Measuring the short-term impact of Sparkle support for families with children, aged 0-5 years, with developmental difficulties.

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Contents

Executive Summary

- Sparkle received funding from the Torfaen Child Development Fund to provide support for families with children, aged 0-5 years, who had developmental difficulties and lived in the Torfaen area. This was to be delivered by Sparkle Family Liaison Officers, who work with ISCAN (Integrated Service for Children with Additional Needs) teams.

- A formal evaluation of this project was conducted, using a combination of quantitative and qualitative methodologies.

- The project ran from 1st February 2021 until 31st March 2021, and supported 30 parents/carers, 16 of whom consented to take part in the evaluation. Data was collected for the evaluation between 1st February 2021 and 15th March 2021.

- The findings suggest the support had a positive impact on family stress experienced by parents/carers, despite the short period of time it was running. However, this small amount of data was not statistically significant.

- Qualitative feedback from the Family Liaison Officers suggested parents/carers benefited from quick access to resources, liaison with healthcare professionals, and having someone understanding with whom to share their feelings.

Introduction

Sparkle and ISCAN's Family Liaison Service (FLS) is delivered by the Family Liaison Officers (FLOs), based at Serennu Children's Centre, Nevill Hall Children's Centre and Caerphilly Children's Centre. The FLS has been in South Gwent since February 2014, in North Gwent since May 2017, and in West Gwent since October 2018. The FLS is accessible to all families within the catchment areas of the Centres and offers extensive support and information for families with a child or young person with a disability and/or developmental difficulty.

The support offered by FLOs includes:

- Acting as a first point of contact for all families and helping with enquiries about the *services and leisure* activities that children and young people (CYP) can access, both at the Children's Centres and within the local area.
- Guiding and supporting families to *navigate the healthcare* system, signposting to the correct professionals and helping to co-ordinate appointments.
- Offering *practical support* filling in forms, such as for Disability Living Allowance.
- Ensuring all families are provided with *access to appropriate services*, and obtaining *feedback* to inform service development.
- Facilitating the running of *Parent Support Groups*.
- Running *information events* twice a year where families can seek information from professionals in health, education, sport, finance and voluntary sectors.
- Organising *drop-in sessions* where families can meet with other charities.
- Producing a regular monthly *newsletter* highlighting current developments at the Centres and maintaining up-to-date notice boards at the Centres.
- Facilitating *First-Aid workshops* for parents.
- *Outreach* work, includes visiting schools (assemblies and parent's evenings), GP surgeries, events held by organisations such as the Gwent Association of Voluntary Organisations (GAVO) and healthcare conferences to present and promote what the FLS offers. This also includes holding events with health visitors, usually bi-annually, to make them aware of the service and that they can refer families.
- Liaising between organisations (e.g. universities and national organisations) and parents, to provide parents with the opportunity to be *involved in evaluations and research.*

The FLOs can support families with a number of issues, such as anxiety, financial pressures, education and stress.

Having a child with a developmental difficulty can place a huge amount of strain on a family. Research into family burden for those with a child with Attention Deficit Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD) or a learning disability, found that families of younger children experience more strain than families with older children (Dovgan & Mazurek, 2018). However, it has also been found that access to social support significantly reduces parental strain in families with a child with ADHD and other conditions (Hinojosa et al., 2012). An evaluation of a home-based, family focused support scheme for families with a child with developmental delay or disability found parents experienced significant and positive change compared to a control group (Davis & Rushton, 1991).

In February 2021, Sparkle received funding from the Torfaen Child Development Fund to provide support for families in Torfaen with a child with developmental difficulties, via the ISCAN FLS. FLOs provided regular support to parents via the telephone due to Covid-19 restrictions, and provided parents with toolkits and resources to help with specific issues, such as anxiety or sleep problems.

The following report outlines the results of a formal evaluation of the service provided during this project. Part of the funding was also dedicated to introducing a ‘stay and play’ style club called Little Stars, which families in Torfaen with a child aged 0 to 5 years with a developmental difficulty would be able to access. The children who access Little Stars are usually unable to access community provisions and very often miss out on these critical early intervention opportunities. The club also provides parents with the opportunity to interact, support each other and share ideas, as well as providing the children with much needed opportunities for social development. Little Stars was unable to open during the period of data collection due to Covid-19 restrictions, and therefore is not included in the evaluation.

Method

Design

The evaluation was conducted using quantitative methodology, using a standardised questionnaire to gauge the impact the FLS had on families over a short period of time. In addition, qualitative feedback was gathered from the FLOs involved in the project. Approval for this service evaluation was granted by the Aneurin Bevan University Health Board Research and Development Department.

Participants

Participants for this project were recruited via ISCAN and the FLS. All parents/carers who were contacted as part of the wider project were invited to take part in the evaluation. Of the 30 parents/carers contacted, 16 agreed to take part. Participants were read a Participant Information Sheet (appendix A) and formal consent (appendix B) to take part in the evaluation was taken over the phone due to Covid-19 restrictions.

Data Collection

Descriptive data was collected regarding the number of parents/carers contacted as part of the project, the child's age, how they were referred to the FLS, and how many contacts were made by the FLO. The impact on parents/carers was measured using the Family Strain Index (FSI) (appendix C). The FSI has been found to be a reliable and easy-to-use measure of family strain when completed by parents of children with additional needs (Riley et al., 2009). The measure consists of six items about how the participant's child has made them act or feel over the past four weeks, and participants are asked to score each item on a Likert scale, where 0 is never and 4 is always. An example of the questions included in the measure is "In the past four weeks, how often has your child made you feel stressed or worried". Qualitative feedback was collected from the FLOs on what impact they felt the service had on parents/carers over a short period of time. The FLOs were asked five questions about the project (appendix D), for example "what was the most common problem or issue you felt families needed support with?"

Data Analysis

Descriptive statistics regarding the number of parents/carers supported as part of the project, and those who took part in this evaluation, were calculated and are presented below. A Wilcoxon signed-rank statistical test was used to analyse the data collected using the FSI, and a summary of the qualitative feedback from the FLOs is also given.

Findings

Descriptive Statistics

The 30 parents/carers all had a child between 0 and 5 years with developmental difficulties, with the mean age being 2.67 years and the median age 3 years. Parents/carers were offered regular support over the month-long project, with the number of contacts made between each parent/carer and a FLO being between one and seven depending on the amount of support needed, with the mean number of contacts being 2.69 contacts and the median being 2 contacts.

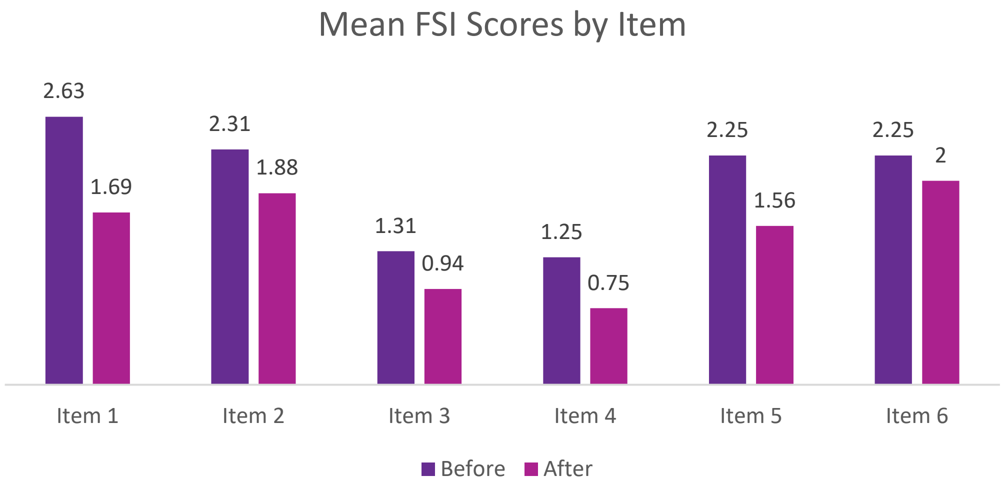
The 16 parents/carers who consented to take part in the evaluation were representative of the group as a whole. The mean age of the participants' children was 2.81 years, with a median of 3 years. The mean number of contacts made between a FLO and participants was 3.19, with a median of 2.5.

Family Strain Index (FSI)

The FSI consists of six items which measure strain on families with a child with additional or complex needs. The items measure issues such as stress and anxiety, effects on family relationships and social activity, and effects on day-to-day activities and planned events. A higher score suggests greater family strain, and a low score suggests low family strain. The mean and median FSI scores before and after intervention from Sparkle FLS for each participant is presented below. The majority of participants seem to experience less family strain following support from a FLO, with 11 participants showing a decrease in their mean score, nine of which also showing a decrease in their median score. A few participants show an increase in their mean or median scores, or their mean and median scores remain the same.

Participant	Age of Child	Number of contacts made	FSI scores before intervention		FSI scores after intervention	
			Mean score	Median score	Mean score	Median score
1	4	4	2	0.5	2.67	3
2	2	2	2.5	2.5	1.33	2
3	4	2	0.67	1	0	0
4	4	2	2.33	3	2.33	3
5	4	3	2	2.5	1.67	2
6	4	2	1.83	2	1.67	1.5
7	4	2	3.33	3.5	3.17	3
8	2	3	0.33	0	0.33	0
9	3	6	2.83	3	1.5	1.5
10	3	7	3.17	3	1.5	1
11	0	2	1.17	0.5	1.67	0.5
12	2	5	0.83	0	1	0
13	2	2	1	0.5	0.83	1
14	2	1	1	0.5	0.83	0.5
15	3	3	4	4	2.33	2
16	2	5	3	3	1.67	1.5

The graph below shows the mean score for each item before and after the intervention. This graph suggests that Sparkle FLS support is impactful for each of the items measuring by the FSI.



Due to the small number of participants, a Wilcoxon signed-rank statistical test was used to determine if the difference in scores for each participant was significant. Using the mean before and after scores for each participant, the Wilcoxon test results are significant at $p < .05$. However, it is usually recommended to use the median scores for more accurate results, and the Wilcoxon test results are not significant at $p < .05$ using the median before and after scores for each participant (appendix E).

Family Liaison Officer (FLO) Feedback

The most common issues parents/carers were presenting with concerned sleep issues and managing challenging behaviours, particularly with the added pressure of siblings being home during the national lockdowns and school closures. Some parents/carers were also experiencing difficulties contacting professionals and services about their child's care.

The FLOs felt they were able to have an impact in the short space of time due to having resources at their disposal, for example to help with sleep issues. It was acknowledged that support over such a short period of time was not going to have a long-term, significant impact on parents/carers' worries and anxieties, however the FLOs felt providing parents/carers someone understanding to share their feelings with and the opportunity to 'off-load' was positive. As the FLOs work in close contact with professionals at the Children's Centres, they were able to liaise with services for parents/carers, which had direct benefits for families.

> *"They listen to every problem you have."*
>
> (Parent)

> *"To know there's someone to help and give advice."*
>
> (Parent)

Conclusions

At first glance, the results of this evaluation suggest that Sparkle FLS support has a positive impact on family strain for parents/carers with a young child with developmental difficulties, even over a short period of time. No statistical difference was shown, although the data is limited in size, and the intervention was only run for six weeks.

Despite the results not being statistically significant, the beneficial impact for the individuals involved in the evaluation cannot be ignored. It has been suggested that FLS support results in improvement for each of the six items included in the FSI, and feedback from the FLOs has shown that participants benefited from quick access to resources to help with common issues, such as sleep problems, and the FLOs working in close contact with healthcare professionals and services resulted in direct outcomes for participants. Feedback from the FLOs also suggests participants benefited from simply being given the opportunity to ‘off-load’ and talk to somebody about the stresses they experience due to having a child with developmental difficulties.

This evaluation was limited by the small sample size and narrow time frame, yet clearly showed encouraging results, and was well received. Given the initial positive results, it would be interesting to determine whether the results would be statistically significant with a larger sample size, and whether scores would differ if support was measured over a longer period of time*.

*Whilst this evaluation has come to an end, participants are still able to receive support from the Sparkle FLS and access other support and resources via Sparkle.

References

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Appendices

Appendix A: Participant Information Sheet

Participant Information Sheet

Research Project: "Measuring the short-term impact of Sparkle support for families with children, aged 0-5 years, with developmental difficulties".

What is the purpose of this research?

The purpose of this research is to measure the impact Sparkle has on families with a child, aged 0-5 years, with developmental delay or difficulties over a short period of time. If you agree to take part in this research, you will be asked to complete a short, six-question survey over the phone with a Sparkle Family Liaison Officer, once when you first receive support and again after a few weeks. You will be asked questions about how your child has made you feel over the past few weeks.

Do I have to take part?

No, it is your choice whether or not to participate. If you agree to participate and then change your mind, you can withdraw at any time without giving a reason. Your decision on whether to take part in the research will have no impact on the support you receive from Sparkle.

Are there any benefits to taking part?

There are no financial or material benefits to taking part in the research, however you may find participating a rewarding experience and find it useful to reflect on how you are feeling whilst receiving support from Sparkle.

Will my participation be confidential?

Yes. All data will be kept confidential and your name will not be used in any written reports or research dissemination materials. However, if any information about harm or possible harm to children is shared, confidentiality will have to be broken and the relevant agencies will be informed.

What happens with the data being collected?

These findings will be written up in a report, which may be presented to interested parties and submitted for publication in academic journals.

Who can I contact for further information?

Please contact Sparkle's Research and Development Officer, Bethan Collins, on 01633 748024 (Monday to Friday, 9am-5pm) or email research@sparkleappeal.org if you have any questions about this research project.

Thank you for your time.

Appendix B: Consent Form

Participant Consent Form

This form is to give your agreement to take part in the research project: **"Measuring the short-term impact of Sparkle support for families with children, aged 0-5 years, with developmental difficulties".** Please carefully read the following statements and, if you are happy to take part, please **initial** each box and **sign** at the bottom of the form.

I am over 18 years of age.	
I confirm I have read the information sheet and understand the nature and purpose of the project.	
I have had time to think about the project and been given the opportunity to ask questions and discuss the project. I confirm I have received satisfactory answers to any questions.	
I understand that I will remain anonymous in any written reports or presentations.	
I understand that all information I provide will be confidential (with the exception of information about harm to children, in which case the researcher has a duty to inform the relevant agencies).	
I understand that I will not financially benefit from taking part in this project.	
I understand that participation is voluntary and I am free to withdraw from the project, without giving a reason, prior to my data being anonymised. After this time, it will be impossible to trace the information provided.	
I know how to contact the researcher (Bethan Collins) if I need to.	
I understand this project may be submitted for publication, reports or presentations.	
I understand that if I feel distressed by any part of this project, I can talk to the researcher or a member of staff for information on where to access support.	
I agree to Sparkle processing my personal data in accordance with the UK GDPR and Data Protection Act 2018 for the purposes of this research.	
I agree to take part in this research.	

Participant:

Name (print) …………………………

Signature ……………………………

Date …………………………………..

Researcher:

I confirm that I have explained to the participant the purpose and nature of the project.

Name (print) …………………………

Signature ……………………………..

Date ……………………………………

Appendix C: Family Strain Index

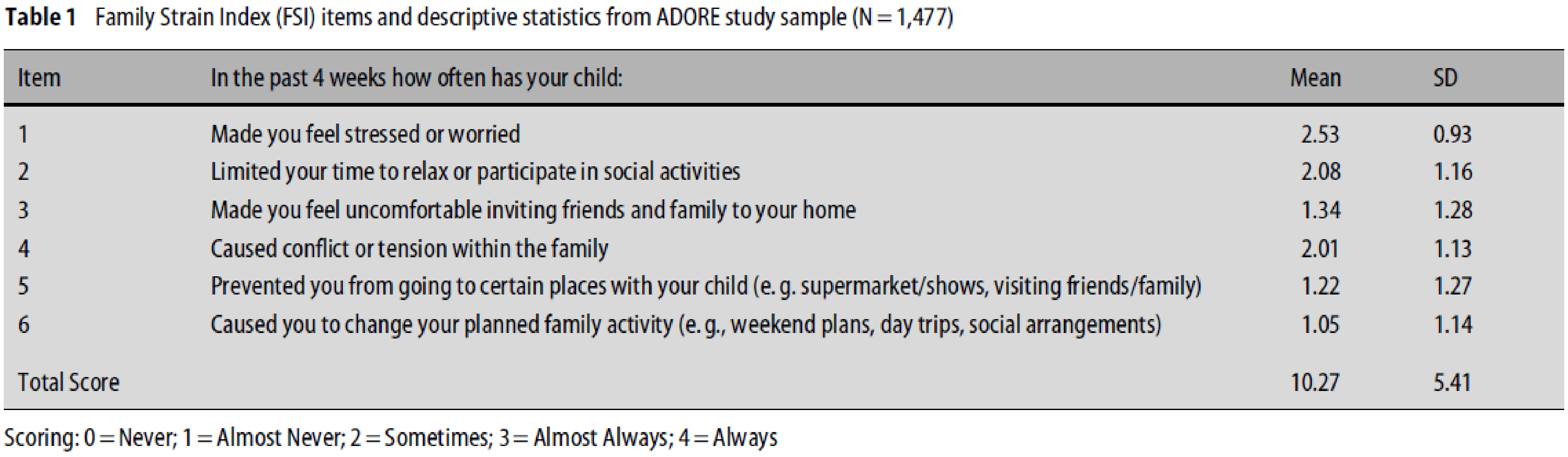


Table 1 Family Strain Index (FSI) items and descriptive statistics from ADORE study sample (N = 1,477)

Item	In the past 4 weeks how often has your child:	Mean	SD
1	Made you feel stressed or worried	2.53	0.93
2	Limited your time to relax or participate in social activities	2.08	1.16
3	Made you feel uncomfortable inviting friends and family to your home	1.34	1.28
4	Caused conflict or tension within the family	2.01	1.13
5	Prevented you from going to certain places with your child (e. g. supermarket/shows, visiting friends/family)	1.22	1.27
6	Caused you to change your planned family activity (e. g., weekend plans, day trips, social arrangements)	1.05	1.14
Total Score		10.27	5.41

Scoring: 0 = Never; 1 = Almost Never; 2 = Sometimes; 3 = Almost Always; 4 = Always

Appendix D: FLO Feedback Form

Family Liaison Officer Feedback

1. What was the most common problem or issue you felt families needed support with?

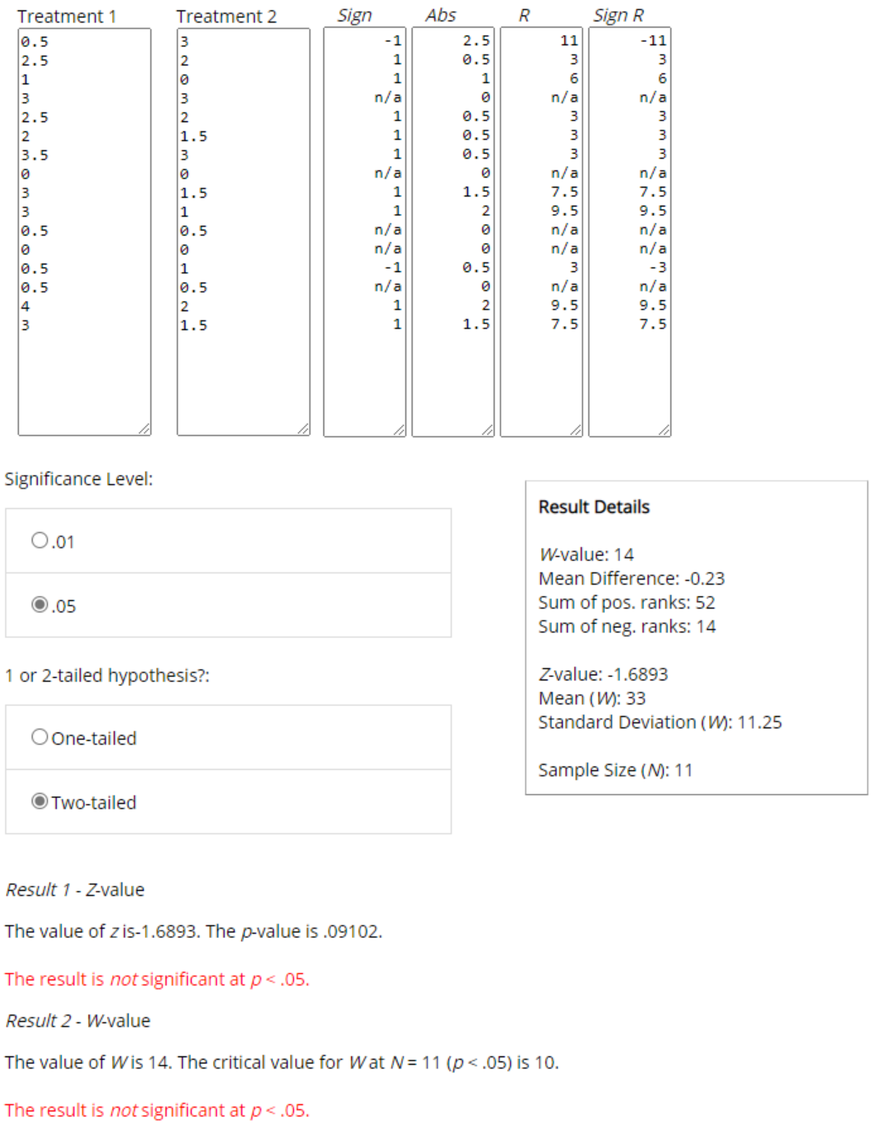
2. Did you feel you were able to support families effectively regarding this problem or issue?

3. Did you feel you were able to have an impact on families during the short timescale of this project? Can you think of an example of a time when you felt this project was having a significant impact on families?

4. At any point during this project, did you feel the service needed improving to have an impact on families? Can you think of an example of a time when you felt more needed to be done to support families?

5. Do you feel there is anything that could help you support families more effectively going forward? (E.g. access to certain resources, training in any particular area, etc.)

Appendix E: Wilcoxon signed-rank tests



Treatment 1	Treatment 2	*Sign*	*Abs*	*R*	*Sign R*
0.5	3	-1	2.5	11	-11
2.5	2	1	0.5	3	3
1	0	1	1	6	6
3	3	n/a	0	n/a	n/a
2.5	2	1	0.5	3	3
2	1.5	1	0.5	3	3
3.5	3	1	0.5	3	3
0	0	n/a	0	n/a	n/a
3	1.5	1	1.5	7.5	7.5
3	1	1	2	9.5	9.5
0.5	0.5	n/a	0	n/a	n/a
0	0	n/a	0	n/a	n/a
0.5	1	-1	0.5	3	-3
0.5	0.5	n/a	0	n/a	n/a
4	2	1	2	9.5	9.5
3	1.5	1	1.5	7.5	7.5

Significance Level:

○ .01

● .05

1 or 2-tailed hypothesis?:

○ One-tailed

● Two-tailed

Result Details

W-value: 14
Mean Difference: -0.23
Sum of pos. ranks: 52
Sum of neg. ranks: 14

Z-value: -1.6893
Mean (*W*): 33
Standard Deviation (*W*): 11.25

Sample Size (*N*): 11

Result 1 - Z-value

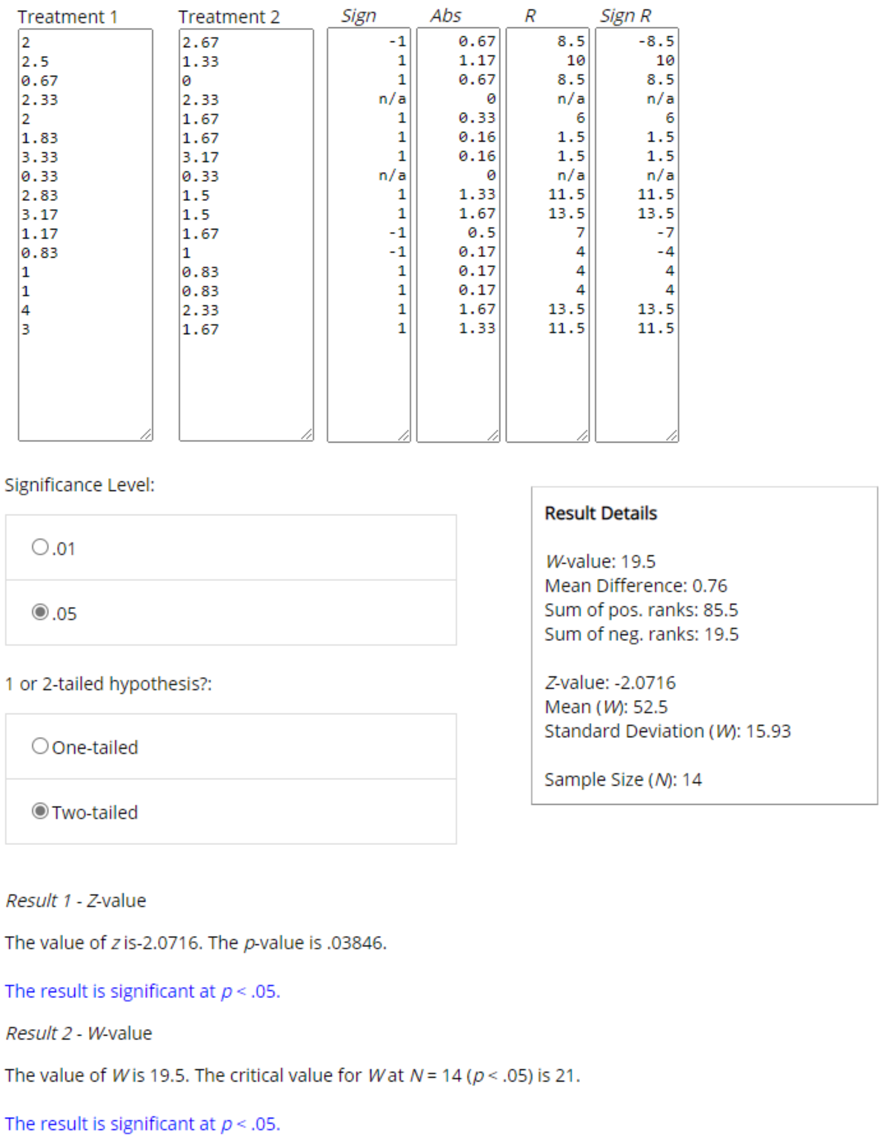
The value of *z* is-1.6893. The *p*-value is .09102.

The result is *not* significant at *p* < .05.

Result 2 - W-value

The value of *W* is 14. The critical value for *W* at *N* = 11 (*p* < .05) is 10.

The result is *not* significant at *p* < .05.



Treatment 1	Treatment 2	*Sign*	*Abs*	*R*	*Sign R*
2	2.67	-1	0.67	8.5	-8.5
2.5	1.33	1	1.17	10	10
0.67	0	1	0.67	8.5	8.5
2.33	2.33	n/a	0	n/a	n/a
2	1.67	1	0.33	6	6
1.83	1.67	1	0.16	1.5	1.5
3.33	3.17	1	0.16	1.5	1.5
0.33	0.33	n/a	0	n/a	n/a
2.83	1.5	1	1.33	11.5	11.5
3.17	1.5	1	1.67	13.5	13.5
1.17	1.67	-1	0.5	7	-7
0.83	1	-1	0.17	4	-4
1	0.83	1	0.17	4	4
1	0.83	1	0.17	4	4
4	2.33	1	1.67	13.5	13.5
3	1.67	1	1.33	11.5	11.5

Significance Level:

○ .01

● .05

1 or 2-tailed hypothesis?:

○ One-tailed

● Two-tailed

Result Details

W-value: 19.5
Mean Difference: 0.76
Sum of pos. ranks: 85.5
Sum of neg. ranks: 19.5

Z-value: -2.0716
Mean (*W*): 52.5
Standard Deviation (*W*): 15.93

Sample Size (*N*): 14

Result 1 - Z-value

The value of *z* is-2.0716. The *p*-value is .03846.

The result is significant at *p* < .05.

Result 2 - W-value

The value of *W* is 19.5. The critical value for *W* at *N* = 14 (*p* < .05) is 21.

The result is significant at *p* < .05.