

Family First is proud to be a registered charity in Jersey no. 383

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familyfirst.org.je



1st December 2021

Dear Deputy Inna Gardiner,

Thank you for your letter of 5th November welcoming any and all opinions in how we work with the Government of Jersey, particularly as we are a children-focussed charity and are interested in how the Government upholds its policy of *Putting Children First*.

Before we respond to the questions please allow me to share some background and work of Family First so that you have some perspective around our submission.

- In one 12-month period, more than 130 Jersey children needed treatment abroad.
- *All* babies born in Jersey before 32 weeks' gestation are automatically transferred to the UK for specialist care.
- Poor mental health in young people is on the increase – we are supporting more families whose children are receiving specialist residential care in the UK.

Needing urgent or sustained treatment abroad is a fact of island life and a stressful scenario for anyone needing treatment, but when children are involved, families can be faced with almost impossible decisions driven by financial, employment or simple logistics.

Family First provide practical and emotional support to families of children in Jersey with illnesses requiring off-Island treatment. We work with government, the hospital and many local charities and agencies to provide a coordinated support and funding mechanism for islanders going through incredibly stressful circumstances - allowing them to spend as much quality time together as possible and focus on what really matters. The recent pandemic has only served to increase the complexity, financial burden and stress faced by these families, and our support is in more demand than ever before.

Since our inception in 2018 we have supported 130 families visiting 13 different foreign medical facilities, often for treatments unavailable on the island, and many of whom need sustained or repeat assistance. We have coordinated over £309,000 of funds from charities and our efforts have resulted in real improvements in efficiency, transparency, and collaboration in the sector, for the benefit of families. Whilst the Board is made up entirely of volunteers, we employ one full time and one part-time professional

dedicated to these activities. Our website is renowned as a vital source of up-to-date information, used by a range of agencies and valued by other islands in the British Isles.

Covid has presented the charity and our families with additional challenges on top of the worry and uncertainty in caring for a sick child. Supporting every family to the best of our ability has become significantly harder as the workload has risen exponentially. Sourcing funding for each family has become even more difficult and time consuming; due to Covid, funds previously available to families have been drastically reduced or stopped altogether and so we must source funding elsewhere. The amount of funding needed for each family has also increased to cover for example, the longer stays in the UK as day-visits are no longer possible; different and sometimes more expensive hotels as the familiar ones are used by essential health workers; the additional transport costs as the airlinks to the UK have been limited and hotels are further away from the hospital, and we are seeing the loss of income rise dramatically, due to unemployment or redundancy of one or both of the care givers.

This year, we have supported fifty-six families, thirty-two of these families were new referrals to the service and twenty-four were previously known to us from 2020 due to their child having long term, complex medical needs. It is highly likely we will continue to support most of these families again in 2022.

1. Please explain how you work with the Government of Jersey to support your organisation

We work closely with the hospital and the health department as they are the main referral pathways for families in need that aren't able to access any health department support (because the child is not on the palliative care pathway for example). Family First is the only organisation experienced with, and offering, any off-island support. In addition we fulfil an administrative role and provide administrative support to clinical staff so that they can focus on their clinical duties.

2. Do you feel supported by the Government of Jersey?

Family First feels that the support is very one sided. We support the Government of Jersey; it is not a two-way street - there is not much support coming the other way. Family First is involved in quarterly cluster meetings which are run by the GoJ and they are very active meetings with up to date information on COVID and best practise guidance. However, we receive no specific support tailored to Family First. For example, we receive no funding to run the service and we are unable to request financial support from the Government for our families. We have some good contacts and communication within the Children's Development Centre, Social Security, the Health Department and the Travel Department but when any staff members change, we are not notified. The Children's Development Centre and the Special Care Baby Unit are the departments where we feel we have greatest support in communication on matters that affect our families.

3. What would improve both your relationship, and the level of support you receive?

To be invited and involved in meetings with families and to be able to access training within Government of Jersey when similar roles within Health benefit from. Working with Parents Level 4 could be rolled out to charities for example. The training that Children's Services and other professionals that work with families receive, would be of great benefit to us. If we could piggyback on the training - could the Government of Jersey allocate a 'bursary' space on each training course relevant to families or children, for example – that would improve our relationships and level of support we receive.

4. Have you noticed any changes to your relationship with the Government of Jersey since the introduction of Target Operating Models and/or the Jersey Performance Framework in 2018?

Family First was established in 2018. We have not noticed any changes to our relationship with GoJ and are not aware of either the Target Operating Models or the Jersey Performance Framework.

5. If you had any complaints or issues, how did you raise it, what was the outcome, and were you satisfied?

We have not been satisfied when trying to resolve a problem and it has escalated to the point of complaint. It is very hard to know who to speak to - we don't know who to contact within the relevant department. We must approach known contacts and get an introduction to the right person to speak to. This is particularly with regards to the travel department, social security, and social workers. It took one of our families to take the matter to the Minister for Health for anything to happen and for anything to change. This should not be the precedent. Family First as a charitable organisation filling a much-needed gap in support services and advocating for that family was ignored. Another issue we encountered was one of our families receiving a Petty Debts Court summons as they were not able to return to work (due to being in the UK) and repay their maternity pay. The Government of Jersey were not at all understanding with the family situation and we came to understand that "due process was being followed." There was no contact to speak with and so Family First intervened and instructed a lawyers to resolve the situation for our family. This was an extremely stressful time for our family already, but we were faced with not knowing who to contact within the government payroll department to advocate and explain our family situation - we believe it shouldn't have reached the point of a court summons.

6. How could that service be improved?

Who is accountable for Putting Children First? We are unclear as to any objectives of what the policy aspires to achieve, let alone any complaints procedure. In our opinion there needs to be a go to person (or team) who works closely with charities and other organisations working with children to ensure effective policy delivery.

There needs to be more visibility on who our main contacts are within the social sector not just the health department, not at a ministerial level and not just at a policy level.

7. Please can you provide an indication of your level of confidence in the department that supports you and tell us how that could be improved?

Family First work alongside many Government departments but the two of which we have most confidence in are the Children's Development Centre and the Special Care Baby Unit. We cannot fault them and have the greatest confidence in them, their partnership working, the information sharing and general level of openness and communication. Working alongside social workers has been incredibly difficult these past few years given the high turnover of staff and results in a high level of inconsistency of support for our families and for Family First. Supporting our families and putting children first needs to start with a consistency of care and support. This extends to consistency of training, communication and involvement of social sector organisations who work with children, to ensure the best possible outcomes.

Yours sincerely,



Rachel French
Director