

**Family Leadership**  
***A Family's Reflections on***  
***Working in Partnership with a***  
***Service Provider***

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# The Vision

- **Marian's Vision for herself:**
  - ❖ *To be happy*
  - ❖ *To be healthy*
  - ❖ *To go to College*
  - ❖ *To have a job*
  - ❖ *To live at home and be in her local community*

# The Vision

- **Our Family's Vision for Marian:**
  - ❖ *That she is healthy and happy*
  - ❖ *That she is supported to achieve her dreams and her vision for herself*
  - ❖ *That she gets the same opportunities as her siblings and her peers*
  - ❖ *That she is treated with respect and dignity*
  - ❖ *That she is safe*

# Historical/Background Information

- Marian was born in 1988 with Down's Syndrome. She is the oldest of a family of four children.
- From the outset her parents decided that they would work to ensure that she got the best of health care, education and support in her growth and development.
- Brothers of Charity Services Galway were involved with the Family through the different stages – Early Childhood, School Age and now Adulthood.

# Maintaining The Vision

- **Parents take on the role of Advocate.**
- **Negotiate with the various agencies – Health, Education, Service Provider.**
- **In Early Childhood the primary concerns were with health and education.**
- **In Adolescence the major challenge was to progress from mainstream primary education to second level.**

# *Maintaining the Vision*

- Marian attended mainstream education up to the age of 21 (May 2009) achieving a Junior Certificate in 6 subjects and Leaving Certificate in 2 subjects.
- During 2009 it was necessary to plan for the next phase.
- Researched the various options available for post-secondary education for Marian
- Examined the options – it soon became apparent that options were limited and not in keeping with the vision that Marian has for herself or indeed the vision that her family has for her.

# Planning for the Individual

- In researching the options I established the funding mechanisms that exist for school leavers with intellectual disabilities (*School Leavers Funding and Funding for RT programmes*).
- The next step - meet with Adult Services of Brothers of Charity, Galway to plan for Marian's needs.

# *Planning*

- Marian wished to pursue a PLC course at the school that she attended for 6 years.
- School could not facilitate this without funding as Marian was no longer entitled to educational resources from the secondary school system.
- The Plan – to source funding that would normally be allocated to school leavers from the HSE and to ring-fence that funding to support Marian to attend the PLC programme.

# The Plan

- Brothers of Charity Services to apply HSE for funding;
- Parents (*supported by School Age Psychologist Brothers of Charity*) to liaise with School and the V.E.C. to agree the necessary resources needed.
- Resources once secured to be ring-fenced for an Individualized Plan for Marian.

# Implementing The Plan

- Funding was agreed and allocated by HSE West to Brothers of Charity;
- VEC and School agreed with the plan;
- A Classroom Assistant recruited (*by the school*);
- Family meeting with Teaching Staff to agree subjects being studied; learning support material required and an overall learning outcome for Marian agreed.

# Implementing The Plan

- From October 2009 to May 2010 Marian undertook modules of the Post-Leaving Certificate course in Office Information Systems achieving Equal Skills Certification (*Fetac Level 3*).
- Resource classes were provided in Communication and English.
- She undertook work experience in local Café/Bakery.

# Next Steps.....

- In May 2010 it was necessary to Plan again
- I secured a place for Marian in a local Adult Education programme with Co. Galway V.E.C.(*3 hours one morning per week*)
- A place on a Computer Skills Improvers Class was granted to Marian for 6 weeks (*Family Support Agency*)
- I sourced work experience in a local supermarket – *3 mornings per week.*
- Marian attended GMIT one evening per week for 7 Weeks – Home Baking Class
- We hired a Personal Assistant for Marian to support her in work experience and other activities.
- The School Leavers/RT funding is being used to pay for the supports that Marian needs.

# These days.....

- **Adult Education – Communications & Computer Graphics (3 hours per week)**
- **Work Experience 3x3 hours sessions per week**
- **Attending an Evening class in Home Cooking in GMIT Adult Education Class**
- **Bowling & Swimming weekly**
- **Planning and looking forward to going to College**

# The Process of Family Leadership

- For us as a family, it means:
  - ❖ *Listening to Marian;*
  - ❖ *Acting on her behalf to follow her Vision;*
  - ❖ *Advocating, Researching, Negotiating*
  - ❖ *Individualized Planning and Individualized Funding;*
  - ❖ *Thinking ahead for the next stage;*
  - ❖ *Ensuring that the system delivers for Marian.*

# **Our Experience in Family Leadership**

- **The current arrangements around Marian with regard to funding are flexible;**
- **This gives us the option to modify the plan, to introduce different elements to it if necessary;**
- **Marian and her family have more of an input into what the service provider needs to deliver for her;**
- **If Marian's needs change, the flexibility that exists allows us to incorporate other things.**

# Our Family's Experience of Family Leadership to date.....

- Family Leadership is a great privilege that carries great responsibility;
- Not without its difficulties;
- As her Advocate - at the front line the whole time;
- There has been a lack of support for the family who lead the way for the '*vision*' or the '*plan*' to become a reality;
- There was a lack of compatibility between the 'Vision' for Marian and the structures of the service provider;
- Family requires strength of character and determination.

# Our Family's Experience of Family Leadership to date.....

- Taking on the role of Family Leadership can be personally challenging, and sometimes very stressful.
- What keeps us focused is the desire to ensure that Marian has a good life.
- It is a whole family effort – and it can impact on family life.
- The structures of systems and services requires families to be able to '*tip toe*' or sometimes '*wade*' through the various processes and procedures.
- The Family has to challenge, to question and to look for systems to change so that the individual's needs are met.

# Family's Reflections - Working In Partnership?

- At the outset ..... Negotiations
- We are on a journey.... like many journeys there have been twists and turns;
- Partnership is developing;
- While the main focus has been on Marian the Family also needs to be considered and supported.
- *“If you treat people as what they ought to be, you help them become what they are capable of being”* (Goethe)

# Developing Responsive Services

*Sean Conneally*

- **Active Listening**
- **Responding to Family and Individual's Vision**
- **Developing different Service Options**
- **Developing different Service Structures**
- **Making it work for different Families**
- **Supporting the Leaders**
- **Interesting Future**