Reluctant Engagement – Part 1

During conversations with some family member in 2015 a recurring issue was **how to work better with funded service providers and funder decision makers**. At the same time conversations with managers highlighted how people using services them are best served by confident, powerful and evenly balanced engagements.

Most of us are uncomfortable in any relationship where there is a power imbalance. This is made worse when we feel we have no other choice but to be part of that relationship. Many have the view that the organization and its officers are in charge of the game and call it, confusingly, a 'partnership'. This relationship is an engagement that reluctantly, has to be lived with.

This discomfort is also what people working in human services sometimes feel. It can come from a personal view that 'inequality' and 'partnership' can't work together. It may come from the job of responding to the myriad of different ways that families communicate. Perhaps it's because they have had a less than positive experience of how wounded, under resourced or exhausted families are able to be together with a loved one. Sometimes it's because the person hasn't had an experience of how powerful a positive mutually affirmative engagement can be.

In part 1 of the 'Reluctant Engagement' project we acknowledge that part of the journey for people who want 'good lives' is to work closely with human service personnel in a different relationship to the one experienced to date. We wanted to;

- *Explore with service providers and the people they serve how to move beyond a reluctance to engage powerfully together*
- *Highlight steps people can take to realize their own authority in a more powerful relationship*
- *Detail how people and their natural allies can build capacity to control the direction, momentum and experience of this 'good life' journey*

Part 1 of the 'Reluctant Engagement' project records and summarizes 10 conversations with leaders from Irish organizations who are funded to serve people who live with an intellectual disability. Part 2 of the 'Reluctant Engagement' project has been to have a similar but more focused conversations with 30 people whose family member avail of these services. This resulted in the 'One Breath', a beautiful publication that records a myriad of shapes that a mutually empowering relationship could look like see www.clanbeo.org/onebreath). The natural follow on from this work is to facilitate conversations between families and services providers so that the structures that constrain their relationship might be reengineered.

The initial conversations with senior managers were directed around 9 questions (see note 1). The outcomes from the human services managers are summarized under the following headings;

1. Landmines and fertile ground – *conditions of success and failure*

2. Awkward questions we need to be challenged with - *tools for productive critique*

3. What people really need to know about how we work – *important non programmatic issues*

4. What's family business – *a picture of purview for an organisation*

5. What powerful engagement looks like – *a vision of for right relationship*

Before going to the guts of what human services managers came up with there are some important points to note;

- The perspective detailed below is only one part of the equation; The 'One Breath' part of the 'Reluctant Engagement' project focuses on a family perspective.
- Powerful engagements are not necessarily comfortable or convenient for any of the people involved as they involve a change in existing way of working together
- The voice and life of the person at the center of the engagement can easily be lost in the intensity of a strong productive working relationship between the other people in their lives
- Discernment around the 'will and preferences' of the person at the center of the relationship is an iterative challenge for each of the people involved in this ongoing dialogue
- Different ideas of 'best interest' are influenced by peoples ordinary subjectivity and is helped by an openness to periodic independent critique
- The suggestion that a different type of engagement brings with it an implicit 'threat' is real for everyone involved, not least in relation to the status quo or the culture of the organization.
- In the minds of many family members 'a different type of engagement' raises the specter of the disturbing and often recurring theme of abandonment in their lives

It is difficult to summarize what 10 individual management voices had to say. However the following themes go some way to reflecting what they had to offer to the research to date.

1. *….. know and stick to what the right thing is* – Have confidence in what you know is the right thing, the right life. Keep reminding yourself, the person you are supporting, your allies and the people who are working with you. Be clear that your intuition is valuable and that sometimes all the 'evidence' in the world is about what happened in the past.

2. *…..have space and time for independent support* – Always ask to go away and think about what's being proposed. When a person/family is seen to have independent 'advocacy' they are often stronger. This 'advocacy' support does not need to be professional – often it is better when it is a friend. Check in with someone you trust before and after any meeting.

3. *…..be relentless when asking the same question* – Keep asking your powerful questions until there is an answer that makes sense to you. This does not mean that the answer will necessarily be a palatable one.

4. *…..look for concrete commitment over a set time* - Be clear about what the different partners do in the relationship especially when going home. Come back on the deadlines and stick to your own

5. *….own success* - When there is an important change for the person the celebration for the progress is something to be shared

6. *…. be mindful of what's going on* – The process is difficult for everyone and takes time and energy to get right. The benefit of the doubt around the 'best of intentions' must go both ways as does respect for different positions, limitations and contributions

1. *Landmines and fertile ground* - *conditions of success and failure*

What our manager collaborators had to say about **when working together is more likely to be positive and achieve greatest success;**

- *Open ticket destination* – Where a person has lived a 'life unexplored' great success has come from keeping an open mind on where that life might end up. Several suggested that a fixed idea of where a person should be in their life can indicate either a lack of experience on their part of all the options open to them or an untested understanding of a persons potential.
- *Well supported person, families and friends* – Where a person is well supported either by their 'own people', community or some sort of 'unaligned' supporter there was a better chance of success.
- *Staff empowerment* – A number of managers highlighted how successful giving front line staff 'their own head' had been. Some had a view that success was more likely when all inputs were intentionally accorded an equal respect, consideration and status (including clinical inputs). At the same time they highlighted the unavoidable weight of authority a high status qualification brought to a discussion.
- *The honest broker* – Passionate engagement generates disagreement. To navigate these choppy waters a manager highlighted their experience of bringing in a third party with an accepted 'honest broker' who stayed 'on the scene' for a brief period.
- *Trust first and eventually everything will be on the table* – Most managers cautioned against expecting 'real honesty', clarity and openness to challenge at the outset of any powerful engagement. They suggested that trust could and should come first, however difficult that leap of faith might be.

Landmines to look out for in a reluctant engagement – In any ongoing long term relationship there will be times when things ar'n't going so well. The following were highlighted as 'landmines' that will hinder a journey that looks to the 'good life'.

- *Sustained misunderstandings* – Sustained personal misunderstanding that create self fulfilling perspectives are a feature to look out for. A casual invitation to ask *'what do you think I think our partnership is about'* can help at least to have different perspectives acknowledged (even if they are not agreed with) and allow the engagement to 'get over this duck'.
- *Feigned interest* – Some people around the table will not be 'up for' affirmative engagements and just want to 'tick the box' to show an interest in. This becomes apparent where there is a change in the faces around a table will undermine any previously established trust.
- *Congregate expectations* – Some people and more especially funders may struggle with the reality of 'one person at a time'. Sometimes direct supporters are forced to apply the values, standards and approaches of 'congregate settings' to 'one at a time' work.
- *Information game playing* - Making information sharing an issue creates a focus on 'non programmatic' conflict that undermines any potentially positive engagement
- *Respite reference point* – When engagement between a person, their own people and a human services provider starts in the context of crisis getting to a place of relative peace is seen as a success. Managers pointed out that this 'peace' is rarely sustained but part of 'a spiral of complacency, crisis and despair'

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- *Absent warriors* - In any organisation (or family) some necessary contributors are not 'at the table' when they need to be. Where this is the case on a continuous basis the perception that 'unknown' or 'imagined' others carry the 'real' authority will undermine the process.

- *Pretend victories* - Celebrating the realization of low expectations carries with it the danger of a a spiral ever lower expectations. When fresh eyes respond to these 'victories' with a 'so what' it is likely that this critique will be regarded as 'unrealistic', 'expecting too much', etc.

- *Befuddled departures* - Leaving any engagement without a clear or common sense of what was said, discussed or agreed was remarked by one manager as a slow burning landmine. It also lowers expectations around the value of some contributions.

- *All guns blazing* – Sometimes a person goes into an engagement with a burning platform concern -*"We hear nothing only the sound of gunfire when we have all guns blazing"*. When this becomes the 'only show in town' it makes it unlikely that other progress can be made.

- *Staying with the blame game* – When there has been a long road of unacknowledged hurt it is difficult to hide a need for recrimination. This can be expressed in assumptions or positions that are held tight to. Not being able to name these 'hurts' can disrupt effective positive engagement. One manager highlighted that this doesn't necessarily mean that they need to be named or heard in the meeting or engagement itself. Just that they need to be acknowledged somewhere.

2. The Awkward Questions - *tools for productive critique*

Here are some of those simple but sometimes awkward questions service provider managers suggested as being powerful and useful questions that would help a reluctant partnership be more fruitful. Choose whatever ones the ones most relevant to you and the person at the center of your partnership. Stick to that question till you are able to agree that you are making progress.   First some general comments from the manager collaborators in 'Reluctant Engagement 1';

Awkward Answers - Sometimes people don't persist with their question because the response they get is an answer already prepared and not the question the person is actually asking. Secondly while the question might be answered in technical language that might not be understandable to an ordinary person. Simple, obvious or stock questions may drive people into 'meeting mode' and …….. go on and on and on and on and on and on, and end up boring, bamboozling or plain distracting the person into a stunned silence.

Keep plugging – While in the face of these awkward answers a stunned silence can be a relief to the manager, the end result is likely to be more frustration. All manager collaborators suggested that when there is an awkward answer to a simple question people need to keep asking the exact same question again and require an answer in the language the person understands.

Vision - The general idea of a 'Good Life' as a starting point can create culturally accepted anchor points that are easy to agree on. The picture of a 'Good Life' for a specific person with a disability is emergent, iterative and particular to that person. For a family living with long experience of devaluation a picture of a typical 'Good Life' is something that may be hard to imagine.

A word of warning before we start with the detail; these questions are the ones suggested by service provider manager collaborators for families to ask. They thought that these would be challenging questions to have to respond to. Of course each person or family approaching a service provider has their own questions that they feel are useful or important. The suggested challenging questions are collated under 5 headings.

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- *Where there is space to consider whether a service offers what's right for the person – Where families feel they have choices and time available to them on who they can work with*
- *For a start then – Where there is space for ground rules to be negotiated*
- *So you have a specific suggestion for the person – Testing the reality and truth of what's on offer*
- *Looking out for the person together…. – How to make the engagement is sustainable*
- *The people who are with the person every day – Being careful about the (service) relationships that matter*

3. What families need to know about human service organisations?

Managers highlighted that what people feel they would *'like to know'* about a human services organization will differ depending on the person. What's *'useful to know'* if a person is to be well served is not always what's looked for or most palatable. Most managers held that their organisations are 'completely open and transparent'. One in particular was keen to point out that this didn't necessarily make for being 'understandable' for most people other than those who are 'within the organisation'. Some managers noted that the "penetration" of some organisations is staunched by offering too much information. They highlighted that much of the information people are referred to (e.g. on the website, in the brochure, etc) is just packaging and has little to do with what goes on the ground between people.

Some managers were keen to highlight that different services, different departments in the same service and different people in services offer different ideas of what they can do and where the persons needs interface with what the service provider does.

THE BASICS

- *Examples of the way support is offered currently*
- *What the human service organisation does not pay for*
- *How many hours of support service impact on the specific aspects of a persons life (home, work, community, etc.)*
- *How staff are managed, supported and supervised and how a staff member is replaced*
- *How the organization works with the person and their family where a person is not being served well and 'a line needs to be drawn in the sand' ('this stops now')*

HELPFUL ADDITIONAL INFORMATION

- *Differentiation between the details of their own budget and the service provision budget (i.e. the 'cost of living' rather than the 'cost of service')*
- *Highlight with family members service provision issues where "our hands are tied" (e.g. Service Level Agreement, Trade Unions, HR requirements etc.")*
- *How a changing oversight relationship effects a person's relationship with us (e.g. HIQA)*

RIGHT FIT

- *What a 'good life' for a person looks like in the organisation*

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- *What happens when more support needs arise or when things drastically change?*

4. What's family business?

On 'Personal Business' one participating manager quoted a person availing of their service - *"My business is my life and all that's to do with it"*. He understood the person to mean that any aspect of the way the service operates that impacts on his life was his business and at the same time aspects of his own life had nothing to do with business of the service.

Because any 'business' arrangement is about what lies between the different people involved what 's offered below is only half the story. Part of this discussion could be about 'who family is', 'when, how and by whom 'family' is chosen' and 'for what business'. However, for the purpose of this exercise we stuck as close as possible to the question - 'What is Family Business?'.

Functional but no consistent picture in theory or practice

There was no consistent idea of how a person is usefully connected with chosen family and friends. When serving adults in particular there is a line of tension around how best to serve a person using services as an individual by themselves and the same person connected (however tentatively) with family and friends.

Family Business and 'Service Provider Business' was thought to depend on a shifting composite of what a family of origin feels they can or should have to do in any given circumstance and what the general service provider is offering. This service provider offering also varies according to the specific personal capacity or training of particular managers or staff who engage with a person and chosen family / friends.

One manager felt that this lack of consistency in the idea of what 'Family' or 'Service Provider' business is means that a person and their own people need independent support to (as one manager put it) "crystalize their ask" in the same way as a provider of services needs to consider how to "crystalize their offer".

Mindsets and context are important

There was a strong narrative among the service provider population that a persons own people generally choose not to engage with the work of service providers. The interpretations of what is constructed as this 'choice' tends to veer towards less positively valued narratives of 'incompetence', 'crisis', 'lack of care', 'entitlement', 'abandonment', 'burnout'. There is little consideration of how service providers choices on how to engage with the person and their people might be impacting on this 'choice'.

When a person and their people are thought to 'choose' not to engage human services or the HSE consider that it is their business to fill the 'vacuum' for considering, advocating for, and deciding what is either in the persons 'best interests' or what is possible for them in a world considered to be impoverished of 'natural relationships.' The language around 'will and preferences' of the person are thought to be rarely part of the discussion.

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One manager suggested that the Assisted Decision Making legislation can be a significant step in emphasizing the role of the person and their own people for what would be considered as 'shared business' with a service provider. Their view was that where representation was needed in a persons life the important decision becomes the 'who', 'when' and for 'what' issue. They pointed out that there has been little discussion about how best to support chosen family / friends independently in this role. If this type of assistance is not available then there would be little additional protection for the person in conducting their business with a service provider.

Collaborating managers felt that front line managers and direct support staff are increasingly having to make calls on how a person could live their life in community without the engagement of chosen family / friends. In order to make progress on what it 'could' be like for a person to 'own' their personal business alongside their own people in ordinary community settings some picture of what that their personal business 'should' be like is necessary if they are to be well served and safe in the natural web of ordinary healthy social relationships.

Support for 'Family Business' is good for everyone

Managers were clear that for a person and their chosen family / friends to be comfortable 'owning' a persons business there needs to be an acceptance that 'natural supports' are good for a person and a safeguard against isolation in community and in institution settings.

There is a tendency for the 'business' associated with a persons life to be considered only as a service provision 'outcome'. Where there is an over emphasis on a formal process it is difficult to have a shared experience in the way a person lives a 'good life'. Collaborating managers questioned the extent to which this is possible where a persons connections were bounded only by institutional relationships.

Managers who were part of the research were consistent in recognizing that for a person and their own people to be able to collaborate and do their business together they needed to be able to be supported to consider;
- ✓ *What owning your 'own' business can look like and how this impacts a person and the people they are connected with*
- ✓ *What service providers should not / would not / cannot 'own' as their business*
- ✓ *How assistance to take on this 'business' can be offered (either independent from or part of what a service provider offers)*
- ✓ *How the idea of a 'persons business' and 'chosen family/friends' business marks a change in relationships and how challenging that change can be*
- ✓ *An understanding of the 'strengths', 'deep personal knowledge' and 'valuable experience' that family and friends (no matter what distance) bring to the business that a person and the service provider share*
- ✓ *How the distinctions between 'caring for', 'looking out for' and 'being responsible for' yourself are understood*

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5. *What does a powerful engagement look like?*

Before recording this final section it should be emphasized that because 'powerful engagement' is about what lies between the different people involved what is offered below only approaches half the story. This is what manager contributors had to say about their experience of powerful and affirmative engagement;

- *There are ground rules* – Agreement about basic things in any open relationship are important - knowing how many times we expect to meet, over how long a period, where we meet or sit together, openness to awkward questions, how disagreement is dealt with, what each are looking for and able to offer at the outset.
- *Mindsets or 'how people think' are out there for changing* - Acknowledge different thinking by starting with the assumptions about the person that brings you together, who each person involved is and what they can do.
- *There is an openness to consider 'risk'* - Most decisions about doing something different have an element of uncertainty about them, are about taking a chance together or risk. Thinking about risk creates the opportunity to imagine how things could work differently for the person is a big ask for everyone.
- *Reference points are invoked* – Keep in sight where the person has come from and where they want to go. If 'today' is either a good place or a 'bad' place make sure that it is never seen as a 'destination'. Reverting to an evolving vision of a persons own 'good life' or 'culturally valued analog' are also important reference points
- *Moving from transaction to interaction* - There are timely conversations to check in on how it is being experienced and a reminder that there are bad days and good days. A relationship between a person, their family and a funder or service provider never just arrives; there are going to be peaks and troughs so any achievement made together needs to be acknowledged. This also means that a picture of a good working relationship includes an acknowledgement of what each others 'red buttons' are

THANK YOU

My thanks to the 10 managers who answered my questions and gave their time to this project. Their generosity was well matched by the 30 families who have contributed to 'One Breath' - part 2 of the 'Reluctant Engagement' project.

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Note 1 - **9 questions to guide the conversation with senior managers.**

1. *What's family business?*
2. *What do family / person need to know about the SP business?*
3. *What does a powerful engagement look like?*
4. *How do you identify willing and potentially useful collaborators?*
5. *What are the landmines that we need to look out for in a 'reluctant' relationship?*
6. *What are the useful stock, obvious or stupid questions needed to be asked?*
7. *What should a family partner know about the service provider they use that would be helpful in negotiating a stronger and more effective working relationship?*
8. *What are the areas where collaborators can achieve the greatest successes?*
9. *What are the necessary assumptions that need to be stated from the get-go?*