OUR EXPERIENCE OF SUPPORTED ACCOMMODATION

How E.W. Tipping Foundation (EWTF) and

the office of the Disability Services Commissioner (ODSC)

failed Christopher Heenan

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Background

Christopher Heenan is a 23 year old profoundly disabled young man with a severe intellectual disability as well as multiple physical disabilities.

At the time of being offered a supported accommodation placement in early 2011, Christopher lived with his mother (the author of this document) and her then partner at Metung, Gippsland.

Following all the years of caring for Christopher, his mother (then aged 51) was mentally and physically drained - suffering from depression and anxiety as well as constant chronic pain from a back injury sustained in providing care to Christopher.

To add to the stress of caring, was his mother's knowledge that if something happened to her, Christopher would be in grave danger as he is not capable of informing others of his care needs or even what he likes and dislikes.

Christopher was born without a pituitary gland and if his dietary intake, medication and general health is not managed adequately, his blood glucose level can drop to life-threatening lows.

At the time of accepting the placement, Christopher had not suffered a seizure or suffered a severe hypoglycaemic episode for about 10 years, so his mother felt able to make the "gut wrenching" decision to accept the permanent supported accommodation placement while she was still able to pass on the information the disability support workers so they could learn how to keep Christopher safe (and happy).

No Previous Incidents

Christopher had previously attended many overnight/weekend/week respite places during the years he lived with his mother. *There was not a single reportable incident or episode of hypoglycaemia during these stays away from home*. This included multiple nights (up to 7) at DHS respite houses both in Bendigo and Sale, years of weekend Interchange respite, school camps and even EWTF's own staff (under the VISTA umbrella) who stayed a few days/nights at a time in Metung on multiple occasions while Christopher's mother and then partner had a well-earned break.

Expectations (No Limits)

Christopher and his family had no previous experience of supported accommodation.

As far as his mother Julie was concerned, she had previously provided information on how to manage Christopher's health and happiness to many organisations who had then proceeded to safely care for Christopher without issue.

According to the EWTF website, they manage over 30 shared houses for people with disabilities in Victoria. It was assumed by Christopher's family that EWTF were capable and had experience of providing adequate support for people with disabilities such as Christopher.

On multiple occasions, Christopher's family was told that whatever support Christopher needed (to be able to live safely and happily) would be provided by EWTF.

Christopher's mother was reassured by EWTF Management telling her that she would continue to have "lots" of input into Christopher's care and that would be welcomed by staff. It was indicated to her that she knew much more about how to manage Christopher's conditions than they did, that she had the knowledge and had kept Christopher safe for many years and they were looking forward to learning from her.

No limitations on either Christopher's support needs or his mother's input were ever specified by the EWTF management.

Hindsight 1: EWTF should not have set that expectation if it were not true. Apparently, the reality of the EWTF supported accommodation service is very different. If Christopher's mother had been made aware of the limitations, it is possible she may have decided to decline the placement.

No Support/Care Plan

To prepare for Christopher moving into his supported accommodation placement at Ligar Street in Bairnsdale, Christopher's mother, as well as providing other written information, created a DVD - "A Day in the Life of Christopher".

The DVD shows Christopher's mother describing some of Christopher's medical history and records her making Christopher's meals, feeding him, changing a nappy, getting Christopher in and out of his wheelchair as well as Gippsland Lakes Community Health support staff showering Christopher (and more).

The DVD specifically mentions that for Christopher "not eating is not an option".

EWTF management and Ligar Street Team Leader threw accolades at his mother for the production of the DVD - "This is fantastic. I wish all our families could do this".

Christopher's mother took the praise at face value. As she had provided far less information to other organisations that had safely cared for Christopher in the past, she was very confident that the support workers at Ligar Street would, as long they followed the information on the DVD, have no issues in caring for Christopher.

Hindsight 2: EWTF had a legal obligation to produce a Support Plan (aka Care Plan) within 60 days of Christopher moving into supported accommodation at Ligar Street. The information provided by Christopher's mother should have been used by EWTF staff to highlight any other inputs required to create an adequate support plan.

Staff Training

Christopher's mother assumed that disability support workers, before being allowed to work unsupervised with Christopher, would have completed at least the following training:

a) Certificate IV in Disability (experience in working with people with disabilities)

b) Safe Food Handling (cooking for Christopher - Gastro is very dangerous for him)

c) How to Strap the Wheelchair in the bus (dangerous in an accident if not done correctly)

d) Infection Control (any infection is dangerous for Christopher)

e) Medication Handling (multiple medications - including steroids)

Hindsight 3: Christopher's mother should have specifically asked the question about staff training. Apparently, the ONLY mandatory qualification for working in a supported accommodation house with six people requiring "high needs" support is Level II First Aid. She now believes this lack of training not only put Christopher at risk but also put disability support workers in an untenable situation.

Hindsight 4: EWTF stated in the DSC Conciliation Conference that in a "high needs" house, they train workers specific to the needs of the residents. If that were the case, disability support workers working with Christopher should have had specific training in autism, nutrition, adrenal insufficiency and hypoglycaemia as a minimum (in addition to the basic training listed above).

First Signs of Distress

Ligar Street was a brand new facility. Christopher was the first resident to move in. As could be expected, there were a lot of "teething" issues when Ligar Street first opened. EWTF opened two houses at the same time.

The Ligar Street Team Leader - with no experience of managing a supported accommodation facility - was overwhelmed. She informed Christopher's mother and family on more than one occasion that she was not getting any backup from "head office". She resigned a few weeks later.

As can be imagined, when Christopher moved into Ligar Street, it was a distressing and highly emotional time for Christopher and his family.

Christopher settled in initially quite well. Two of the disability support workers who applied for and got positions at Ligar Street, were people who had worked with Christopher under the "VISTA" umbrella. This gave Christopher some familiar faces and people who knew how to care for him.

As the first resident in the house, Christopher had adequate support for meals and his other needs.

On the other hand, Christopher's mother had to let go of responsibility for Christopher's health and happiness. Christopher, being both non-verbal and intellectually disabled, is 100% dependent on the skill (and attitude) of the disability support workers.

Christopher's mother at that time acknowledged (and has many times since) that Christopher was not going to get the same support she was able to provide at home. She did however, expect Christopher's basic needs of health and safety would be met.

Hindsight 5: EWTF stated in January 2013 (22 months later) that EWTF were not receiving enough funding from DHS to provide staff support for Christopher's breakfast. This is interesting as he was the first resident to move into Ligar Street, so the funding was obviously seen as adequate at that time.

Working Away

Forced by financial reasons, Christopher's mother began living and working in Melbourne in June 2011, three months after Christopher moved into Ligar Street. She came home every other weekend and saw Christopher only for very short periods.

Christopher was now showing increasing signs of distress. Dark bruises were regularly present on both wrists where he had bitten himself. Other unexplained bruises were on his body. Christopher's personality became more "cranky" and he became easily distressed.

Other residents had moved into Ligar Street and staff had inadequate time to care for Christopher. Christopher's mother raised this issue with EWTF in an email on 31st July 2011 following a situation where her then partner (Chris) had visited Christopher.

Prior to this incident, Christopher's mother had specified that a Ligar Street staff member must be present when a particular resident was in Christopher's room. (This was because Christopher had started to mimic some self-harming behaviour when distressed).

During Chris's visit, this resident was in the room with Christopher and Chris for over 40 minutes. The Ligar Street staff working that day were so busy, they had not even looked for her. This was also the day Ligar Street staff asked Chris to assist with "disconnecting a tube" with one of the paraplegic residents (which he did).

In the email, Christopher's mother stated "this is obviously not an issue with the particular staff involved ... and potentially puts Christopher in a very vulnerable situation".

EWTF management replied that more staff would be rostered on and that she had requested that the issues raised in the email to be recorded on the EWTF feedback/complaints database.

Hindsight 6: EWTF should have reviewed the staffing vs support needs at Ligar Street once all residents had moved in and identified any potential issues with support needs not being met. This should have been done in conjunction with the support plans.

First Complaints

After keeping quiet about the majority of "little" things that were occurring at Ligar Street (for the sole reason of being frightened that there would be repercussions if complaints were made), Christopher's family got more and more frustrated that issues were not being dealt with.

For example, on many, many occasions, Christopher's mother and/or her partner would arrive at Ligar Street to find that Christopher was dressed in a t-shirt and was freezing cold to the touch at the same time that staff and residents all had jumpers on (or vice versa). It is part of Christopher's condition that he cannot control his body temperature.

Another more disturbing one, was to see staff preparing Christopher's lunch without washing their hands first - and not using gloves.

After raising these issues and some others such as those listed here with EWTF management, Christopher's mother - who was still living in Melbourne - became more and more concerned.

When she had to return from Melbourne after Christopher became ill and staff were unable to get him to eat, Christopher's mother found staff were not following the information on the DVD. For someone with severe autistic tendencies like Christopher, this would have been incredibly distressing - and difficulties with eating are a sure sign of distress.

Eventually in October 2011, Christopher's mother wrote a formal complaint to the then CEO of EWTF asking for his help. The letter, which can be seen here, specifically stated that EWTF were being asked to fix this rather than going through the process with the Disability Services Commissioner as a long relationship between Christopher and his mother and EWTF was anticipated.

Hindsight 7: 99% of the issues being raised were to do with lack of staff training and no support plan. The blame for this is not with the disability support workers. EWTF did not identify nor provide sufficient training to staff to enable them to adequately support and care for Christopher and keep him healthy and happy.

Initial Complaint Response

A meeting was held in Melbourne with the new EWTF Regional Services Manager Gippsland and then EWTF Complaints officer. Further meetings were held over a period of time with them and/or new Ligar Street Team Leader and new EWTF Service Co-ordinator Gippsland.

In November 2011, EWTF Regional Services Manager sent an email which identified the need for EWTF to (quote) "go back to the drawing board in relation to Christopher's care plan at Ligar Street".

Minutes from the first of the following meetings held in December 2011, show that EWTF Regional Services Manager said that "there are many issues within the service with a new house, new staff ... this has meant that some needs have not been met". He went on to say "EWTF would like to make a fresh start".

It was also mentioned in these meetings with Ligar Street Team Leader and EWTF Service Co-ordinator that staff had been made aware that Christopher's mother is (quote) "very approachable and that her interest is in ensuring that Christopher receives the best possible service".

At no time was evidence or otherwise given that Christopher's mother was "disruptive" or "dishonest". She herself acknowledges that her communication style is direct but this was described as being a positive at different times by EWTF management.

Hindsight 8: EWTF admitted they hadn't done the right thing and this is the second opportunity where they should have ensured a support/care plan was developed so that staff could be given specific training in how to support Christopher. Without this, both Christopher and staff continued to be at risk.

Disability Services Commissioner Complaint

The problems with Christopher's support continued even as the meetings with Ligar Street Team Leader and EWTF Service Co-ordinator continued through to June 2012.

Still working in Melbourne and only able to visit Christopher every other weekend, Christopher's mother went to the Office of the Disability Services Commissioner to ask for information. In particular, it was regarding the information that EWTF were required to provide to her about Christopher's service provision (as she had been legally appointed accommodation guardian by VCAT).

She also asked other questions for example, wasn't it mandatory for supported accommodation support workers to have (or be studying for) Certificate IV in Disability, about P-platers driving the Ligar Street bus and also staff were allowed to strap wheelchairs in the bus with no relevant training.

The staff member at the ODSC asked many questions and suggested very strongly to Christopher's mother that a formal complaint should be lodged as it sounded like the service Christopher was receiving was inadequate.

In June 2012, Christopher's mother lodged a formal complaint with the ODSC.

Hindsight 9: In June 2012, the very first question the ODSC should have asked EWTF when they began investigating this complaint - what does the support/care plan say and is it being followed? The lack of a support/care plan would then have been apparent.

Risk of Hypoglycaemia Increases

In August 2012, Christopher was unwell and taken to the GP by Christopher's mother and Christopher's Ligar Street key worker. Christopher's steroid medication was tripled and his mother discussed with the overnight support worker that first thing in the morning is the highest risk of hypoglycaemia and she should look out for Christopher being lethargic or being cranky or being pale or .. in fact .. anything unusual.

The next morning, Christopher's mother got a call from the worker to say Christopher had not eaten breakfast and had "chosen" to go back to bed. As Christopher has never "chosen" to go back to bed, Christopher's mother raced in to Ligar Street and found him seriously ill.

Christopher's mother asked for the glucometer so she could take a blood glucose level - only to be told "the strips were out of date so someone's going to the pharmacy when they're open to buy some".

She then asked for Christopher's temperature to be taken as he felt very hot. The worker took his temperature and reported it was 35.1°C (very low). Christopher's mother asked for the thermometer, retook Christopher's temperature and got a reading of 38.9°C (very high).

An ambulance was called and Christopher was hospitalised for four days. On discharge, in the presence of Christopher's Ligar Street key worker, his GP ordered a daily blood glucose reading to be taken first thing in the morning before breakfast. Staff were to be trained by the Diabetic Educator how to do this before Christopher returned to Ligar Street.

Hindsight 10: EWTF should have discussed the situation with Christopher's GP and training should have been given to disability support workers on the severe risk of Hypoglycaemia caused by Adrenal Insufficiency (not Diabetes). They should also have been trained in how to take a temperature correctly with an ear thermometer.

ODSC Complaint Process on Hold

The details of Christopher's hospitalisation were given to the Office of the Disability Services Commissioner. 90 days is provided for the ODSC to investigate when a complaint is received. Christopher's mother received a letter from the Office of the Disability Services saying that a conference would be held because there were "issues that require attention and remain unresolved".

In September 2012, Christopher's mother was diagnosed with cancer and required treatment. The complaint process was put on hold.

Hindsight 11: Both EWTF and ODSC were fully aware of the content of the complaints - and as described above, EWTF had previously agreed that a support/care plan was needed. ODSC could have overseen the creation of the "action plan" during this time instead of it being delayed for months. This is the third opportunity where EWTF should have identified the lack of a support plan and taken action - but they did nothing.

ODSC Assessment Conference

In November 2012, an "Assessment Conference" was held in Bairnsdale with EWTF, Office of the Disability Services Commissioner staff and Christopher's mother.

EWTF's Executive Officer - Services attended the conference in person and stated that EWTF had not put in place the correct processes when Christopher first went into Ligar Street.

Christopher's mother at the end of the conference indicated to ODSC she was concerned that all the "big picture" items like ensuring minimum induction training and complaint handling training for staff at EWTF was to happen quickly, but the plan to be produced did not address the day-to-day support provided to Christopher. She was assured that the assumption was that would occur alongside the official process.

EWTF's Executive Officer - Services apologised to Christopher's mother for what she and Christopher "had been through".

Following the conference, answering a specific question from Christopher's mother, the Office of the Disability Services Commissioner staff stated EWTF "have certainly not communicated any sense that your expectations are unreasonable".

EWTF management at no time during the conference raised any issues, evidence and/or concerns about Christopher's mother being "disruptive" or difficult to deal with.

Outcome of the conference was that EWTF would create an Action Plan.

Hindsight 12: The first discussion at the Assessment Conference in November 2012 should have been about the lack of a support/care plan and the legal requirement for one. EWTF staff demanded a Comprehensive Health Assessment Plan and other assessments to be done but neither ODSC or EWTF explained they would be used as inputs to a mandatory support/care plan. If had been explained adequately, Christopher's mother would have insisted on other inputs and that a support plan should be created immediately.

"Breakdown" in Communication

On 3rd January, Christopher's mother was forced to complain again.

On a visit to her, Christopher had once again been put at risk (wheelchair not strapped in bus properly, medicalert bracelet not on etc.) and shown no dignity (dressed like a hobo in inside clothes).

In the email response, EWTF management sent an email which included saying that EWTF had "staffing shortages over the Christmas period which meant that some of the key staff that work with Christopher had not been in the house. These are unavoidable".

Hindsight 13: Christopher's mother should not be told in the middle of an active complaint with the ODSC that EWTF could not support Christopher adequately over the Christmas period and that "it was unavoidable". As an organisation, EWTF should be able to manage their staff rosters to ensure their residential houses are adequately staffed.

Low Blood Glucose Readings

In mid-January 2013, Christopher's mother expressed extreme concern to both EWTF management and the ODSC about Christopher's low blood glucose readings and her belief that Christopher was not being fed adequately and was at risk.

Christopher's mother also told the ODSC that she had contacted DHS and told them that "I have to get Christopher out of there.".

Low blood glucose can result in seizure, coma and/or sudden death.

Christopher's mother was extremely distressed and concerned when Christopher continued to be put at severe risk.

She literally screamed (on the phone) at EWTF Services Manager to get the staff to feed Christopher adequately. EWTF Services Manager met Christopher's mother at Ligar Street and with information Christopher's mother provided, EWTF Services Manager promised to immediately create a "food plan", implement it and ensure the Ligar Street staff understood and followed it.

During this meeting was the first time that Christopher's mother heard from EWTF management "well, we can't force feed him".

Christopher's mother proceeded to show how easily distraction could be used as a strategy to feed Christopher after he initially refused - and it certainly was not "force-feeding" - right in front of EWTF Services Manager.

EWTF management at that same meeting also told Christopher's mother that his funding from DHS was inadequate and so Ligar Street was unable to support Christopher eating his breakfast.

To rule out any other causes of the low blood glucose (e.g. illness), Christopher's mother brought Christopher home for two days. His blood glucose levels returned to normal when he was fed adequately.

Hindsight 14: Christopher's mother should have taken unpaid leave from her job and kept Christopher home until the food plan was done. EWTF Services Manager did not do the food plan as promised. The excuse given was that a "bush fire plan for Maffra" was done in place of Christopher's food plan. Both could have resulted in injury or death - but only the bush fire plan was given priority.

EWTF Services Manager should have allocated one of the plans to someone else so they both got done and ALL residents were protected.

Ambulance Called - Life Threatening Blood Glucose Readings

On 28th January, just two weeks after the food plan should have been done, Christopher's mother received a phone call from Ligar Street saying that Christopher "did not eat his dinner last night" and that his blood glucose reading was 2.6. The support worker asked what to do.

Christopher's mother instructed the worker to follow the written protocol (call an ambulance if the reading was less than 3.0). She also asked staff to try and get Christopher to drink some 100% fruit juice while waiting for the ambulance (assuming he was still conscious). The staff did this successfully and so the paramedics chose not to take Christopher to hospital.

Obviously distressed, Christopher's mother drove to Ligar Street and found Christopher very pale and very shaky with Ligar Street staff attempting to feed Christopher toast which was not made to the instructions (very thick vegemite which Christopher hates).

Christopher's mother watched as Christopher showed the first sign of minor resistance (noise) and the worker immediately asked Christopher's mother what to do as she "didn't want to get her finger bitten".

Christopher's mother asked the worker what the protocol was if Christopher "chose" not to take his medication. The worker detailed a comprehensive protocol that was in place for that event. It appears there was no strategy or protocol in place if Christopher didn't eat - even though Christopher's mother had raised that specific issue with EWTF Services Manager in December 2012.

Christopher's mother arranged for staff to send Christopher home in a taxi (as the Ligar Street bus was once again unavailable for Christopher's use). Even this ended up putting Christopher at risk - he was not wearing his medicalert bracelet when he arrived home.

Believing that Christopher was (and would continue to be) at severe risk in Ligar Street, and not feeling she had any alternative, Christopher's mother began the process with DHS to get Christopher assessed for an aged care placement.

Hindsight 15: Christopher's mother found out weeks later from the memory in the glucometer, that 30 minutes earlier on that morning Christopher's actual blood glucose reading was 1.4. Two minutes later it was taken and it was 1.9. The incident report raised by EWTF and sent to DHS only indicates 1.9 - it does not record the lower reading. It was negligent (and very disappointing) for EWTF staff to not inform Christopher's mother of the lowest reading when she was contacted on that day.

ODSC Requires Transparency

Christopher's mother, from the time that Christopher's blood glucose had been getting lower and lower had written some distressed, despairing, angry and confronting emails about EWTF to the Office of the Disability Services Commissioner.

On 4th February, Christopher's mother had a call with the resolutions officer from the ODSC who suggested that EWTF did not understand the seriousness of the situation and that more transparency from Christopher's mother was required.

Christopher's mother forwarded a series of emails to EWTF Executive Officer - Services and then acting Regional Services Manager. Those emails which are distressing, angry and talk about despair can be seen here.

The following day, Christopher's mother was telephoned by EWTF Services Manager who demanded to know if Christopher had been withdrawn from service.

She did not, at any time during the phone call, ask how Christopher was.

Christopher's mother informed the EWTF Services Manager that as no formal notice of withdrawal had been sent, Christopher had not been withdrawn.

Following the "transparency" emails, this phone call, and one further email sent by them, EWTF management then directed all communication must go through DHS.

Hindsight 16: Christopher's mother should have ignored the ODSC request to be more transparent. It was asked at a time that she was understandably frustrated, angry and distressed after her son had been put in danger - after 15 months of warning EWTF that this would happen. Christopher's mother should also have recognised that EWTF management were now going to be as obstructive as possible.

Getting the Incident Reports

Christopher's mother, originally asked on 3rd February 2013 for the incident reports for both the August 2012 and January 2013 episodes from EWTF.

On 11th February, EWTF management told Christopher's mother to get them from DHS.

Christopher's mother went back to EWTF and stated that Christopher has a right to see incident reports - and that she had several that had been emailed to her by staff - and requested them again.

EWTF management again refused - and stated that she was no longer Regional Services Manager (acting) and that a new EWTF Regional Services Manager had started on 29th January. This was the 3rd EWTF Gippsland RSM in 15 months.

DHS were contacted and Christopher's mother was told she would have to use FOI to get the reports, but to try ODSC as they now had copies.

Christopher's mother then asked Office of Disability Services Commissioner, who said they were same as DHS and so FOI would need to be used.

After persistent questioning and multiple emails, ODSC determined Christopher did have a right to see the incident reports and that EWTF should provide them.

Christopher's mother was then asked by EWTF Services Manager to use an FOI request the incident reports from EWTF.

Astonished that the organisation could make such a fundamental error by not understanding their own legal situation, Christopher's mother answered that as EWTF is not a government organisation, FOI does not apply - but that the Health Records Act does!

Christopher's mother sent a request for all incident reports while Christopher was at Ligar Street (March 2011 - January 2013).

She eventually received ten "redacted" incident reports - but has evidence of at least another six, so EWTF did not fulfil their legal obligations with this.

The incident report for 28th January confirmed that disappointingly, Ligar Street staff had also lied about the blood glucose level on the formal incident report sent to DHS.

Hindsight 17: ODSC and EWTF staff should have some training in the legal requirements of the Health Services Act as it applies to information collected in the provision of services by Disability Service Providers. Ligar Street staff should be reminded that being dishonest on an incident report is not acceptable.

Villamanta Disability Legal Service

In mid-February, Christopher's mother sent a formal notice to EWTF management that Christopher was going to withdraw from Ligar Street.

A couple of days later, Christopher's mother contacted Villamanta to discuss access to incident reports and what the legal situation was. During that conversation, she informed Villamanta that Christopher had been approved for a nursing home placement.

The immediate response was that EWTF's failings should not consign a 23 year old to a lifetime in a nursing home.

Realising that Villamanta was right, Christopher's mother withdrew the notice from EWTF but obviously said that Christopher would not be returning until EWTF could provide a plan on how Ligar Street staff would support Christopher on a day-to-day basis and keep him safe.

The second response from Villamanta was - "where is the support plan?". Christopher's mother did not know if there was a support plan - let alone have a copy of one.

Hindsight 18: Christopher's mother should have asked for the support plan earlier. EWTF confirmed later once again, that no support plan exists. Villamanta confirmed this is a breach of the Disability Act.

Christopher Refused Access to Ligar Street

On March 1st, Christopher's advocate contacted EWTF management to suggest that Christopher return to Ligar Street - and that Christopher's mother would go to Ligar Street each night and feed him his evening meal.

This would do three things - (a) reassure Christopher's mother that his blood glucose level would be ok in the morning, and (b) would show staff how to feed Christopher - including strategies to use if Christopher showed any resistance. Lastly, (c) it would allow Christopher's mother to return to work.

EWTF immediately refused access to Christopher. He was banned from Ligar Street.

EWTF also had put out an edict to Ligar Street staff that they were not allowed any contact with Christopher's mother.

At a professionals meeting in March 2013 was the first known time where EWTF Services Manager attempted to portray Christopher's mother in a bad light and specifically lied. The term "disruptive" was used to describe Christopher's mother - even though this had never been mentioned at any time in the previous two years - either in person or in emails or minutes or at the ODSC conference.

Hindsight 19: Christopher's mother should have recognised that this was now a lost cause. Lies were being told about her by EWTF management and she was being demonised. EWTF management were obviously responding to the contempt being shown for them after their incompetence put Christopher at risk. They should not have confused that with the sympathy Christopher's mother felt for Ligar Street staff who had been placed in such a terrible situation by their own management.

ODSC should have stepped in because EWTF management were certainly not acting at this point as if it was OK to complain.

Media Involvement

Christopher's mother in abject despair and complete frustration went to the media.

DHS imposed a moratorium until a media program was aired.

On Easter Monday, a segment with Heather Ewart was shown on the ABC 7.30 program. It can be seen here on the ABC website.

Hindsight 20: Christopher's mother got a compassionate response from everyone .. except EWTF management .. who still have made no enquiries about Christopher's health and well-being. The general public who contacted Christopher's mother are astonished that media involvement made matters worse not better.

ODSC Conciliation Conference

On 6th May 2013, a conciliation conference was held in Bairnsdale as the Office of Disability Services Commissioner made a decision to refer on the basis that "there are issues of substance that remain unresolved".

Two members of staff from the ODSC, Christopher's DHS case manager and another senior manager from DHS, Christopher, Christopher's mother, her then partner, a representative from Villamanta acting as Christopher's advocate and two EWTF management representatives new Regional Services Manager and EWTF Services Manager attended in person while on the speaker phone, EWTF Executive Officer - Services also attended.

At one point in the conference, EWTF Regional Services Manager - who began at EWTF after the ambulance was called for Christopher in January 2013 - labelled Christopher's mother's emails as "argumentative".

Perhaps if the EWTF Regional Services Manager was in the situation where one of his loved ones had been put at severe risk of seizure/coma/sudden death after 15 months of warning that would be the result (and two weeks after being promised a solution to prevent it), his communications would also have become argumentative.

Once again, EWTF management agreed that they had failed to create a support plan for Christopher during the whole 22 months he had been in their service.

The outcome of the conference was that EWTF were to produce a plan on how Christopher was to return to Ligar Street.

The following day, Christopher's mother emailed ODSC, DHS and her team and thanked them for their support. She felt very safe and believed that she had been given an opportunity to be heard.

She also made the comment that she found it "offensive" that neither of the EWTF management representatives came around the table to say "hello" to Christopher.

For over three hours they sat across the table from Christopher and did not acknowledge him in any way.

Everyone else present including people from DHS and ODSC who had not previously met Christopher went out of their way to say hello and exchange "hi-fives".

Hindsight 21: It became obvious that EWTF management see Christopher's mother as the enemy. If Christopher's mother could put aside the terrible experience of her son being put at risk, then surely EWTF management should have been able to act professionally and not ignore their client.

Christopher's Mother Finally Gives Up

On 14th June, Christopher's mother informed EWTF, ODSC and DHS that Christopher would not be returning to Ligar Street.

The reason seems inconsequential compared to all the serious (including life-threatening) issues that have been raised over the period EWTF were failing to provide an adequate support "service".

The straw that broke the camel's back was that EWTF management did not acknowledge Christopher when he sat opposite them for over three hours.

If they themselves do not see Christopher as a person, then not only is that offensive but it says a great deal about the management and culture of EWTF.

Hindsight 22: EWTF management in Gippsland completely ignored a person who is non-verbal and has an intellectual disability and was sitting directly opposite them for hours.

With EWTF management telling lies and demonising Christopher's mother, what attitude and culture would flow down to direct support staff?

This made it impossible for Christopher's mother to have any confidence that EWTF management have any compassion for - or have Christopher's best interests at heart.

Very sad - and a terrible indictment of the organisation. As Christopher's mother stated (in a probably argumentative email) "Bill Tipping would be turning in his grave.".

Not Quite the End of the Trauma

EWTF Services Manager subsequently banned Christopher's mother from going to Ligar Street to collect Christopher's belongings because "she might be disruptive".

Christopher's mother (and DHS and Villamanta) found this incredibly petty. It just added to an already distressing situation.

Christopher's mother has placed the blame for Christopher's situation on EWTF's management - and not on the individual disability support staff working at Ligar Street.

As is common, some staff are more caring, capable and compassionate than others, but on the whole, Christopher's mother believes very strongly that EWTF management not only failed Christopher, but it failed the Ligar Street staff too.

EWTF paid for removals (Note for ODSC - was that from the "housekeeping" account which contains funds provided by the Disability Support Pensions of all the Ligar Street residents - or was it from head office accounts?) and completely mismanaged the delivery to Christopher's house.

It was to be the final turn of the screw.

Hindsight 23: EWTF management seem to blame Christopher's mother for their failings. While they do that, they can kid themselves they do not need to be accountable.

NOTE: Using the same criteria for labelling Christopher's mother as "disruptive" in the professionals meeting, the EWTF Services Manager should be banning some of the Ligar Street staff from the house.

The incident reports show they have been much more "disruptive" at the house than Christopher's mother (which shows just how ridiculous the claims made by the EWTF Services Manager are).

Current Situation

Christopher is living permanently with his mother and is very happy.

Christopher eats all his meals easily and his blood glucose is stable.

Two new workers are showering him (without incident) three times a week.

A new worker is doing five hours 1-on-1 with Christopher (without incident) each week.

In May 2013, Christopher's mother had no alternative but to resign from her IT job (after months of unpaid leave) and is now trying to work out a way to care for Christopher AND pay her mortgage (which at more than $1,419 per month was not an issue on her salary, but is much more difficult on no income).

The next big task is to work out with DHS and possibly some charities how to fund a wheelchair accessible vehicle.

(*Perhaps EWTF could tip in some of the money they were paid between January 28th and June 14th to look after Christopher when he was not present at Ligar Street and was being cared for by his mother! No? Oh silly - probably argumentative - question.*)

Christopher's mother is working with DHS, Scope, CDDH and other professionals to create a comprehensive support/care plan for Christopher.

An emergency care plan is now in place for Christopher. If something happens to his mother, he will go to Melbourne and his care will be initially managed by his older brothers.

CONCLUSION:

EWTF management completely and utterly failed Christopher and his family.

EWTF breached the Disability Act.

In all the years of caring for Christopher and dealing with Disability Service Providers, Christopher's mother has never experienced the level of incompetence, lack of professionalism and lack of accountability shown by the current EWTF management.

The current EWTF management in Gippsland showed an astounding lack of compassion to Christopher and his family, along with a high degree of arrogance and a complete lack of awareness and understanding of people with disabilities.

This is extraordinary in the face of EWTF's admission (again) that they did not create a support plan during the 22 months of Christopher being a resident and in their care.

The ODSC process failed too. Five separate issues were raised in the original complaint to ODSC. They have not been addressed individually and EWTF were not made to be accountable to Christopher and his family.

This traumatic episode could have been prevented had a proper support/care plan created by EWTF when Christopher first became a resident OR on ANY of the multiple occasions complaints were highlighted to the following members of EWTF management:

Services Co-ordinator 1, CEO 1, Executive Officer - Services, Regional Services Manager Gippsland 1, Services Co-ordinator 2, Regional Services Manager Gippsland 2 (acting), Services Manager, Regional Services Manager Gippsland 3, CEO 2.

It was not Christopher's mother who caused the problem - she was forced to become Christopher's voice and highlight the issues again and again for over 15 months - because EWTF management failed to fix them.

Is it any wonder her emails to EWTF management became "argumentative" and then vitriolic?

EWTF management have succeeded in making life a lot more difficult for Christopher's mother who, at age 53 and recovering from cancer, once again faces a lifetime of caring, chronic pain and poverty. So much for improving the lives of people with disabilities and their families.

EWTF management should be ashamed of themselves.