“The survey was undertaken to understand the experience of parents and families of children who have been diagnosed with a brain tumour.

Our sample was drawn from the parents of these children. The sample size is small because of the rareness of the condition.

We used an online survey approach and methodology, with a questionnaire design by Amárach in consultation with Brain Tumour Ireland.

The survey questions were designed to understand the aspects of service provision that need to be improved to ease the pressure and stress on parents and families at a pivotal time in their lives.”

- Michael McLoughlin, CEO Amárach Research
Almost two thirds (63%) were diagnosed before the age of five...

Diagnosis had significant impact on lives of...

Parents 78
Siblings 50
Other relations 34
Child's friends 16

66% were less than an hour away from a hospital...
97% drove

Two thirds were not given a plan for their child on discharge, of those that were, one quarter were involved in a family conference

The social work department made themselves known to three quarters of parents

There was a considerable variation in the services provided

Plan on Discharge

Survey Results 2022
Almost half 47% have no ongoing access to specialist rehabilitation services.

Almost two thirds 59% pay for private therapy sessions for their child.

POST TREATMENT CHALLENGES

SCHOOLING AND EDUCATION

Many acquired additional learning needs since diagnosis...

Parents are the key communicators...

Aware of school support programme?

Vast majority unaware of the School Support Programme offered by the NCSE

68% think school would benefit from additional training
**HAD A NEUROPSYCHOLOGY ASSESSMENT OR COGNITIVE TESTING**

Most have not had a neuropsychology assessment or cognitive testing.

- Yes: 47%
- Planned for future: 3%
- No: 41%
- Don't know: 9%

**FINANCES AND RELATIONSHIPS**

**Had to make changes?**

- Myself/ partner had to change work arrangements: 75%
- We had to cancel other planned expenditure: 41%
- We have to rely on other family members: 38%
- There was financial impact on what we could provide: 25%
- We incurred debts: 9%

**Financial impact**

- We were able to manage within our existing income and budgets: 13%
- We had to reorganise ourselves but we could manage: 22%
- It had a negative impact: 22%
- It had a hugely negative impact: 25%
- We had to borrow money: 6%
- Other: 13%

**Illness undoubtedly impacted relationships:**

For your child – 66% yes
Other family – 59% yes
For you – 69% yes

**Online support group for parents**: 63%
**One to one counselling support**: 56%
**Play therapy support for your child/ children**: 56%
**Online webinars/ Q&A sessions/ Podcasts**: 47%
**Support for siblings**: 41%
**Family information day**: 41%
**Online bereavement support for parents**: 13%

**Received Acquired Brain Injury support from National Council for Special Education?**

- Yes – 16%
- No – 68%
- Don’t know – 16%