Diagnosis: _____

Traditional Respite Program

1. How has respite care impacted your child?
2. How has respite care impacted you and your other children?
3. Did NRRS help you find a respite worker? What was that experience like? Did you feel supported?
4. Does your child use the respite apartment for respite? Is it a useful service to you?
5. If you feel we can improve the service please provide comment here.
6. Additional Comments on traditional respite services.

Extended Respite Programs

Fun Friday

1. Did you create networks with other parents? What kind of impact has that had?
2. Did your child create / build friendships? What kind of impact has that had?
3. Did your other children create support networks / friendships at Fun Friday events?
4. Do you like that the whole family is able to attend Fun Friday events?
5. Additional comments / areas of improvement for Fun Friday events?

Circle of Friends

1. Did Circle of Friends enable your child to create/build friendships?
2. Did the Circle of Friends program have an impact on your child's overall experience in school?
3. Additional comments on Circle of Friends program.

Summer Recreation Program

1. Did you feel like the Summer Recreation program provided an inclusive environment for your child?
2. What part of the program was of greatest interest to your child?
3. What impact did the Summer Recreation Program have on your child?
4. Did the Summer Recreation program have an impact on your child's level of independence

Respite Events – Christmas / March Break

1. Did you feel like the respite events provided you and your family with a period of respite?
2. Did your child enjoy the respite events?
3. Additional comments or areas of improvement for the Christmas and March Break Respite Events.
4. Additional Comments / areas of improvement for summer recreation?

Appendix B

On-Line Survey

Please note this survey is restricted to families registered with Northern Region Respite Services

Introduction

Northern Region Respite Services (NRRS) is a program that has been funded by the Department of Community Services for the past 15 years. The primary role is to help families match their child's respite needs with a high quality respite worker(s). In addition, NRRS also offers several extended respite programs in the Pictou County area.

Northern Region Respite Services is seeking feedback from families registered with the organization. Your feedback will guide NRRS in evaluating the program. The survey results will help NRRS to develop programs that respond to changing needs and funding requirements.

Important Notice: If you are not currently receiving services from NRRS, please complete the survey with information relevant to when you did receive services.

Part 1: Demographic Information

1. What is your child's gender?
a) Female b) Male
2. What is your child's primary diagnosis?
a) Down Syndrome b) Autism Spectrum Disorder c) Cerebral Palsy
d) Intellectual Disability not otherwise specified e) Brain Injury f) Other
3. Is your child over the age of 19?
a) Yes b) No
4. Does your child have a physical disability?
a) Yes b) No

Part 2: Traditional Respite

The term traditional respite as used in this survey refers to a child being matched with a respite worker. The respite worker is meeting the respite care needs of the child and family

5. Are you a current or previous client of Northern Region Respite Services?
a) Yes my child is a current client b) Yes my child is a previous client c) No
6. Current clients: How long has your child been involved with Northern Region Respite Services?
Previous clients: How many years was your child involved with Northern Region Respite Services?
a) Less than one year b) 1-3 years c) 3-6 years d) 6-9 years
e) More than 9 years
7. Has your child received respite care?
a) Yes b) No
8. Does your child qualify for respite funding by the Department of Community Services (DCS)?
a) Yes b) No

9. If your child does not qualify for DCS Funding, what restriction caused him/her to be ineligible? Please select one.

- a) Over the family income threshold b) Diagnosis based

10. How many hours of respite does your child typically access each month? Please select one:

- a) 10 to 20 hours b) 20 to 30 hours c) 30 to 40 hours d) Over 40 hours

11. Has Northern Region Respite Services ever helped match you with a respite worker?

- a) Yes b) No

12. How many different respite workers have you used in the past? Please select one.

- a) One b) Two c) Three d) Four e) Five f) More than five
g) my child does not receive respite care

13. Has your child and family benefited from having a respite worker? If no please provide specific comment.

- a) Yes
b) No - Comments:

14. When does your child access respite services? Please select all that apply.

- a) Evenings b) Weekends c) Overnights d) Summers

15. What type of respite care does your child use? Please select all that apply

- a) Volunteer b) Volunteer friend c) Volunteer family d) Paid friend
e) Paid family f) Paid respite worker

16. Please Rate your experience with Northern Region Respite Services on Traditional Respite.

- a) Poor b) Acceptable c) Satisfactory d) Good e) Very Good

17. Did you know that there is a respite apartment available for use (Free of charge) to all those registered with Northern Region Respite Services?

- a) Yes b) No

18. Have you ever used the respite apartment?

- a) Yes b) No

19. Would you ever be interested in using the respite apartment?

- a) Yes b) No

Part 3: Extended Respite Programs

20. Which extended respite programs has your child used? Please select all that apply. a) Fun

- Friday Events b) Circle of Friends c) Summer Recreation Program
d) Christmas Respite Events e) March Break Respite Events
f) My child does not use extended respite programs

21. Which extended respite programs were of interest to your child? Please select all that apply.

- a) Fun Friday b) Circle of Friends c) Summer Recreation Program
d) Christmas Respite Events e) March Break Respite Events

22. Which extended respite programs do you believe provided the greatest benefit to your child. Please select all that apply.

- a) Fun Friday b) Circle of Friends c) Summer Recreation Program
d) Christmas Respite Events e) March Break Respite Events

23. If you used the extended respite programs, did they supplement traditional respite, or did they replace traditional respite? Please select one.

- a) They supplement traditional respite b) They replace traditional respite

Part 4: Program Outcomes (Traditional and Extended Respite Services)

24. Have respite services helped expand your child's: Please select all that apply.

- a) Social Life b) Community Independence Level of inclusion

25. Have respite services helped your family provide the supports needed by your child?

- a) Yes b) No

26. Have respite services helped you extend the period of time that you were able to support your child in your home? Please select one.

- a) Yes b) No c) Not applicable

27. Have respite services improved your family life?

- a) Yes b) No

28. Please provide any additional comments and feedback here:

If you have any further questions, comments or concerns please contact Northern Region Respite Services by e-mail at nrrs@hcrsweb.ca or by calling 902-752-9452. As a thank you for completing the survey we are having a draw for one of three \$25.00 Sobeys gift-cards. If you would like your name entered into the draw please send your email address to nrrs@hcrsweb.ca

References

Respite Care in Canada, Canadian Healthcare Association, 2012

Nova Scotia Respite Guide, Mental Health Foundation of Nova Scotia, 2014