

Firefly Autism: Impact on Families

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Executive Summary

Firefly Autism works to help neurodivergent students learn skills and strategies which can make them more successful and happier in a neurotypical world. Their work, however, also impacts families of the learner and leads to a better quality of life, improved parenting skills, and lower rates of parental burnout. This report examines the differences between families new to Firefly Autism, families at the beginning of the school year compared to those at the end of the school year, and differences between Firefly families and other similar groups of US parents. Highlights from the report include:

- Firefly’s supports to both the child (learner) and the family compounds with time to lead to an overall positive shift in the quality of life. Quality of life scores grew by 16 points (a 28% increase) over the course of the year and grew five points (an 8.3% increase) as tenure increases from one or fewer years to five or more years.
- Parents report their child has made progress in the past six months, reporting much higher rates in the spring (81.9%) than in the fall (75.0%). This reflects the positive influence of working closely with Firefly.
- Among families with the highest tenure (five or more years) almost all (87.5%) strongly agreed that they knew how to assist their children whereas only three-quarters of those with one or fewer years tenure felt similarly. Parents also report a better ability to use their parenting skills (compared to having knowledge they cannot apply), rising from 71.4% among those with one or fewer years’ tenure to 85.0% for those with five or more years’ tenure. Considering the diversity in needs and skills among individuals with autism, Firefly’s assistance helped families increase these skills rather than contribute to a cycle of frustration many parents of neurodivergent children feel when they cannot understand how to help their children (Estes et al., 2013; Greene, 2021; Woodgate et al., 2015).
- Firefly parents report lower parental burnout levels (score of 44.3) than the average US parent (66.0% report feeling burnt-out) and other parents of children with autism (58.0% of mothers and 69.3% of fathers, as reported by Paisley in her 2022 dissertation).

Table of Contents

Executive Summary.....	2
Results.....	3
Recommendations	11
Appendices	12

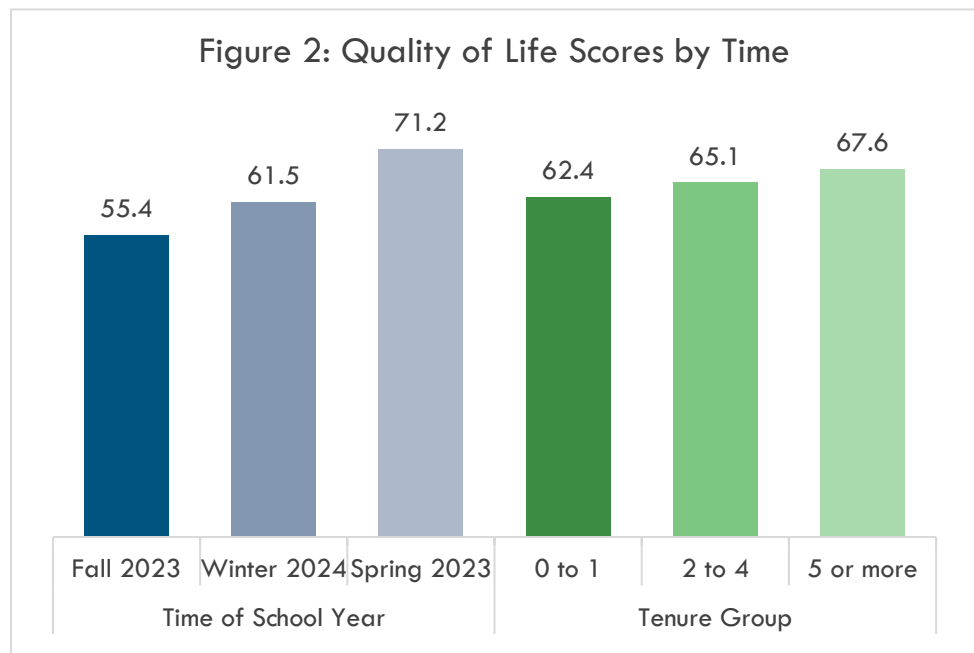
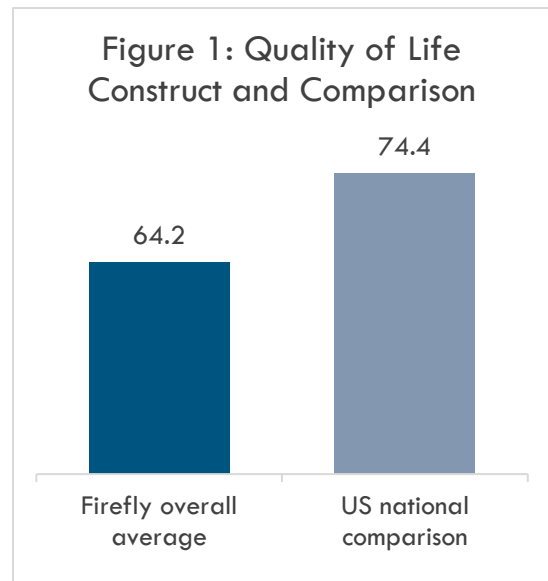


Results

1. Quality of Life

Firefly Autism’s parents have a quality of life construct score of 64.2 out of a potential 100, which is lower than the national comparison score of 74.4 for all US adults (significant difference using a Chi-Square test, $p < 0.05$). However, data from surveys of Firefly parents collected over the course of a school year (Fall 2023, Winter 2024, and Spring 2023¹) and capturing parents at different levels of experience or tenure with Firefly Autism reveals that Firefly’s supports to both the learner and the family compounds with time to lead to an overall positive shift in the quality of life. As shown in Figure 2, quality of life scores grew from 55.4 to 71.2 over the course of the year² and grew from 62.4 to 67.6 as tenure increases from one or fewer years to five or more years.³

Firefly parents’ quality of life measures were captured with a construct comprising of satisfaction with relationships (friends and family members), satisfaction with work and work-life balance, the amount and quality of personal time they have, where they live, and their health.



¹ Data collection began in spring of 2023 using a tool that would capture the effects of association with Firefly Autism. Although data were collected in spring of 2023 first, these data represent the post-treatment or end-of-school year scores for families. Fall 2023 data represent the beginning of the school year and Winter 2024 data are the mid-school year data.

² Differences are statistically significant using an ANOVA test, $p < 0.05$

³ Differences are not statistically significant, using an ANOVA test, $p < 0.05$



Figure 3 shows the weighted percent for respondents' satisfaction in each of these elements reported over the school-year and by tenure groups.

All components of the quality of life score rose from the fall to the spring (over the course of a school year). This suggests that stresses present with the beginning of the school year are ameliorated both as families settle into school and as families receive assistance from Firefly.

Tenure data show a slightly different pattern with rising satisfaction with relationships with family, relationships with friends, work-life balance satisfaction, satisfaction with amount and quality of personal time, and satisfaction with their place of residence. Satisfaction with their job fluctuates by tenure, more likely driven by factors beyond the influence of Firefly. The causal connection between satisfaction with work-life balance and personal time is stronger with the actions of Firefly: helping families manage their children's needs, behaviors, and providing structures. These types of labor were most likely previously the work of parents, taking personal time and energy (D'Arcy et al., 2023; Little et al., 2022).

Health satisfaction lowers with increased tenure, more likely a product of the increasing age of respondents when health complications begin to arise and become more influential in individuals' quality of life.

Figure 3: Quality-of-Life Components

	All Respondent Average	Time of Survey			Years Tenure		
		Fall	Winter	Spring	0 to 1	2 to 4	5 or more
Relationship with family	74.7%	63.9% [†]	68.3% [†]	84.1% [†]	67.0% [*]	79.3% [*]	79.2% [*]
Relationship with friends	68.0%	57.4% [†]	63.3% [†]	76.9% [†]	66.0% [°]	68.1% [°]	72.8% [°]
Job or career path [°]	66.1%	59.6%	65.0%	71.1%	68.0%	64.3%	67.0%
Work-life balance [°]	61.6%	56.7%	58.3%	66.0%	57.0%	60.7%	68.5%
Amount and quality of personal time	53.0%	43.5% [†]	53.3% [†]	59.4% [†]	50.0% [°]	56.0% [°]	56.5% [°]
Place of residence	72.2%	61.1% [†]	75.0% [†]	78.8% [†]	71.9% [°]	71.6% [°]	76.1% [°]
Health	59.9%	52.8% [†]	53.3% [†]	67.3% [†]	64.0% [°]	58.9% [°]	56.5% [°]

[†]Differences were statistically significant based on an ANOVA, p < 0.05

^{*}Differences were statistically significant based on an ANOVA, p < 0.10

[°]Differences were not statistically significant based on ANOVA or T-tests, p < 0.05

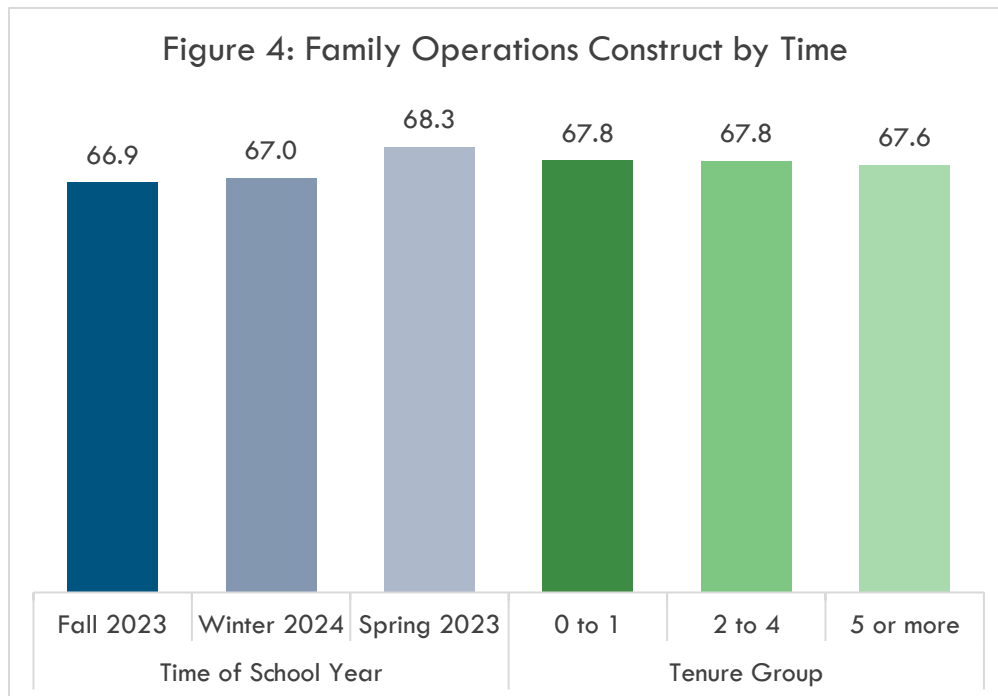


2. Family Operations

Firefly families are functioning well, although the score capturing family operations is not affected either by the passage of time of the year or by tenure⁴.

Looking at the component parts of this construct provides clues as to why.

Elements of this construct are shown in Figure 5



(next page). Families report running on a regular schedule (75.3%) and enjoying activities together (semi-structured activities, 67.5%; valued activities each week, 76.6%). While these rates varied slightly by time of the year and the number of years tenure, the variations were not large enough to be statistically significant.

Parents reported increased levels of time for self-care and time to exercise regularly as the school year went on and as tenure increased. While these changes were not statistically significant, they do show the effect of Firefly’s help for parents who face additional parenting demands.

Feelings of isolation peak in Winter and for families with two to four years of tenure. Firefly could find additional opportunities to provide support for their mid-range tenured families as well as families during the middle of the school year.

While the data about parents’ relationships with their children (looking forward to time when children are not in school and discussions about their child’s diagnosis) show little variation⁵, there is an effect of tenure on parents’ understanding of how to assist their child in everyday activities. Families with the highest tenure (five or more years) almost all (87.5%) strongly agreed that they knew how to assist their children whereas only three-quarters of those with one or fewer years tenure felt similarly.

⁴ Differences are not statistically significant, using an ANOVA test, $p < 0.05$

⁵ Differences are not statistically significant for either tenure or time-of-year data, based on ANOVA or t-tests $p < 0.05$.



Figure 5: Family Operations Components

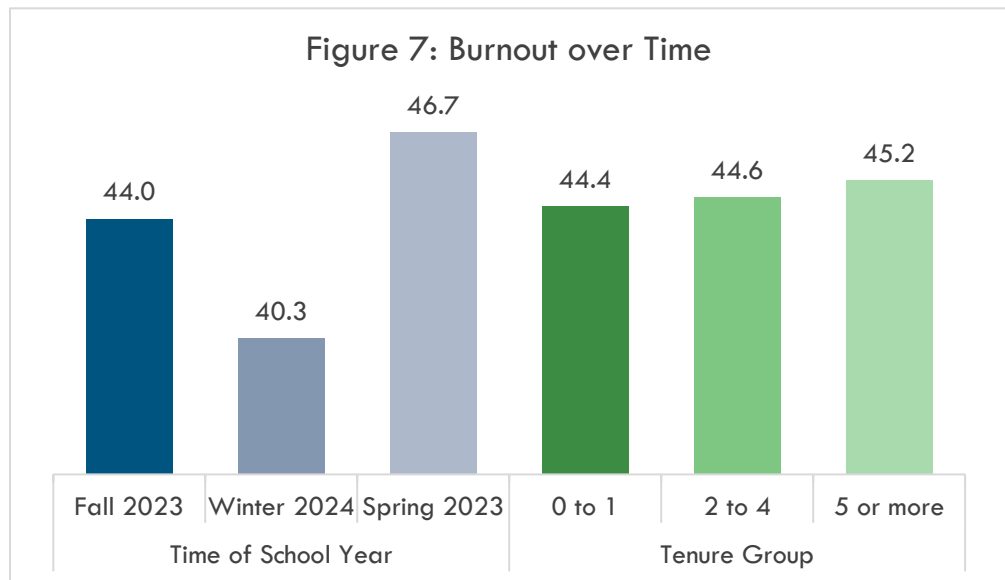
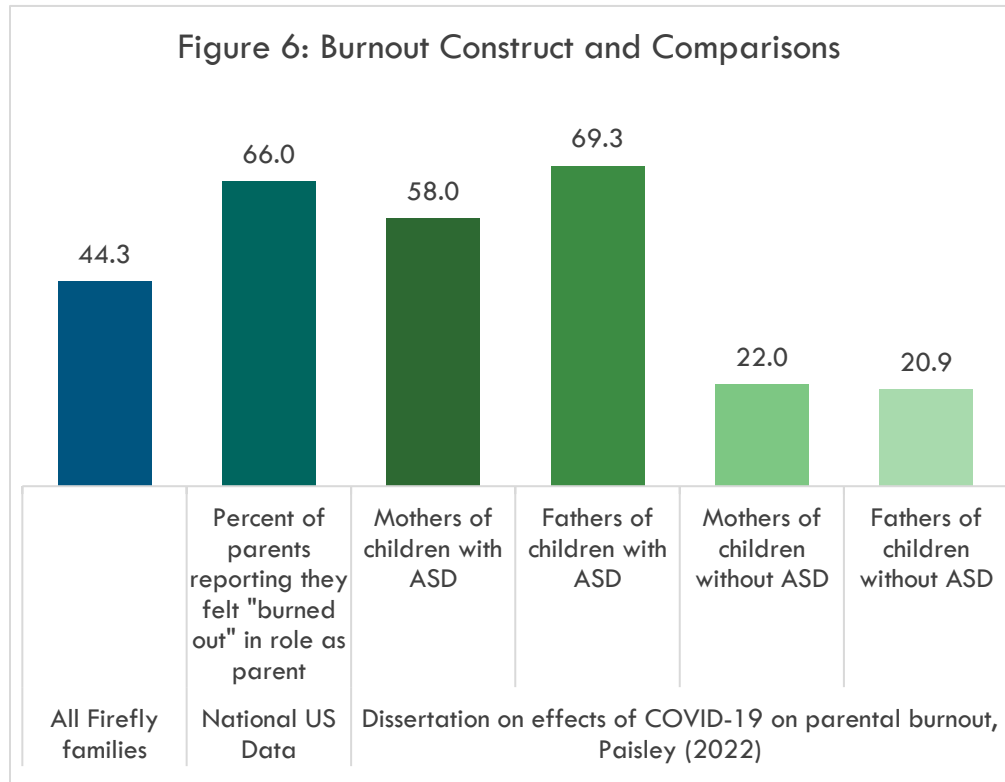
	All Respondent Average	Time of Survey			Years Tenure		
		Fall	Winter	Spring	0 to 1	2 to 4	5 or more
Family runs on a regular schedule ^o	75.3%	74.2%	76.6%	75.8%	77.9%	73.1%	73.9%
Family regularly enjoys semi-structured activities together ^o	67.5%	70.0%	64.1%	66.9%	68.3%	64.4%	70.7%
Family participates in valued activities each week ^o	76.6%	75.8%	78.1%	no data	73.2%	78.3%	77.1%
Time for self-care every week ^o	60.9%	58.3%	59.4%	64.0%	57.7%	59.6%	67.4%
Exercise regularly ^o	62.5%	60.8%	62.5%	64.0%	60.6%	60.6%	67.4%
Feel isolated ^o	59.7%	56.7%	68.8%	58.1%	59.6%	67.3%	53.3%
Look forward to days when children are not in school ^o	66.1%	65.0%	60.9%	69.7%	69.0%	65.4%	65.2%
Discussions about child's diagnosis and needs are part of everyday lives ^o	84.5%	86.7%	75.0%	87.1%	85.6%	85.0%	81.5%
Understand how to assist child in everyday activities ^o	81.5%	85.0%	75.0%	no data	75.0%	81.7%	87.5%

^oDifferences were not statistically significant based on ANOVA or T-tests, p < 0.05



3. Burnout

Parental burnout is higher among parents of behaviorally difficult children, feeding into a cycle of increased strain on the parent-child bond (Greene, 2021; Paisley, 2022). Firefly parents report relatively low levels of burnout with scores between 40 and 47 out of 100 possible. Burnout appears to be lowest at the mid-point of the school year, potentially because children are spending much of their time at school whereas fall scores are higher with the end of summer and spring scores show an uptick with parents' needs to plan for summer activities⁶.



⁶ Differences are not statistically significant for either tenure or time-of-year data, based on ANOVA or t-tests $p < 0.05$.



Individual elements of the Burnout score remain at similar levels throughout the school year (see Figure 8). However, one item reflects changes over the school year: parents feeling their child has made progress in the past six months in the spring than in the fall (81.9% compared to 75.0%), reflecting the influence of Firefly Autism’s work.

Figure 8: Burnout Components

	All Respondent Average	Time of Survey			Years Tenure		
		Fall	Winter	Spring	0 to 1	2 to 4	5 or more
Tired of the day-to-day mental/emotional care aspects of parenting ^o	65.5%	65.7%	61.7%	67.2%	62.5%	63.5%	70.0%
Exhausted by the physical parenting duties ^o	67.3%	68.5%	61.7%	69.0%	62.5%	66.7%	70.0%
Child has made progress in the past 6 months ^o	78.2%	75.0%	76.7%	81.9%	83.0%	76.0%	75.0%
Other parents are critical because of our child(ren) ^o	67.9%	68.5%	66.7%	67.9%	61.9%	68.8%	72.5%
Consider self a good parent	82.7%	79.8% ^o	85.7% ^o	83.9% ^o	83.8% [†]	86.5% [†]	77.6% [†]
Ability to utilize skills as a parent has improved since being at Firefly	79.7%	81.5% ^o	78.8% ^o	78.4% ^o	71.4% [*]	81.3% [*]	85.0% [*]
Other parents at Firefly are a useful source of information ^o	49.2%	50.0%	53.8%	46.4%	45.8%	50.0%	50.0%

[†]Differences were statistically significant based on an ANOVA, p < 0.05

^{*}Differences were statistically significant based on an ANOVA, p < 0.10

^oDifferences were not statistically significant based on ANOVA or T-tests, p < 0.05

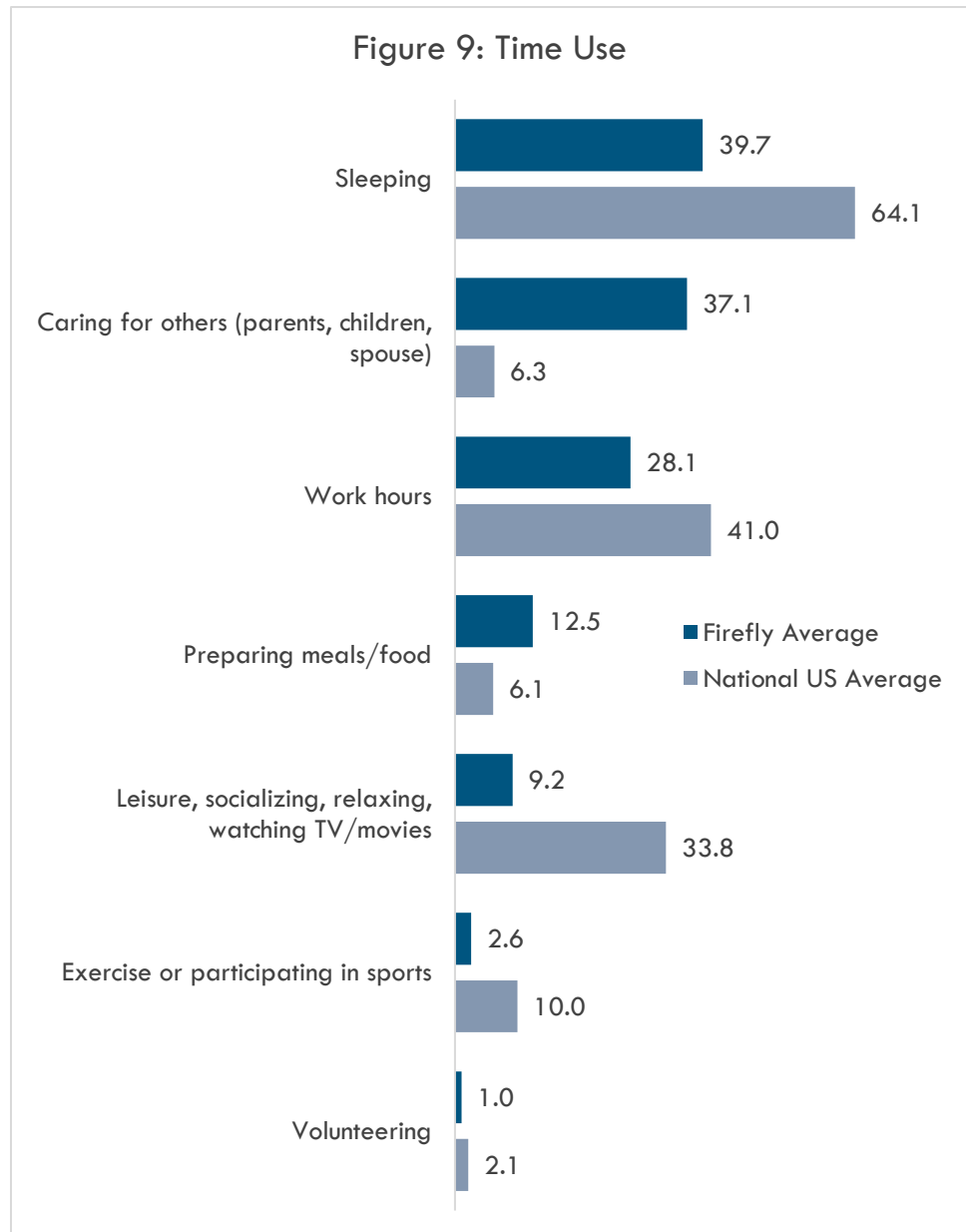
As tenure increases, more parents report the ability to utilize their parenting skills improving, rising from 71.4% for those with one or fewer years tenure to 85.0% for those with five or more years’ tenure⁷. Unexpectedly, parents also report an increase in other parents being critical of them and their families as tenure increases (61.9% for a tenure of one or fewer years, up to 72.5% for those with five or more years’ tenure). There are also declines in the percentage of parents who would consider themselves to be a “good parent,” declining from 83.8% of those with one or fewer years’ tenure to 77.6% for those

⁷ Statistically significant difference, ANOVA test, p < 0.05



with five or more years tenure⁸. This could be an instance of “the more you know, the harder you judge yourself” where parents who have more knowledge about parenting neurodivergent children feel they must meet the higher bar of what is possible. It could also be that parents of older children feel less support for the social-emotional challenges of parenting teenagers (Christin et al., 2015; Cui et al., 2014; Rabin et al., 2018).

Looking at how Firefly parents spend their time shines additional light on how Burnout can occur. Figure 9 shows that Firefly parents spend over 24 fewer hours sleeping every week compared to the US average of adults and spend over 36 more hours caring for others. They also spend an additional 6.4 hours on average compared to their peers preparing food. This is potentially due to food sensitivities and texture aversions common among neurodivergent children that make eating out or relying on conveniences and cooking shortcuts less available to Firefly parents (Alibrandi et al., 2023). Firefly parents also spend



fewer hours working for pay (12.9 fewer hours a week), relaxing (24.6 fewer hours a week), and volunteering (1.1 fewer hours a week).

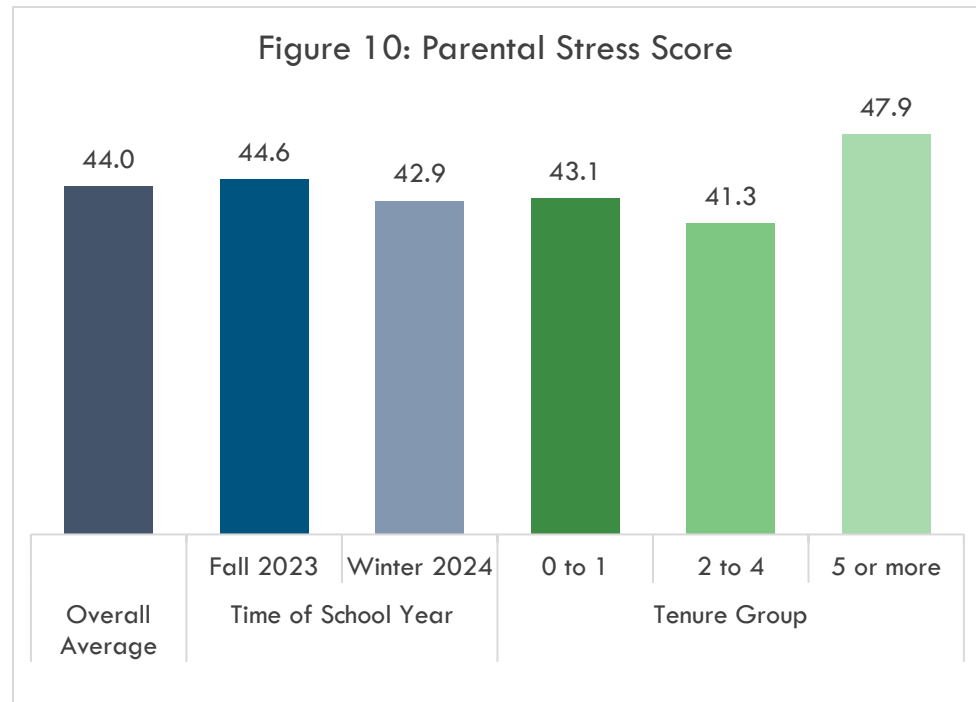
⁸ Statistically significant difference, ANOVA test, p <0.10



4. Stress Scores

Increased levels of parental stress are common among parents of children with additional or special needs (Davis and Carter, 2008; Estes et al., 2013; Hartley et al., 2010; Laili et al., 2021). To capture the stress experienced by Firefly parents, parents were asked to complete the 18-item parental stress scale (PSS) developed by Berry and Jones (1995). The scale was developed to capture the outcomes of parent support programs and includes items that address parents' feelings about their parenting role (both the positive and the negative or challenging elements). In addition to capitalizing on the validity and reliability of the PSS, its use allows for between groups comparisons to understand how Firefly parents compare to other populations of parents, especially those with high-needs children.

Firefly parents had an average stress score of 44.0 on a range from 18 (low stress) to 90 (high stress), which is higher than the midpoint (36). Shown in Figure 10, stress levels among subpopulations of Firefly's parent population do not differ substantially with slightly higher stress for parents who have high tenure (five or more



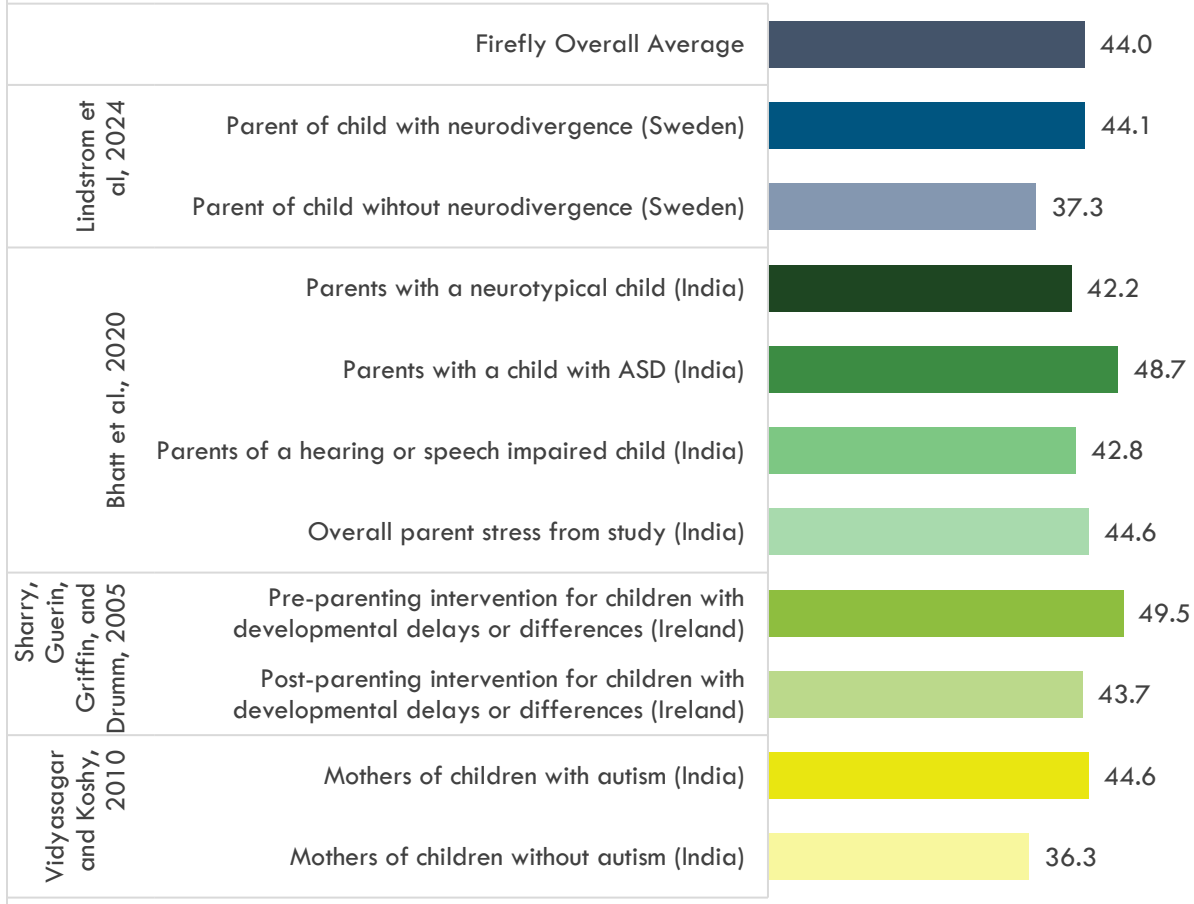
years, 47.9 score) and slightly lower among those with two to four years' tenure (41.3 score)⁹. It is possible that higher stress is present among the high-tenure group because these parents are navigating teenage years with their children when the combination of teenage-parent relationships begin to cause stress as well as parent concerns about if and how their children will pursue independent or semi-independent lives after turning 18.

These stress scores are on par with other studies of families with neurodivergent children, as shown in Figure 11 (next page). Where studies included a control group of parents without neurodivergent children, stress levels were lower than the study group and the average at Firefly Autism.

⁹ The difference between those with one or fewer years' tenure and five or more years' tenure is not statistically significant (t-test, $p < 0.05$), but it is statistically significant between those with two to four years' tenure and five or more years' tenure (t-test, $p < 0.05$).



Figure 11: Parental Stress Score Comparisons



Recommendations

Firefly Autism’s impacts on families shows the power their work has beyond helping individual learners. There were a few patterns in the data that suggest avenues for Firefly Autism to increase its impact on families.

While parents improved their parenting skills and had a better understanding of *how* to help their children, parents also reported feelings that other parents were critical of them and their families due to their children. This pattern was more pronounced among families with higher tenure. Perhaps efforts to help parents improve their confidence and ignore judgment or gossip from other parents would help families reduce stress and minimize burnout. This programming could also address the decline in parents judging themselves to be “good parents” as tenure increases.

Additionally, the data suggest that Firefly parents feel more isolated in the winter than during the fall or spring. This could be a result of isolation during holidays or increased stress felt mid-way through the school year. Either way, additional support for Firefly parents to connect with other Firefly parents could mitigate some of this isolation and build community.



Appendices

A. Methods





Parents of Firefly Autism clients (learners) were sent a survey at one of three times: in the spring of 2023 (March 1 through March 24), in the fall of 2023 (October 16 through October 27), or in the winter of 2024 (January 30 through February 16). Figure A1 shows the number of responses and the average response time for the survey.

Figure A1: Response Rate and Times for Surveys

	Fall 2023	Winter 2024	Spring 2023
Completed surveys	30	16	41
Average time spend on survey	52 minutes 28.1 seconds	8 minutes 31.4 seconds	25 minutes 35.0 seconds
Average time with outliers removed	12 minutes 18.3 seconds	8 minutes 31.4 seconds	10 minutes 21.4 seconds

To understand the impact of Firefly Autism on the families of their clients, this report utilizes two approaches: (1) examining the effect of client tenure with Firefly, based on their oldest currently enrolled student and, (2) looking at the effect of the time of the school year. The first approach hypothesizes an increased impact from each additional year of working with Firefly (a long-term effect) and the second approach hypothesizes that as the school year progresses, improvements will be seen (a short-term effect). However, each approach contains modifying variables or potential confounding effects. The first approach has the potential of capturing changes as children age, especially as they move into teenage years and approach transitioning either to additional education or the workforce and the independence or semi-independence thereof. The second approach can capture seasonal changes in family dynamics or stress, including winter holidays or the end of the school year. Therefore, considering both allows QREM to capture the effect of Firefly Autism and minimize the power of these modifying factors. ANOVA and T-tests of statistical significance were used to determine differences between groups.

Additionally, data are presented from comparison populations identified from publicly available datasets and the academic peer-reviewed literature. Datasets used include:

-  American Psychological Association
-  American Time Use Survey (Colorado data)
-  Gallup
-  Pew Research

Chi-squared tests were used to determine differences between Firefly data and publicly available data.

QREM utilizes the following programs for statistical analysis, data management, and checks on articles in the peer reviewed literature: Excel, R Statistical Software, Scite.AI, SurveyMonkey, and SPSS.



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