



FAMILY LEADERSHIP - IT'S OUR TENT

There is plenty of FAMILY LEADERSHIP around. Families and people with disabilities have plenty of different pictures or visions for the future. They have more than enough ideas for how those visions can be fulfilled. There is and always has been strong family leadership. The hard questions are; where are the followers for these visions? Maybe different FAMILY LEADERSHIP visions do not suit 'would be' followers or the other stakeholders that families need to walk with them on their journey? Who is willing to be influenced? Who is able to listen to families and people with disabilities who are trying to lead out in their life? Who listens?

For people in working in services to follow or, come 'into our tent' they need to feel comfortable. They also need to be clear about what it is they are expected to follow. People providing services need to be able to feel a confidence in the capacity of the family leaders.

They need to be open to influence. These 'visitors to our tent' also need to have acknowledged that they have been carrying a burden of expectation and service provision for some considerable time. It needs to be acknowledged that they have had an unhappy experience of being bossed around by their own paymasters, in particular over the past number of years. Unsurprisingly they have 'authority' issues themselves. The key to successful leadership is influence, not authority. If FAMILY LEADERSHIP is to work the 'followers' need to feel welcomed and liked. Like any guest in any persons home they will not look forward to a further visit 'to our tent' if they feel that they have bossed around during their last visit.

FAMILY LEADERSHIP has been for many years. It has come in many shapes and sizes. It can be messy, uncoordinated, and sometimes desperate. It is often a reflection of an ever evolving 'New Normal'. So expressions of family leadership are difficult to get a handle on. It's the responsibility of FAMILY LEADERS to be clear about where their great passion and concern is coming from. They need to be mindful of how it can effect the way they conduct their relationships with other stakeholders.

These different versions of FAMILY LEADERSHIP mean that it is difficult for a PROVIDER OF SERVICES to respond. It is difficult for a provider of services to resist the temptation to try and resolve or fix, or make coherent this tenacious and sometimes confusing passion they are having to respond to. It's hard to lay off trying to corral or control FAMILY LEADERSHIP when the family is conceived to be in your effective domain by a narrative that comes from a health service paymaster. PROVIDERS OF SERVICES are welcome to get to know what FAMILY LEADERSHIP is about. However their job after that is to merely to 'Walk with' the person and their family. Their job is to listen.

WHAT FAMILY LEADERSHIP LOOKS LIKE

Types of FAMILY LEADERSHIP range from a person or family who works to organise a good life and the relevant supports around themselves alone, to people who work together to support each other in meeting their shared challenges. Family leaders campaign for systemic change. They provide peer support. They take action that allow them to take more control over their lives. In the normal course



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of their everyday normal lives families in their own communities are working to more effectively realise a better present and a more secure, inclusive and naturally interdependent future. So the business of FAMILY LEADERSHIP could be like any of the following;

- a. the advocacy / engagement / consultation and political activism *e.g. NSPA*
- b. issue focused advocacy and grassroots action *e.g. CPN*
- c. disability focused support work *e.g. DSA, GAP, Ballina AA, Hands Together, IAA*
- d. local service provision lobbying, fundraising and activism *e.g. the Clare Crusaders*
- e. the parents and friends associations that were set up specifically to provide/ fill the gap in service provision *e.g. SMH, DARA Residential, CoAction, WCA, MAA*
- f. professional national lobbying activist and resourcing organisation *e.g. Inclusion Ireland*
- g. methodology / process focused FAMILY LEADERSHIP alliances *e.g. Microboards, Clan Beo, PossibilitiesPlus*
- h. family education, support and resource group *e.g. LEAP*
- i. a specific company, or discretionary trust set up to manage the living arrangements for a single person *e.g. XYZ Ltd.*
- j. intentional circles of friends assisting a person with their normal, routine and natural desire to live a valued life at home, with family, among friends, in the community

The list could go on and on. The point for those in the FAMILY LEADERSHIP business is not just about their experience of impairment. They need to be clear about the type of FAMILY LEADERSHIP work they do, the vision they are aligning themselves to, and how they engage with would be 'followers'. For providers of services they must be clear about what type of family leadership they are willing to listen to. More importantly they need to be clear about whether they are willing to be influenced about the way they do their business 'in our tent'.

FAMILY LEADERSHIP IS NOT

When trying to figure out what makes FAMILY LEADERSHIP work it's sometimes easier to say what it's not. It's not;

- a. Family Partnership in the provision of services (*your tent*)
- b. Family Participation in the provision of services (e.g. Rights Review Committees, Fundraising, Outcomes Planning, Service led circles of support) (*your tent*)
- c. The provision of person centred services where a PROVIDER OF SERVICES takes the lead on opening up opportunities for a person to lead a different life. This is PROVIDER Leadership no matter how it is dressed up. (*your tent*)
- d. Family/person guidance in service procurement by a PROVIDER OF SERVICES (*your tent*)



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PROVIDER OF SERVICES cannot avoid a level of engagement with a person or a family. They are certainly able to sit in a room and talk about the idea of working with families. However as they say about the idea of inclusion: 'Just because you breath the same air'.

FOR FAMILY LEADERSHIP TO WORK THERE NEEDS TO BE - *Our Tent*

A Starting Point

Clarity around the starting point - *respect for human rights* (UN CHRPD), enablement of *personal power* (access to funding and choice of where to spend it), *community inclusion*, and *personal responsibility*. Being focused about what you are about:

- "When in a meeting and everyone is stuck about what to do about a (young) person's behaviour, simply ask: Who loves (the child). Whatever the answer start there" Herb Lovett, 'Learning to Listen'

Acknowledgement of the independence and primacy of the picture a person has for their own life, their ownership of it, and our responsibility to support their personal capacity to take control.

Responsive Followership

An honest, specific and direct response to that picture from a PROVIDER OF SERVICES as a follower offering a relevant and effective contribution to making it happen (whether paid / unpaid, private/public sector)

Values based service provider 'followership' - A PROVIDER OF SERVICES that is flexible enough to be able to follow a person or their family and acknowledge their place in that relationship

Flexible, ongoing engagement with an evolving picture of where a persons life is at as preferences, capacities, dreams or life stages evolve

Intentional Support for FAMILY LEADERSHIP

Leadership development supported for the person and their family or natural circle of support

Context specific community intentionality – Funded supports for community development focused work with business, faith, recreation and social enterprise

Non partisan / independent family support in choosing the types and sources of assistance for delivering on a persons vision or picture of a 'good life'



FAMILY LEADERSHIP IS NOT POSSIBLE WITHOUT INTENTIONALITY

The family, person (and their natural supports) own their vision, their plan and the process. A PROVIDER OF SERVICE is outside the tent until they are invited in to respond to that vision. When they are given that opportunity there must be some clarity and an understanding of the intentionality around what the person wants today, an agreement on how useful and expensive a PROVIDER OF SERVICES contribution is to be, and a respect for each person's 'inputs'. There also needs to be an acceptance of the prospect of a PROVIDER OF SERVICES earning an involvement in decision making that may approach but can never attain the status of equality. This is not possible where the starting point for that relationship is a crisis.

FAMILY LEADERSHIP IS NOT FOR EVERYONE?

Taking more control of your life is a decision you can take when opportunities for realistic choice making is supported by the people around you.

It is said that *some people with impairments do not want to take control* or that this 'taking control' doesn't suit them. I have not met the person who is willing and happy for someone else (no matter who they are) to decide all the time what they do, when, with whom, how often.

Stepping back may just be what works just now for a family member. However because blood is thicker than water people are rarely successful in outrunning their memories of love and filial attachment. Where a person can invite a family member back into their life they must have a place in the circle. We do well to trust family in the end (no matter how far isolated they have been in the past).

People in any community make assumptions around their right, obligation or capacity to contribute to the love and care of a child born into it. These assumptions have a habit of developing a self serving mythology and may take hold and become a norm, an accepted truth. Norms have a habit of clouding both a memory of the past and ideas about potential. Community assumptions around the capacity and contribution of a person change very quickly when people living there are asked to do specific things that make a real difference. Attitude follows action.

FAMILY LEADERSHIP is not for every PROVIDER OF SERVICES where they cannot offer flexibility in response to a person's personal vision. Neither is it in the interests of either a person or family to work with a monopoly PROVIDER OF SERVICES who presents as being 'all things to all people' (or even 'all things to one person'). This can easily perpetuate a norm of co-dependency, isolation and learned helplessness.

Norms have a habit of shifting quickly. The assumptions that sustain accepted norms of what a person, family, community or PROVIDER OF SERVICES has a right, obligation or capacity to do is sustained where there is a monopoly around ways of thinking. However when things are tough over a sustained period of time these norms have a habit of evaporating quickly in the face of a more efficient approach and in a flash an unimaginable 'New Normal' can replace old ways.



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NEW NORMALS

The prospect of 'new ways' of doing things does not always work for a person, their family, their community and the current configuration of service providers. This is particularly the case in relation to the 'Mergers and Acquisitions' theme of the ID sector VFM report and program. Publicly funded organisations are waking up to the fact that they have to start making a choice. Small PROVIDERS OF SERVICES can either follow the FAMILY LEADERSHIP or be swallowed up the bigger (lets call them) 'Multiples'. They can support FAMILY LEADERSHIP by giving the trust, power, information and access to support choices to those who look for it. As a first step they need to be honest about their inability to be all things to all people. They need to be clear about where they can contribute to the achievement of a person's vision. The balance of power needs to be shifted so that a person's autonomy is the starting point for any decision made about the supports they are presumed to need or want. Not until the shoe is on the other foot will it be possible for the 'follower' in the relationship to fall into step.

In a world where individualised funding is a reality the QUESTION for family leaders who take more control is how they choose to engage and lead a PROVIDER OF SERVICES. In order to do that they must discover in themselves a welcome for support providers and resolve a relationship with them that both leader and follower are comfortable with. If they have a belief that a PROVIDER OF SERVICES has undermined the dignity, inclusion and wellbeing of their family this QUESTION will be one of the biggest challenges. It will be made easier if they know they have power to consider realistic choices.

FOLLOWERSHIP

'Followership' is a hard role to take on when labouring under the twin pressures of managing a budget and trying to change to a better way of operating. If a PROVIDER OF SERVICES is to engage in the FAMILY LEADERSHIP business the questions they have to answer for themselves are difficult;

- What are you willing to do to earn the trust of families?
- Are you small enough to remember where you came from?
- Are you big enough to make the choice to follow and 'Walk with me'?
- What type of FAMILY LEADERSHIP do you choose to engage with?
- Have you acknowledged how you have been brutalised by institutionalised discrimination?
- What specific use are you to a person who wants to inhabit valued social roles at home, with friends, in the community they choose to belong to?
- Are you big enough to survive with your vision intact or so small that you get swallowed up by the multiples?

The questions for those who would be followers are not easy to grapple with. They throw up the prospect of some difficult choices, changes in the way power is distributed and how family influence is to be welcomed. The baggage and issues that come up in looking at those questions belong to the PROVIDER OF SERVICES - their baggage to carry, and their issues to resolve.





IT'S OUR TENT – YOU ARE WELCOME TO 'WALK WITH ME'

The decision to let families lead and for a PROVIDER OF SERVICES to commit to followership is a decision that they take when they face up to the fact of having to make a choice. Like families a PROVIDER OF SERVICES needs support in coming to terms with the importance and many facets of this task. In particular they need support facing up to the fact that community based family leadership is about the person, their family and their community. It is not about service provision.

Like families a PROVIDER OF SERVICES need to be afraid of not realising a vision that sees the person and families leading out on the supports they need. The stakes are too high. To approach this challenge with an attitude of anything other than the same weighed sense of responsibility and love that a family feels when caring for each of their own people is to be out of step with a person and their family. For each person who faces the prospect of a “wasted life” what’s at stake is no longer a mere ‘tragedy’. If we didn’t know the brutalising consequences of the ongoing ‘devaluation’ of a person you could be forgiven for being out of step with a person or their family. We do know the impact and being out of step is not some unlucky tragedy. It’s a choice you make.

For people involved in FAMILY LEADERSHIP as well as PROVIDERS OF SERVICES there is a realisation that being either “special” or “interesting” is not enough. For anyone coming into the tent the visit is all about just “being ordinary”, working hard and staying in step with a family and all the people who belong there. A PROVIDER OF SERVICES can come into the tent if invited and respect it until it is time to leave. They leave when their job is done and their status approaches closer to redundancy. Be clear that what goes on in the tent in the first place is the business of the family, their community and the people who live with them in the place where they belong.