

*In Conversation Series, Irish  
Families Leading Change,  
Positive Pathways Ireland.*

# The Enduring Bonds of Families



**The Power and Strength of Families.**

# OVERVIEW

To begin this conversation we need to first examine what it is we actually mean when we use the word “FAMILY”.

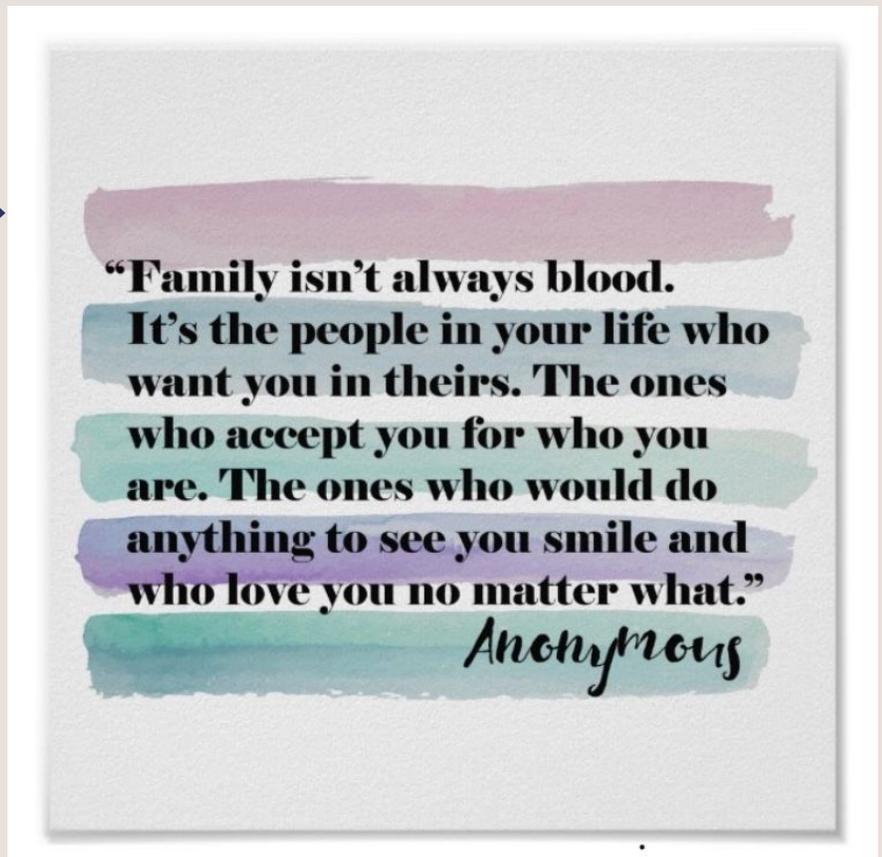
A medical definition of the term family begins with the identification of  
*“ a group of people related by blood or marriage or strong common bond, such as those descended from a common ancestor, or a husband, wife and their children”.*

However, the definition does go on to also express the term family in a range of realities within today’s society, including blended, nuclear, extended, single parent, and dysfunctional family.

For the purpose of this conversation, I am going to use this definition.....



In using this definition, we still need to acknowledge that each family is unique, with their own lived experience, set of values, and code of conduct in how they behave towards each other. In doing so the starting point with any conversation with a family must then be.....



“.....”TO EARN A SEAT AT THEIR FAMILY TABLE”.

## What makes us Families

1. It can be a biological connection or simply a connection of choice.
2. It is based on positive feelings and love. This means that our relationship is freely given, it is unpaid.
3. We show up for each other in good times, bad times, and times of crisis.
4. We show up because our only vested interest is in each other. We care deeply about what happens to each other.
5. We know and understand each other at a deep level, as we have invested time in our relationship.
6. Our relationship is based on a lived experience and trust.
7. We celebrate our gifts and talents and support each other's vulnerabilities.
8. We are part of each other's lives in a meaningful way.

## What does other good support look like?

Good family support works when it is appropriate to the needs of families. Support that is helpful, positive, and affirming. It can be a service, a professional, an advocate, or someone with specific expertise.

1. It is paid for, hence the engagement is formal.
2. It takes place because of a need.
3. It should help the person and their family.
4. The relationship has a beginning and an end.
5. The relationship is based on mutual trust, respect, and earning a seat at our family table.
6. There is an understanding of what is the purpose of the relationship.



# The Power of Families – Helpful reading

In the context of this family article, I will draw upon four helpful sources of information created for and often used by families;

1. Chapter 4, Supporting Families, Pathfinders John O'Brien and Beth Mount.
2. Michael Kendrick, The Natural Authority of Families.
3. Social Role Valorisation, Wounding
4. Homes West, Choreography of the Dance of Life.

## The Natural Authority of Families

Michael Kendrick

With great regularity, consumers of services and their families will find themselves having to confront professionals, bureaucrats and others in roles of authority. Not uncommonly, the authority of these persons tends to overshadow the authority of "small people". It can sometimes help to remember that families have a natural authority of their own which can go a long way to reducing this imbalance of power and authority. In order for this to happen, however, families need to appreciate this natural authority and be willing to act on it. What follows is a brief description of some of the common sources of authority that families can call on when they are acting in the interests of a family member.

1. The public generally recognises the primacy of families in terms of their responsibility for a person's wellbeing. In this way, families have the authority to be highly engaged because they also tend to have greater responsibility for the wellbeing of their family members.
2. Families have authority (normally arising from knowing their family member the most fully and over the longest period of time). In this way they have the authority that arises from long-term observation, insight and personal relationship.
3. Families typically care about or love their relative more than would be true of others, however committed the others may be. Not only do families usually care more but they are also expected to care more.
4. Families have a stake in outcomes. For example, they have to live with the long-term consequences of service failures to a greater extent than any other party, except the person themselves.
5. Families are expected to advocate for their own members. Not uncommonly, they are granted considerable presence in their decision-making processes affecting their family members, even where legal formalities do not require it.
6. The family is an authoritative witness to the performance of professionals and systems and may have special (though not necessarily exclusive) insight into events that take place.
7. Family members bring to their role a wide range of talents and experiences which can give them additional authority on many matters. For example, a parent might also be an expert educator.
8. Families are often best positioned to see how everything, in its entirety adds up in a person's life. For this reason they can often see the incongruities of different interventions.
9. Family members are often free of the vested interests which call into question the credibility of other parties. Frequently family members are granted a degree of independence which highlights their credibility and purity of motive.

While these common sources of authority do not, in the end, resolve the question of ultimate authority, they do offer families some measure of security that their views should matter as much as, or more than, others who also claim authority in deciding what will happen to a person. Because it is very difficult for a person to advocate if they hold some doubt about the legitimacy of taking on the role, these points may help to strengthen the resolve to hang in there and advocate for your family member.

CRU/aid/Times July, 1996 6

PLUS  
Voices from the Irish  
family Lived experience

## Choreography of the Dance of Life

## The Homes West Experience

### The Homes West Experience – Clarity about Authority and Responsibility in Everyday Life

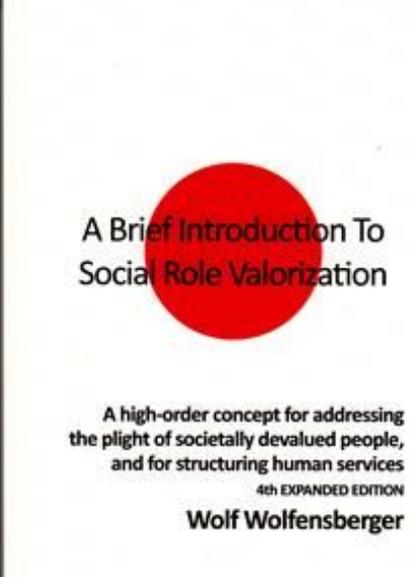
| Family Business  | The shared dance in between  |  | Service Business  |
|--|--|--|---|
| Aspects over which the person, family and trusted friends maintain the authority and responsibility and lead the dance   | Aspects that could be negotiated and delegated to a trusted worker   | Aspects where responsibility is shared between the person, family and trusted friends and people employed by the service   | Aspects over which the service maintains the authority and responsibility and leads the dance   |
| <ul style="list-style-type: none"> <li>Daring to dream the seemingly impossible</li> <li>Holding onto the dream about what life could be like</li> <li>Developing a practical vision of a home of one's own and being an active and valued member of the community</li> <li>Imagining what a good life would actually look like with and for the person</li> <li>Ensuring that committed people are there now and into the future</li> <li>Planning for a financially secure future in a home of their own</li> <li>Ensuring that support will be there in the future</li> <li>Considering how the person's future health and well being will be catered for well in later years</li> <li>Having a high degree of influence on matters that affect the person's life without having to expend a lot of energy to achieve this</li> <li>Deciding where the person lives and with whom</li> <li>Naming the nature of supports the person needs</li> <li>Selecting or approving who comes into the person's life to provide paid support</li> <li>Rejecting who comes into the person's life to provide paid support</li> <li>Allocating supports in ways that reflect the vision for the person's life and well being</li> </ul> | <ul style="list-style-type: none"> <li>Providing aspects of personalised care</li> <li>Preparing healthy food</li> <li>Maintaining the person's home, pets and garden</li> <li>Maintaining personal clothing</li> <li>Maintaining a fashionable wardrobe</li> <li>Compiling calendars and diaries</li> <li>Organising daily activities</li> <li>Organising daily personal administration, budgeting and travel</li> <li>Providing transport</li> <li>Arranging holidays</li> <li>Supporting other aspects of daily life that are highly relevant to what the person needs the most</li> <li>Suggesting changes to everyday lifestyle in relation to how supports are arranged</li> </ul> | <ul style="list-style-type: none"> <li>Working in right relationship with one another involving mutual respect, humanness, individuality, honesty, trust, modesty and a sense of 'whiteness'</li> <li>Respecting the personal dreams of and for the person as well as their plans, history, values and customs and the vision for their life</li> <li>Supporting the vision of life as a valued member of the community to become a reality</li> <li>Ensuring that the person's fundamental needs are met</li> <li>Ensuring that the person's needs are addressed in a responsive and personally relevant manner</li> <li>Upholding the customs important to the person's life</li> <li>Expousing the person's humanity, beauty, talents and gifts</li> <li>Ensuring positive imagery of the person</li> <li>Ensuring protection in relation to vulnerabilities</li> <li>Ensuring safety while carrying out daily tasks</li> <li>Remaining loyal to the person over time</li> <li>Defending privacy and integrity</li> </ul> | <ul style="list-style-type: none"> <li>Developing the vision and planning for the organisation and its work through its board</li> <li>Acknowledging the importance of friends and family in the life of the person</li> <li>Ensuring processes are family friendly</li> <li>Working respectfully alongside others building on supports that are already there</li> <li>Providing the paid support to each person to pursue their unique daily life</li> <li>Providing support around delegated aspects of daily life so that the person is included in the life of the local community</li> <li>Knowing each person's situation well and being respectful of their culture of home life</li> <li>Ensuring relevant and respectful response to each person's aspirations and needs</li> <li>Thinking creatively about how things can be done rather than putting up barriers to the support of ordinary life</li> <li>Managing the paid element of a person's life</li> <li>Managing the work of staff in line with organisational vision and values</li> <li>Fulfilling expectations that lead to positive outcomes for each person</li> <li>Maintaining separate individual accounting records of funds received and expended, with allocation to budget available to families or trusted friends</li> <li>Employing workers</li> <li>Developing and supporting staff teams</li> <li>Organising staff development and training</li> <li>Supervising and appraising staff</li> <li>Paying wages</li> </ul> |



## PATHFINDERS

People with Developmental Disabilities and Their Allies Building Communities That Work Better for Everybody

John O'Brien and Beth Mount



## A Brief Introduction To Social Role Valorization

A high-order concept for addressing the plight of societally devalued people, and for structuring human services

4th EXPANDED EDITION

Wolf Wolfensberger

## The Family Lived Experience

For most families, the arrival of new life is a joyous occasion. However, when a child is born with an intellectual disability the experience for families can be somewhat like a death, as they grieve for the life they had imagined and wished for their precious child.

Instead of celebrations, there is the silence of an unknown future. Parents who had once dreamed of their child's life including; school, friends, college, relationships, a career, love, marriage, belonging, and a family of their own are now transported to a strange unfamiliar landscape. Their dreams often at this point can be replaced with intervention, therapy, special or separate pathways, uncertainty, a world of professionals, staff, clienthood, and potential dependency on a system. There can be a .....

Wolf Wolfensberger, Social Role Valorization, (SRV)

### SRV

**The major goal of SRV is to create or support socially valued roles for people in their society, because if a person holds valued social roles, that person is highly likely to receive from society those good things in life that are available to that society.**



Devaluation is a concept within SRV developed by Wolfensberger. It is a powerful way of understanding what can happen to a person who is devalued by others and seen by them as other or less than. Devaluation within SRV, describes how a person with a disability can be vulnerable to social exclusion.

Devaluation can happen to a person who is marginalised within their society. It can take place in many ways, throughout their lives. It is extremely painful and does impact both the individual and their families.

Loss of their Hopes & Dreams

<https://socialrolevalorization.com/5>

## The Family Lived Experience

In the midst of this new reality for families, we can experience the first wound... "rejection". We can often feel that the world rejects our newborn and in doing so, us also. Extended families often don't know how to be supportive, what to say, or do so they stay away, removed from us.

*"For many families in Ireland, it can appear at times to be a barren landscape devoid of practical information on how to engage with the disability system, or how to access appropriate supports. Families can feel abandoned, left isolated, and often in crisis. They face the challenge of extra pressures; not just financial, but the demands of providing long-term care, advocating for their loved ones, dealing with the uncertainty of the system, along with the emotional, physical, and mental journey that does not end when their loved one reaches adulthood." ILN Member*

## The Irish Voice – A mothers reflections

The first wound for me was grief. I grieved the loss of the life I had imagined for my precious newborn son. I got a clinical diagnosis and then as a family, we were abandoned to it. My child received a lifetime label. When I look at my son, I see him both as the system sees and has labeled him. But then I also see him as his mother, his true self a unique wonderful human being. I found that the disability system has caused many wounds to us as a family over the years. While he can be allocated 2:1 support within services as a family we are offered no supports for him to live at home within his community. This impacts all of us including his brothers and sisters which makes me sad. But I know that they are.....

Better, kinder human beings because of him in their lives.

## The Surplus Difficulty

In their book, O'Brien and Mount helpfully name some of the challenges that families face under the heading "Surplus Difficulty". It is important for us as families to name these, as it enables us then to figure out positive support strategies to counteract them and build resilience.

"Family knowledge and authority is discounted on the assumption that the administration has better judgment about what will be of assistance than family members do." *Pathfinders* pg 121

If we can understand as families the challenges we face, but also why we are key in the lives of our loved ones; then we can begin to have different conversations, based on our strengths as a family and the supports that would best serve us as a family.

In Conversation Series, Positive Pathways Ireland



"Families are people's most durable support. Enduring bonds among people, not law, delineate a wonderful variety of family forms. Family love energizes and shapes development and nurtures desire for a good life. Family knowledge and heritage forms identity. Family resourcefulness buffer crises, and provides long term assistance. Family networks open opportunities, family commitment supports educational, economic, and civic involvement. "

John O'Brien and Beth Mount,  
*Pathfinders*, Inclusion Press,  
Page 113.

<https://inclusion.com>

## by Michael Kendrick

In his article Michael identifies and articulates a number of key ways of the authority "that families can call on when they are acting in the interests of a family member".

In doing so he helpfully reminds us as family members of things we do that are often overlooked by others. While the full article is a must-read, <https://www.kendrickconsulting.org/>.

Please find a summary of some of the key points from his article outlined below for the purpose of this conversation.

As a family supporting a loved one with an intellectual disability;

- we are often naturally committed and responsible for the well-being of our loved ones over a lifetime.
- we often have a lifetime of knowledge and a natural understanding of our loved ones.
- we are there for the long haul, our commitment is not based upon a paid support role.
- it matters to us as we have a "stake in the outcomes", we see the benefits of when the supports work and the cost of when they fail our loved one.

# The Natural Authority of Families

by Michael Kendrick

- ✓ we are often part of the decision-making process and also in an advocacy role for our loved ones.
- ✓ we often bring other gifts outside of our family role, professional training or expertise that is helpful.
- ✓ we have no vested interest, our commitment to the person comes from love.
- ✓ we often hold the history and the lived experience of our family members. We "witness the performance of professionals and systems".

Understanding and acknowledging why we are important as family members and being able to articulate that to others enables us to build our confidence, find our voice and advocate for our loved one. It helps to remind us why we deserve to be respected and listened to.

For more information on Michael's work and other writings please log onto

<https://www.kendrickconsulting.org/>.

# The Homes West Experience, The Choreography of the Dance, Clarity about Authority and Responsibility in Everyday Life

This document is extremely useful and breaks up the partnership between formal supports into three sections:

## Family Business, The Shared Dance in between, Service business

The Homes West Document shows us as family members the importance of deeply understanding;

**what is ours to do** within our supportive roles

and

**what is not ours to do.**

This can also be described as understanding our **purview**.



Often as families, through our lived experience we can at times become overwhelmed with the need to do everything, this can come from bad experiences, being left down, or being abandoned by the system in times of need.

Even when we do encounter good supports it can be fleeting, it takes time and energy to build trust so the whole cycle of change can be exhausting for us.

The Homes West Document shows us as family members the importance of what we can offer. When we understand our role, what we bring, and what best serves our loved one, we then can focus our energies on our purview.

**This enables positive change for our whole family.**

## As Families... What we need to say YES to!!

- understanding our key values, culture, and what is right for us as an individual family.
- Being respected, our voice heard and listened to.
- Knowing what the ask is....? Not being afraid to ask lots of questions before reaching a decision or agreement.
- Being really clear and specific on what supports we are looking for, what supports work best for us, and what does not.
- Understanding what we what to achieve and what we can develop with paid support.
- Understanding what we will comprise on or what our red line for saying no is.
- Taking our time to make a decision, to ensure it is the right one.
- Looking at all options in the context of what works for our whole family v's fitting into a service.
- Having the highest expectation for our loved ones and the supports they can avail of.
- Community-based, family led supports that lead to freely given relationships around shared and positive interests.
- Being open to listening to alternative options, trying new pathways, and stepping out of our comfort zone with the right supports.
- Following our gut instincts.

"Family, a circle of individuals with a shared lived experience, those we dream, hope, and weep with. Those who stand with us in the good and bad times. the greatest gift". ILN Member



## What we say no to!!!

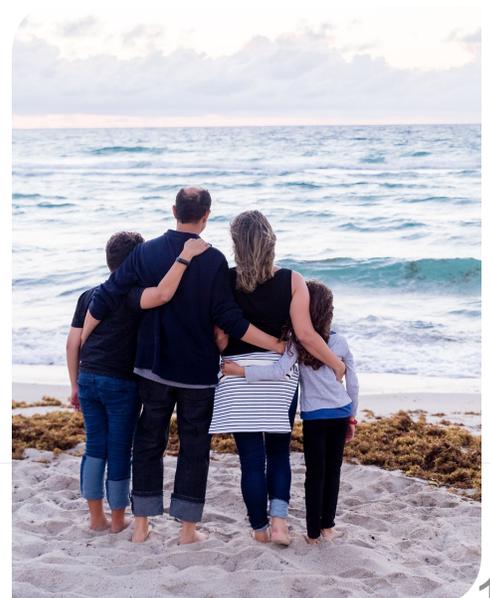
- Not being listened to because we are labeled as family members.
- Being disrespected because we are family members.
- Being rushed to make a choice within limited options, or choosing options that will not best serve us and our family.
- Being bullied into a traditional style process.
- Being asked to make final decisions if and when in crisis.
- Being devalued within the process by our voice, wisdom, and lived experience being dismissed.
- Lack of regular clear and respectful communication.

Do not dis-honour your truth, because you fear it will cause upset. As a family member our gut feeling about something can offer us our greatest insight.

- Actions that are taken by others, which do not match what was agreed upon.
- Being left out of discussions, meetings, or decisions.
- Decisions being made for us and about us without us.



A Family of Irish birth will argue  
and fight,  
but let a shout come from  
without and see them all unite.  
Irish Proverb



# Where do I begin and you end.....

Often as family members over a lifetime, we can lose ourselves in our role as a family member or parent, carer, advocate, driver, the list can be endless and exhausting.

"For most of us our lives are busy no matter what the challenges. I first heard the phrase "Where do I begin and you end", from another parent and I knew what it meant straight away. I have learned so many valuable life lessons because I live in a family with lived experience of a disability and I am grateful for all of that. There have been many joys along the way but I would be lying if I didn't say that there are also many challenges.

When times have been challenging people have advised me to take some time for myself, told me it's important to take care of myself and that's how I will stay strong. They were right but taking care of myself felt like something in the distance, something I couldn't relate to, it felt like a luxury I couldn't afford.

I have great friends who have shown me by their lives how they do this. They are a joy to be with. I have seen how they naturally take time for themselves to do something they enjoy and I have learned from them. And here is the thing, it's not the massive bit ticket things that make the difference, it's the small everyday things that matter. It's doing something nice for yourself everyday; going for a walk, having a cup of coffee, meeting a friend, having a chat with a neighbour, watching a movie, reading a book, working in the garden, meditating, taking that class you always wanted, going on that holiday because you love holidays.

## Where do I begin and you end.....

I love to read, having a chat with a close friend will make my day;  
during Covid I did a Zoom exercise class,

**I thought of it as going upstairs to go out.**

I am happier when I do something that I love, I am happier when I connect with a friend, I am happier when I do that class I was always curious about. I am an easier person to be with when I have in some small way taken some time for myself.

**It seems simple but it is not!**

We all take time to honor and help our family members to develop their strengths, gifts and interests and connections with others in the community. I have learned that it matters that we also take the time to do the same for ourselves. "

Irish Mother &  
ILN founding Voice



## The voice of the others... the lived experience of the siblings.

So, I sit here looking at my older brother wondering how to begin the conversation. It is not something we often talk about, our childhood in the context of having a sibling with an intellectual disability and if or how it impacted us. So, let me set the stage. We grew up in the '80s in the countryside in the south of Ireland. We were neither poor nor rich and lived in a small but helpful community.

My brother is a quiet reflective human being, he still lives in the country, a farmer who enjoys the simple pleasures of life. Someone, who people share their biggest secrets with, why because he will guard them safely and never judge the person for sharing them.

So I simply begin with... "do you think it was really challenging or did we miss out in our childhood?". "No"... he says simply, "yes it was different and at times hard. Mam had to give a lot of time, energy, and focus to our sister, some things were difficult, like having friends over, or family occasions. But it was our normal so probably harder for our parents. **Frankly, I think it made us better human beings**".

"What were the gifts it gave us?" I ask. There is a pause....

"You and I understand **what is important in life, what really matters** which means we never get bothered over a fancy car or a designer label or superficial stuff. We were not demanding as children, we appreciated the small things. We look at life differently, with compassion, kindness, and empathy. We don't judge, we know how precious life is and **our sister gave us those gifts**.

Frankly, I am emotional by his response. I didn't imagine we would both feel the same about the importance of our sister in our lives.

The voice of the others... the lived experience of the siblings.

"Do you remember what it was like when she was away?" I ask. "No, not a lot, things were easier but it wasn't the same, we all knew she wasn't there. I hated having to drive six hours up the north to collect her, that was scary with the guns in the window at us by the army at the checkpoint. It wasn't fair that there were no good services in the South and so for her to have her best chance to learn and grow she had to leave us.

"Did you ever get fed up?" I asked him, however, was asking more for myself. Sometimes as a child, I did feel the heavyweight of it all, during my teenage years when I was embarrassed enough about myself without having to cope with us being different as a family.

"Sometimes, he said, "but I was out on the farm so I didn't spend as much time with her as you did I guess. Sometimes not being able to have friends stay over was annoying but mostly I never felt fed up about her. I did worry about mam and dad and how really hard it was for them when we were all young, especially mam".

"What is it like having her now living next door to you?" "I like that she is home, I like knowing that she is close, I like to be able to pop in to see her, I like that I can keep her close and safe", "What about your own children, do you feel it important that she is part of their lives?" Yes, I love when she comes to my house and watches them and then that big smile of hers arrives. I want them to know her so that they can also understand what is important in life. That they can appreciate the small things. That they know her and spend time with her.....



I think she will also give them gifts.

## Final Reflections

Family, is not a physical structure. It is more than a surname. It is a place within ourselves, a shared lived experience with a chosen few. Family, in its truest form creates an unbreakable bond, built with time, energy, laughter, tears, and love. Family is important to all of us as it offers us a place to belong, a place to grow, where we discover our gifts. Family is often the gate way to community. Families shares a deep knowledge that is only known to the members of that family. Family is the core element of society, if it flourishes then society as a whole flourishes.

*So the message is simple.*

You are part of a family. A wonderful group of individuals who are unique beautiful beings who bring gifts and love to your life. This is true no matter what their vulnerabilities. When families are supported in the right way, at the right time by the right people they can achieve a life of meaning and access to the good things of life.

“

*"Family, Like branches on a tree, we all grow in different directions yet our roots remain as one."*

