

IMAGINE
BETTER

*Community
Conversations:*

TALKING ABOUT
IMAGINING BETTER

'There will be moments when we simply must
move beyond "what is" to "what might be."
(M.J. Kendrick—international leader in disability)



TALKING ABOUT . . .

IMAGINING BETTER

This short paper has been written to provide a platform for a Community Conversation about creating a vision and imagining better. It is designed to offer brief, but important information and thoughts on the topic which will enable all who participate in the conversation to have a common starting place. It is not intended to answer all the possible questions about creating a vision, or to provide clarity for individual situations, it is offered in the spirit of 'a conversation starter'.

INTRODUCTION

This conversation covers how to imagine new or better possibilities for a disabled person including ideas about:

- Ways to think about all of the possibilities and life potential for a person, taking into account their needs, their likes, dislikes, interests, hopes, dreams, vulnerabilities and safeguards.
- Why and how we are conditioned to limit the life possibilities of people who live with disabilities; and the impact of low life expectations for people.
- What conversations we need to have to bring a more powerful future into reality.

What makes a good life is within the reach of all of us. The barriers that so often prevent disabled people from attaining what others take for granted are barriers that we ourselves have erected. They are the limitations that we place on our hopes and on our dreams for that person. Yet good lives are already being led by many, many disabled people worldwide and there are examples all around us of disabled people living richer and more rewarding lives than we might once have thought possible. When we see that this is happening for one person, then we know it can happen for more, the number is unlimited. All that is limited is our capacity to imagine better.

While they were saying among themselves it cannot be done, it was done.

Helen Keller

Being able to have a clear picture of a good life for a person with a disability is really about being able to imagine for that person the right to the same kind of ordinary everyday hopes, lives and dreams that all people have. It means believing a person with a disability can have the same kinds of hopes and will need the same kind of opportunities in their lives as everybody else. It is important to keep holding on to these thoughts about hopes and opportunities when you are thinking about the activities, places and people that might be involved in the person's life.

THE IMPACT OF PLACING LIMITATIONS ON YOUR VISION

If you can't imagine better, or if you have set your sights too low, you can be sure that other people, generally paid service professionals, will have options for you, options that they believe will be the best for your family member. While these options are offered with good intent, they are generally options that have been designed by service agencies around what works best for the agency rather than designed around you and your family member. They are options that your family member is required to fit in with, rather than being designed around their life, their needs, their hopes and aspirations.

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 and the lives of many disabled people have been essentially wasted because others could not see a future for them.

Without a clear vision as a guide, families can misdirect their energies, thinking that more funding, more services, or more programmes are what is needed. However while funding, programmes and services may look appealing as easily obtainable options, they tend to lead to people being trapped in services, often for a life time with very little development. Many families then come to realize that they have settled for services that are very disappointing, and find they are left with very few alternatives available to them. This can then become a vicious circle, where families continue to seek more and more of what is not working.

Where good lives for people with disabilities exist it almost always because families hold a big vision and hope for that life and will not be discouraged from it. Where no vision is held it is like families saying, "We want our child to live below the poverty line, somewhere chosen by others, with people they do not know, and that we want others to choose their day to day activities and routines for them, that they should have few opportunities to contribute, and never have intimate relationships and real friends."

WHY IS IT IS ESSENTIAL TO IMAGINE BETTER?

Getting a good life for people with disabilities is seldom easy and involves overcoming many obstacles. Not least of which are stereotypes and assumptions that condition how families, society and disabled people themselves think about who they are, what they are capable of and what they can aspire to in life. These stereotypes and assumptions almost always lead to people holding low expectations of people and limiting the opportunities and challenges that are then presented to them.


A good life can be achieved but it needs a clear vision of what that life is, then a determined plan of action to make it happen. It is important to be clear about your vision and really committed to pursuing it, because if you are to achieve the good things in life for your family member then you will find yourself challenging the expectations commonly held for most disabled people. You will be working against the norm.

Imagining better then is a description of the future that you aspire to on behalf of your family member. It may be as simple as all the basic, good things that ordinary people and families value, such as a good education, loving lifelong relationships, a home of their own, work and a purpose in life, financial stability, and autonomy over the major decisions of life. Even such ordinary expectations can be an overwhelming challenge for disabled people as society (including families) often accepts, if not expects, that people with disabilities will have limited opportunities to attain even these very ordinary things.

It is important to start thinking and planning as soon as you can. Often your hopes and dreams for what is possible are driven out because you cannot imagine how to overcome the many difficulties such as legislation, money, support services, and so on. If we can only imagine better when we have everything in place, the funding, the facility, the support, etc. then we have already settled for a solution before we really recognise what it is we want to achieve, what could be possible. Once you have settled for something then your sons and daughters have no choice but to settle for it as well, even if it falls far short of what could be possible in their lives.

While all these practical issues will certainly need to be addressed, the time for that is once you have a clear understanding of what it is you are wanting to achieve. To imagine better you need to be positive and hopeful and think of possibilities, not be bogged down by the negative or by the many challenges and problems. Once you are clear about your goals and objectives and are working on your plan of action that is the time to address the practical problems and obstacles. But by then you will be in a better place to think of the potential solutions in a creative way.

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. Dreams are part of keeping hope alive, and we must never let hope for what could be better die. Indeed hope is more important and powerful than money.



Unless we ask new questions we are in danger of slipping into old answers.

A. Etmanski – PLAN Canada

GETTING STARTED

To build an understanding of what might be possible in a person's life you must always start with the person; with **who the person is** and what their **gifts, passions** and **skills** are. Often we find when a person has a disability, people start with everything the person is not, or never will be. So we know about all the things the person cannot do, all the stresses the person may create, but nothing about who the person is or could be.

Key Points in Imagining Better

- 1.** First get clear about the person. Start exactly where they are and focus on their undeveloped potential, what is really needed and wanted by the person. Avoid placing the focus on the person's disability as you will quickly become overwhelmed by what they cannot do and the challenges that you are confronting right now. Rather, begin to push the boundaries of what you are open to trying.
- 2.** Get very clear about the type of life that you want for the future. Is that to be a life lived with all of the opportunities, joys, struggles and challenges, alongside of others, in the shared spaces of our community? Or is to be a life that is segregated from the ordinary opportunities and challenges of life, lived with others who share only a diagnosis or set of vulnerabilities in common, in the managed spaces of our community?
- 3.** Focus on relationships that will connect you and your family with others. Share the vision you hold with others, that way you will know who is going to be there to support you and who is not. It is very difficult to imagine better all by yourself, you need to look for examples of different lives being lived and keep drawing people in to walk with you, to be your 'dream carriers'.
- 4.** Don't worry if you do not know how to get there. Most of our hopes and dreams do not come fully formed. They start in the rough and we bring in people and ideas that help us to shape them up and move them towards a clearer reality. In this way the hope and vision that you hold might not always seem to be practical. Just because it is not practical to achieve today does not mean it could not be practical if we strive for it over time.

Otherwise the lives of disabled people are restricted by our limitations not by theirs. The good, practical ideas will come. They may well need some figuring out, they may need the support of other minds, but if these ideas are pursued they will eventuate. A powerful vision is one that is what Dr Michael Kendrick would call "sensibly unrealistic". What he is telling us by this is that just because something looks unrealistic now, does not mean that it is not a good idea. A lot of things we think are impossible are in fact solvable and we can solve them, it is in working to solve them that we will get to what is better.

Making a Start

1. Think about what a good life means for you and your family. Get very clear about it. Write it down. Revisit it regularly and ask yourself 'Is what we are doing taking us closer or further away from the life we are seeking?'
2. Identify the things that are crucial to achieving and sustaining this good life. Have you got the people around you who will stand with you through the hard times and the good times? Are you in control of the decisions that are being made or are you being pushed away from the good things in life by others? This may be by family, friends, professionals, or systems. Do you have the resources you need to stay on the path towards a good life and if not what can you do to bring those resources around you?
3. Work as a family - a good life is for everybody. The good life for one person should not come at the expense of other members of the family. Although this can often seem hard to achieve it is important that what will sustain everyone is regularly discussed and revisited. When seeking a good life for one family member is continually disproportionate to that of other members of the family this is generally an indication that the family is lacking in essential supports and resources.
4. Make your vision big. 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 have to offer. We begin to embrace a true reality, a reality that is life enhancing rather than life denying.
5. Bring in others and share the vision. Once you can imagine a life that is better, a future that is possible, this future then becomes much more attainable if that vision is shared with others. It is only in the sharing of your hopes and dreams for the life of your son or daughter that you will find the allies you need to stand with you in the pursuit of that life.
6. Turn your vision into reality. Once you are able to hold a picture in your mind of what is possible then you must take those steps that begin to bring what is possible into reality.

QUESTIONS TO GUIDE YOU IN CONVERSATION ABOUT IMAGINING BETTER

- What are the hopes and dreams of the person with disability?
- What are your hopes and dreams for them?
- Describe your dream of the good life; for you, and your family member/focus person.
- What would you most want to prevent, or what is your worst nightmare?
- What barriers do you see to attaining your dreams?
- What support would you need to assist you to achieve their hopes and dreams?