

What do we mean by person-centred principles and values?

1. The agenda that everybody is working to is the **agenda set by the person...**;
2. The agenda is informed by a clear and **appropriately ambitious vision** of the life the person wants for themselves.

When critics say we can't afford choice, they have typically confounded what is important to people with what might be nice to have,

John O'Brien & Connie Lyle O'Brien

3. The engagement with the family is full, considered, and two-way – we are not passive participants, we do “push back”;
4. The focus is on building **a life in the real everyday world**, not within the parallel world of disability services;
5. The commitment is to build **individualised arrangements**, based exclusively on what the person requires – all forms of group provision, of lower-common-denominator trade-offs are avoided

If it involves groups, if it involves centres, we haven't got there yet;

6. Particular care is taken to ensure that the arrangements profile the person **in a valued and status-enhancing way** – we must scrupulously avoid reinforcing associations that socially marginalise;
7. What we are supporting is an evolving, open-ended life story, not a version of a life frozen at a single point in time;
8. There is uncertainty – but it is the uncertainty of growth, of possibility, of opportunity.

Safety first, but not safety only.

Signed:

Brendan Broderick
CEO

Making sure the focus is Right

- Over the years we have been working off the assumption that the best contribution we can make to citizens with disability is to **build really good services**. The assumption has been that *if we can build fantastic services, “they” will have fantastic lives*.

This has led us to focus on what *we are providing*, rather than *checking in constantly* with individuals **on** what their **actual lives** are like.

The focus on what we are providing leads us to emphasise aspects such as:

- * The impressiveness of our physical facilities;
- * The credentials, qualifications and prestige of our staff;
- * The profile and professionalism of the paraphernalia associated with our services (publications, quality systems, accreditations, media coverage, the profile of our associated events).

The end result of this mindset provides very untypical, “special” lives for citizens with intellectual disability – lives which struggle not to be empty and marginalised, often profoundly lonely, episodically relieved by special events (the Summer Garden Party, the Christmas Concert, Special Olympics).

This confirms the view that if your starting focus is misdirected i.e. isn’t focussed *exactly* where it should be, if you pay attention to the wrong things, you will end up in the wrong place.

We are now learning that the proper starting point is the question: “*How can we help you build a typical life, one that is as full and as good as it can be, one that keeps you at the heart of your family, neighbourhood and community?*” The focus is on helping the citizen with an intellectual disability to **get a life**.

This is a hugely different way of coming at things. It leads us to pay attention to very different things – and leads us to different destinations.

Most people recognise that the “good services” and “getting a life” approaches have very different starting points. However, we assume that they soon link up, share the same road thereafter – and ultimately deliver similar results. **Not so!**

The “getting a life” approach pays little attention to buildings, centres, credentials and prestige of staff, or the profile of the service provider. Its defining characteristics are:

1. Paying close and constant attention to the aspirations, goals, capacities and talents of the citizen with disability;
2. A belief that the primary source of opportunity and value in the life of the person with disability are the ordinary everyday currents of activity;
3. A very open approach to involving whoever might have something to offer to the person with disability in the context of their aspirations and goals, notwithstanding their background or formal qualification;

4. A belief that much of value will spontaneously occur if people are maintained in the midst of the flow of everyday community life – and that what is not occurring spontaneously is only likely to happen when **directly** and **intentionally planned** for and **actively supported**.

This “getting a life” approach moves us *away* from thinking about buildings and centres, *away* from bringing people together in groups to pursue lowest-common-denominator activities, *away* from a focus on what *we are providing to* **what is actually happening for the person**.

It leads us to work with people in ways that are less high profile, perhaps less “impressive”, and towards more organic, individually focussed approaches that cumulatively have a much bigger impact on the actual life of each individual.

Signed: 

Brendan Broderick
CEO
**Muiriosa Foundation/
Sisters of Charity of Jesus & Mary**

HOW CAN WE TELL IF WE ARE GETTING IT RIGHT?

1. When we're **investing** a lot of **time** in trying to work out **what the person really wants**, not just a superficial or reactive opinion (which may be more a reflection of an impoverished sense of possibility, or of limited exposure and life experience);
2. When we're spending time **opening up new possibilities** for the person, planning opportunities and safeguards;
3. When the kind of things we are planning for the person take place in **inclusive settings** and are embedded within an **intentional strategy to develop** particular **relationships** and particular **roles**;
4. When the **focus is on** introducing/**widening/deepening relationships** and **roles** – and not just on time-tabled activities and programmes;
5. When we are **building independence** (via skill development or functional alternatives) that will make a *direct and immediate impact* on the level of control the person can exercise over their life;
6. When our whole **way of working** with the person (the settings we place them in, the way we talk about them and represent them to others, the materials we use) **projects an appropriate and reputation-enhancing image**;
7. When we are **revising/adapting the original plan** on the basis of new information **or** on the basis of the person having changed their mind;
8. When all our focus is on **how we can be of maximum service** to the person in the light of what *they* are communicating about what *they* want and need, rather than being primarily focused on *our* role, *our* achievement, *our* professional goals;

9. **Where the focus is on building a life for the person** (opportunities, relationships, roles, lifestyle) that extends *beyond* the world of specialist services and paid staff support. (This is not to undervalue the important contribution which specialist services have to offer or the huge contribution which paid support makes. Rather, it is to underline that these investments are means to an end, the end being a full and fulfilling life which ranges well beyond the world of specialist supports – a life beyond the “disability bubble”);
10. When we are working *with* and *alongside* the person rather than providing professional inputs *to* them;
11. When we are **making time to have personal contact** with individuals, rather than just *processing people*.

Signed:

Brendan Broderick
CEO

What are the characteristics of a fit-for-purpose service-user Vision Statement?

Why the need for a Vision Statement for each service user?

- A fit-for-purpose vision statement provides **direction** and **guidance** for goal setting and action planning. It **also** injects **motivation** and “**lift off**” momentum. The best vision statements can have **an inspirational effect**, can sustain the efforts of all involved during those times when we have yet to see an actual return on the investment of time and resource.

While most of us get by and enjoy worthwhile and satisfying lives without the support of an explicitly worked out vision statement, we often navigate our lives guided by an implicit vision – “own my own house.... raise a family career advancement”.

It is essential, however, that persons with an intellectual disability have a well-thought-out and **explicit vision statement** to:

1. **Counteract the low expectations** that others (including, sometimes, family) generally hold of persons with intellectual disability – low expectations often internalised by the person himself / herself;

What would the person envision for herself had she been encouraged and supported to hold appropriate expectations for her evolving life story?

2. **Challenge** the kind of **inertia**, “*sure, isn’t it good enough / won’t it do?*” **passivity, complacency** that can sometimes take root in very busy and pressurised settings;
3. **Counteract** the very real **risks** to vulnerable people, dependent on systems, of their fundamental needs **being displaced and discounted** by the everyday demands and pressure of “**keeping the show on the road.**” It is very easy for people’s needs as individuals not to be recognised, certainly not prioritised, within large “systems.”

What a vision statement should look like

- A statement setting out a vision for a service user will have at its core an outcome **that gears the person up for a qualitatively better and richer life**. It should be something fairly ambitious, something that will require significant thought, planning, and implementation to bring about.

The vision statement aims at placing the person's life on a *new plane of possibility*, including the opportunity to **exercise more self-direction** over his / her own life and the **opportunity to acquire new relationships and roles**. The very best vision statements will inspire / stimulate a chain of actions which will reframe the person's life in a richer, more positive way.

Preferably the vision will be centred around the kind of change that would introduce a new phase of ongoing value-add within the person's life. The vision should not be centered on *once-in-a-lifetime-type* experiences e.g. a holiday in Florida – though planning a holiday in Florida with a view to rekindling 3-4 important relationships would be of a different order of significance and could be regarded as a legitimate component of a vision.

Vision Statements are sometimes equated with the *What is your dream?* question. This can be problematic. Much depends on how one deploys the term *dream*. “My dream” in the sense of *Something I aspire to, though it will stretch and challenge my capacities and / or the capacities of my personal network of support* is a useful and helpful way of working towards a vision statement. “My dream” in the sense of “My dream is to meet the Queen of England or Beyoncé” (or some other celebrity) is too narrow and once-off to inform and guide the development of a fit-for-purpose vision.

- A device I used many years ago when trying to assist groups to jump-start their thinking on vision was to suggest that the group might think of a documentary-style DVD of **the person's life in 5-years' time** and identify the kind of material (actual visual images, preferably) which they will feature in the documentary. The documentary would offer a contrasting image of the person's life *now* and the person's life *post the successful implementation of the vision*.

The vision should be **authored** as much as possible by **the person himself / herself**, along with his / her key supporters. This does not mean that members of staff who know the person well should feel inhibited about contributing to the emerging vision-design work. **However, they should be very careful not to “take over.”** Neither does it mean that family members or staff members who have significant concerns that some of what is being proposed may not be in the person's best interest should remain silent. The vision statement will be all the better **if it** has been **exposed to significant questioning and stress-testing**.

- The vision statement should focus on a limited number of high priority goals and aspirations and should emerge *after a process of consultation*, generating option proposals, checking for feedback, testing and refining ideas.

It is not something which should be pulled together after a single meeting – nor after consultation with only one or two people.

A vision statement within a person-centred planning context needs to be **focussed and definite**. If it is too general, it will fail to provide the kind of grip and forward momentum which implementation of the person-centred plan requires.

- A vision statement should not read anything like a care plan.

- Nor should a vision statement and person-centred plan look like a risk-management plan – although competent implementation of the action plan (linked to the vision statement) will involve significant investment in ensuring that appropriate safeguards (risk-management plans) are in place.

What is not appropriate material to see featured in a vision statement

- Statements about **ensuring the continuity of the current situation** (e.g. that “Thomas will continue to live in St Benedict’s Unit”).
- Generalities such as “maintain her health”; “continue to be treated with dignity and respect”.

As these are things which should be happening in any case, they reflect poverty of vision rather than fit-for-purpose vision.

Signed:

**Brendan Broderick,
CEO.**

Optimising the value we add to the lives of service users

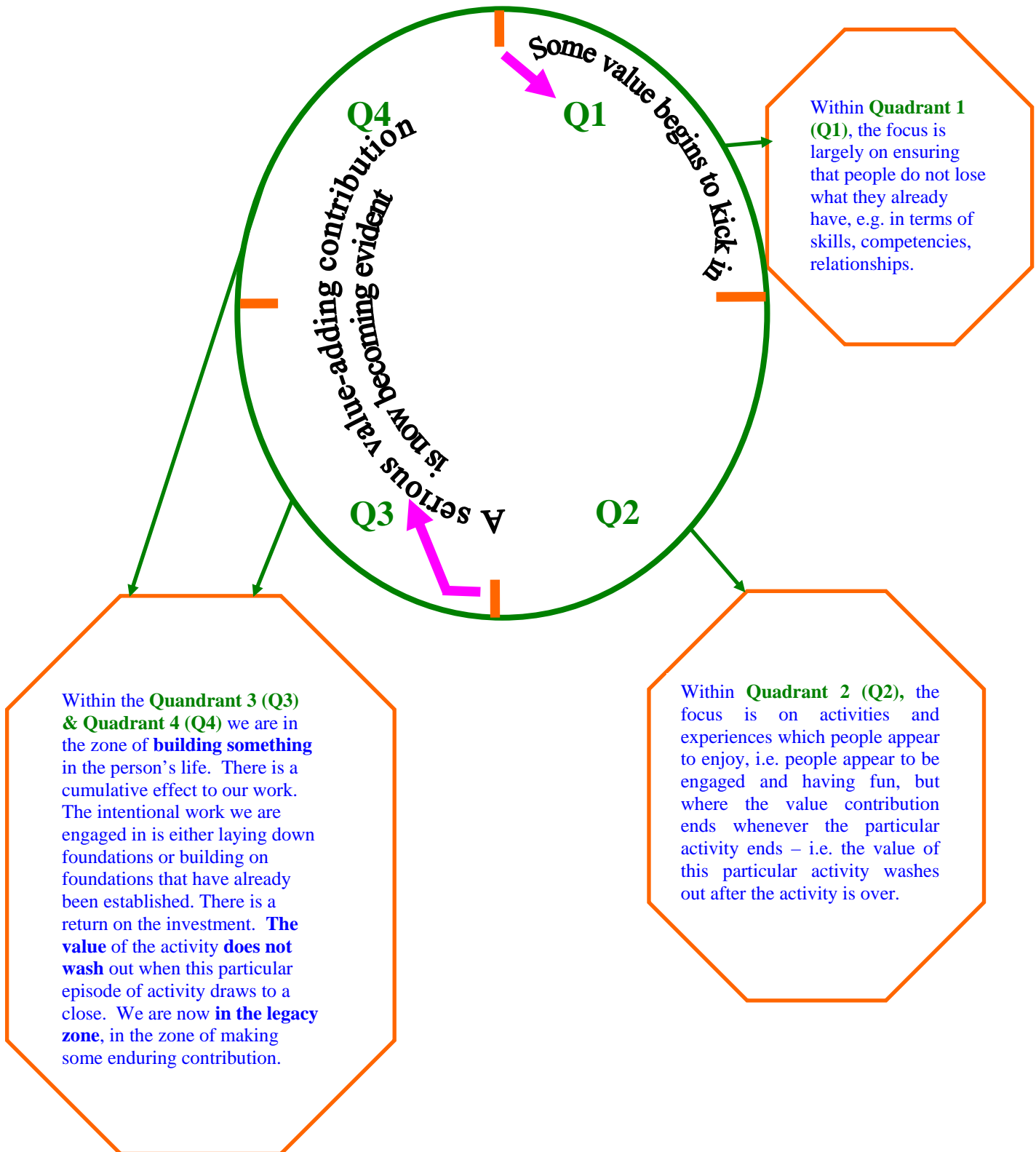
Assumptions

- a) The fact that a particular activity or routine adds *some level of value* does not mean that there aren't better (more cost-effective) ways of delivering that same level of value or **higher-value alternatives**;
- b) We can draw no confidence that we are optimising the value-adding contribution we can make to the person's life just because we are committed and are personally working very hard – we may be as committed as anybody could possibly be but if we are focused on lower-value-adding things, we will not be optimising value for the person;
- c) Developing impressive *services* does not necessarily translate into delivering impressive lives or lifestyles.

If our service closed in the morning, what enduring legacy would we have left in the lives of the service users?

- What would help us feel confident that the things we are busy spending time on are the most value-adding things? (Are we building sandcastles or foundations?)
1. If we gave ourselves *the time it takes* to find out what **really matters** to each of the individuals we work with. (This will involve us removing the immediate pressure to be “doing something.”)
 2. If once we have got a fix on what these value-adding contributions would be, we ensure that we spend as much of our time as possible *doing only these things*, i.e. not allowing ourselves to be blown off course, caught up in activities and routines which add only marginal value.

THE VALUE-ADDING DIAL



Less driven ACTIVITY and more considered ACTION might deliver more VALUE.

An ability to facilitate a conversation about *what adds value* is a key competence for the organisation.

We have got to give ourselves permission to turn off the music, to stop the dance, to develop a crystal-clear sense of what really adds value – and then commit ourselves *as exclusively as we can* to **intentional work on these agreed priorities.**

An example of how additional layers of value can be grafted on to essentially the same activity

Focus: Exercising in a gymnasium for a 25-year old service user

- * Exercising in the gym in the service day centre (e.g. Cill Cuan) +
- * Exercising in the Mullingar Park Hotel gymnasium during a specially reserved hour for Special Olympians + +
- * Exercising in the Mullingar Park Hotel gymnasium under the direction of one's support worker during a sparsely attended concession hour for old age pensioners, unemployed persons + + +
- * Exercising in the Mullingar Park Hotel gymnasium between 7.00p.m. and 8.00p.m. when most other working 25 year olds attend, while being supported by one's 45-year-old female Cill Cuan staff member + + + +
- * Exercising in the Mullingar Park Hotel gymnasium between 7.00p.m. and 8.00p.m. alongside other 25-year-old men while being supported by a 25-year-old male with an avid interest in gym work, one who is socially well connected within the gymnasium + + + + +

As one can see, the essential focus here is on “*how can one make it even better in terms of value-adding impact?*”

Signed:

Brendan Broderick
CEO

RISK MANAGEMENT & DUTY OF CARE

Our Vision Statement commits us to becoming a **more inclusive service**, i.e. developing roles and relationships for people which involve them spending much more time in ordinary, everyday situations with ordinary, everyday folk (i.e. people other than those directly employed by service provider agencies like Sisters of Charity and other than fellow citizens with an intellectual disability). One inescapable implication of this is the need to radically overhaul **our perspective on risk** and on our way of managing risk. We need to dramatically increase the number of **inclusion opportunities** we generate for people. Risk is an inherent element of opportunity. We cannot and should not be trying to eliminate all risk – the elimination of all risk will also ensure the elimination of “getting a life”, of all sense of possibility. However, we must remain hugely preoccupied with identifying potential risk and developing practical and proportionate measures to reduce risk (i.e. real risks, not theoretical or mythical risks) to an acceptable level – an acceptable level of risk does involve *some level* of risk.

Historically we have been risk averse, i.e. “*whatever you do, don’t do anything, that way nobody can every say you did something that you should not have done.*” A direct consequence of this **safety at all costs** has been stagnation, boredom, inertia, empty lives, wasted lives. This is too high a price to pay.

Risk management is closely connected to the idea of *duty of care*. *Duty of care* is as much about ensuring that good and worthwhile things happen for people as about ensuring that bad things do not happen. Historically we have been inclined to interpret *duty of care* in only one direction – in the direction of making sure that nothing bad happens (by closing off many activity channels).

We need to create a new culture, one in which we are as prepared to hold one another accountable for *what we have failed to do* to make sure that a person has a good and fulfilling life, as to hold one another accountable when we have not been as painstaking in our analysis of risk as we ought to have been. This new culture will recognise that heavy costs are incurred by any unbalanced position on risk, i.e. by being fixated on eliminating all risks or by being less rigorous in our risk management planning than we need to be.

Within this new culture mistakes will occur. Things will go wrong. Lessons will need to be learned. It is critical that the appropriate lessons are learned. But we must avoid adopting a finger pointing or blaming position. We must not tolerate attempts to opportunistically seize on such mistakes to reinstate old risk-averse ways and the massive opportunity and life-wasting costs which we know to be associated with them.

“Insurance” is often invoked as a reason for not taking the initiative to run with more imaginative suggestions. We take out insurance to protect ourselves in the event of things going wrong. Our insurance company do not require us to provide guarantees that we are providing a zero-risk service. They recognise the impossibility of giving such an undertaking – moreover, they also recognise the undesirability of seeking to run a zero-risk service. They do insist that we have thorough and rigorous systems to identify risk and that we have appropriate and proportionate risk-management plans in place. The standard which they expect us to reach is that of **taking all reasonable measures** to counteract the identified risk.

From time to time one picks up extreme and distorted views among staff members about what is permissible or not in respect of risk assessment. Some staff members who used to bring service users to their own home or to social settings outside of working hours have become inhibited about undertaking such activities on the basis of perceptions that such initiatives are “not allowed because of insurance” or because they are not in a position to guarantee that every person whom the service user might interact with was not the subject of the an appropriate Garda Clearance process. These are over-the-top and hugely distorted versions of what our actual policy is. Staff members should not lose time or inhibit their sense of initiative and generosity on the basis of such mythical risks.

This letter is an initial communication on this issue. Over the next few weeks we will be organising some follow-on arrangements to further explore and clarify these issues with a view to promoting a significantly more life-affirming orientation to the management of risk.

Signed:

Brendan Broderick
CEO