

It is my task this afternoon to act as a key note listener for the day and make an attempt to do some justice to a summary of what has been laid down for us as we begin this exchange. So I will do my best to be at least reasonably coherent as I try to assemble these thoughts.

He aha te mea nui o te ao
What is the most important thing in the world?
He tangata, he tangata, he tangata

If I was giving a title to this summary, I think I would call it The role of Families in Bringing about Transformational Change.

I guess my first comment is that what I am beginning to get a sense of is how we might perceive of the critical role of families if the reform agendas which are taking place in many of our countries are indeed going to lead to the level of change necessary for people with disabilities, their families and Whanau to be able to pursue lives that are rich, meaningful and fully inclusive.

While we need to acknowledge that personalised budgets or individualised funding is a major step in the right direction, and a potential safeguard against The exploitation and oppression people have experienced within the systems designed to support them. It is however, as well described by Rachel, not a panacea for all the ills of the system.

One of the reasons for this of course is that money, in itself does not think, and as Bobbie, Bruce and Robin have said to us “ some things can not and should not be paid for. So if personalised budgets are to authentically change life opportunities for people with disabilities, clarity around what is both desirable and achievable is a necessary pre-requisite for success. Otherwise as Robin has said, money without a vision can lead to nothing more than a more expensive, miserable life. It is important to acknowledge from the outset that such clarity, for many people with disabilities, will be required to sit with families. This means that if we want self direction and personalised budgets to be effective as an authentic approach to change that families must hold and relentlessly defend a strong vision for what is both possible and desirable in the lives of their sons and daughters. Or as Janet has said, “who can the

person be in their own lives, families and communities. It will require as defined by Rachel, Bobbie and Avril, that families recognise, understand and defend the need for the family to govern the services and supports made available to their family members and it will be beholden on families to sustain each other in the pursuit of the vision they hold for their family members.

Listening to Marg and Bruce I am reminded – probably because I am so old, that many of the assumptions and stereotypes that confronted us when I began on this path we appear to have already overcome over the 30 years that CRU and Durham Assoc. or Inclusion Alberta for 50, have been challenging these assumptions. Which shows how resilient they are. However before turning our attention to the many assumptions and stereotypes we are still left with that stand as challenges to our children attaining a good life, it remains beholden on us to revisit old assumptions as unfortunately they are never really far from re-emerging. As Avril so eloquently showed in her presentation, a placement is not a good life, and for families striving for what is ordinary for their family member there remains a continuous battle with these old assumptions

when I first found myself confronting the issues around what constitutes a good life and why society appeared to believe that a good life was domain of the privileged. That for people with disabilities life in the managed space rather shared space was as good as we could hope for, group homes and sheltered workshops looked like real advancement and progress. Yet today we recognise that they lead generations of people to a life time of oppression and marginalisation. That was a time when young people with an intellectual disability were still being sent into institutions as little children, where access to education and community was not considered feasible, where outside of an institution the living options available were large hostels, or a life at home in perpetuity.

How fortunate we are that at this period in our history there were families who were not prepared to believe that this was as good as it gets, and that there were professionals who dared to imagine better for the lives of disabled people.

How fortunate we are today that we have young parents like Avril, Carey-Ann, & Nicole, who are with us this week as part of our IIDL exchange. Because the reforms and opportunities, that Marion spoke too, and we can see from the developments defined by our other presenting IIDL member countries, along with the issues and challenges that we addressed today will be the challenges of your time. The time of children still to be born and of those young families only now beginning on this journey. That is, the legacy that you as families here today, who are involved with the work of Leap and Possibilities Plus, who are relentless in your advocacy for greater authority and autonomy over the assumptions held about your children and the supports available to them, are laying down. What I do believe, however, is that if you do not fail to underestimate the extent of the challenge, and have the same courage and determination as those that have gone before you to continue to imagine better the young people of today will continue to outstrip what could ever have been imagined.

As we have heard expressed today by Marion from the Irish experience and Marg from the Australian, We live at a time when there is much emphasis on seeing people with a disability as being people just like everyone else. We see these values and principles are familiar across all of our countries and This as Marg expressed is in itself a big and ambitious vision, and a most welcome development, as people with a disability have suffered greatly in not being seen as fully human, and not being treated as unique and interesting individuals in their own right. All of the attention has seemingly gone to endlessly evaluating what people are not, what people can not do or become, rather than unleashing the hope and potential in people's lives. It is almost always true that people will tend to underestimate, rather than overestimate, what could be possible in life for people with a disability.

A key factor in much of this as Bruce identified, is the extent to which most of us are limited by what we have not yet seen or experienced. Our beliefs about what is actually practical, and reasonable tend to be things which are already part of our life, what we already know and are familiar with, rather than options which are as yet untried or unfamiliar. Marion spoke to the need to be realistic. However As Bruce identified what we consider to be "realistic" is most often more of what we already have, more of what has already happened rather than what has not yet happened, or

may yet be possible.” As families then, if we are to build, sustain, and deliver on a vision for our family member, perhaps rather than settling for what is realistic, we need to be sensibly unrealistic. Marion also quoted Michael Kendrick, however I would like to offer another quote from Michael where he says “ In many cases, we are deeply sceptical of what is new simply because what is old is so comfortable, even if it is not all that satisfying. This may well be the ultimate result of settling for what we consider to be realistic today, rather than actively pursuing the Good Life, as we heard from Avril and her family around the building and sustaining of a full life for Stephen.

For families needing to take a key and powerful role in expanding what is possible this is a trap that must be avoided if any meaningful change is to occur, and if we are to avoid the traps of my generation where we believed “just another form of institution, (eg. Group homes – sheltered workshops) would transform the life opportunities for people.

From all of the presentation and conversations we have engaged in today and from the experiences and challenges we experience and live on a daily basis, it remains a tragedy that the lives of people living with disabilities are still most often not lived to their potential or as Aoife identified, essentially invisible, in our communities. Not because of any personal limitations that the individual may have but because, those of us responsible for the promotion and development of what might be possible in their lives, including families, are ourselves beset with fears, with anxieties and with stereotypes and have limited vision of the potential that disabled people have for a full and purposeful life.

Even as families, who have the deepest commitment to our disabled children, we often foreclose too early on the possibilities and as a result people with disabilities have very little choice but to themselves settle for, or rather conform with, our own limited expectations.

Despite this however, we can see from the work of people like Janet Klees, the life opportunities of people living with Disabilities are better in the year 2018 than ever in human history, and we have not reached this situation by accident. Such change happens when people realise that the lives of disabled people have become stuck.

Generally they have become stuck within the very systems designed to support them to grow, learn and develop. It is only when we come to realise that more is possible, that the life opportunities being offered to disabled people are not good enough that we are compelled to imagine better and to move towards what is possible.

This requires that we have vision or a picture of what is perceived as being possible in life. To improve vision you really need to imagine it, to picture it. Imagining better is the beginning of finding better in the lives of people. To imagine better requires that we change the stereotypes and assumptions that have surrounded the lives of people with disabilities. That we place our focus on the competencies and abilities that people have rather than placing our emphasis on the struggles and challenges.

Just imagine, if instead of presuming incompetence we were always to presume competence in people. By presuming competence and providing supports, encouragement and opportunities for people to demonstrate what they are capable of, we create different expectations within themselves and their families about what they are capable of doing and being, and create different expectations in others about what might be possible for their lives. After all people will live up to the expectations that others hold of them, if you hold low or no expectations then don't be surprised that people will live up to that. By holding few expectations we deny people the opportunity to take up those life opportunities that not only enable them to demonstrate their competencies but also provide them the bridge to relationships and real participation in the valued fabric of social life.

However, the opposite of course can also be true. If we are not clear, or do not struggle to become clear about what could be possible, if we hold no vision or a very weak vision, then it is very easy for us to be driven this way and that depending on what is happening at the time, who is advising us and our energy for engaging in the challenges. That is, if you stand for nothing, you will fall for anything. Indeed the reason that we have already come so far is because there have been people, largely families, such as we have heard from most of our speakers today, who have refused to accept reality as it is, or as it is presented to us.

So you can see that holding onto a vision is not a trivial act. If your vision passes the test you will have a powerful tool that will change lives. Vision is key in keeping hope alive, and we must never let hope for what could be better die. Indeed hope is more important and powerful than money.

Whenever we hold a powerful vision for a life that is better, we embrace hope, we look beyond the moment, to the promise of what life might yet offer. We begin to embrace a true realism, a realism that is life enhancing rather than life denying.

To pursue the vision we must have clarity of the underlying values. The conversation today brought to mind for me some of the life Affirming principles that Michael Kendrick speaks of: I can't remember them all of course, but they would include

1. Recognizing The Humanity And Dignity Of People; No Matter What Their Impairments
2. The Dignity Of all people being able to express their Human Will, Freedom and autonomy
3. People Will Thrive Best When The Fullness Of Community Is Available To Them
4. Growth Is Ever Possible And Brings Greater Life

To conclude then the key messages for me from today are that so much of what is important in life requires vision, values and faith. As Owen demonstrated for us, It often requires that we believe in something before it comes true. If we don't have faith then we won't do any of the great things that need to be done, because we do not believe; we will not put ourselves out there; we won't take a risk. We must be sincerely convinced within ourselves or we will always defer committed action, and when it is the hopes and dreams of life that become deferred or ignored, then life itself and its potentials will fade.