

family

A D V O C A C Y

Clarity of Vision: A Compass for the Journey

Wendy Stroeve

This paper has been called, in the metaphor of the Odyssey, *Clarity of vision: a compass for the journey*. In the *Pirates of the Caribbean* movies, for those who have not seen them, Captain Jack Sparrow has a compass that is rather special in that it points only to that which the user most wants to find. In a way that is the kind of compass I am talking about... something which will give us direction and keeps us focused on what we want to achieve for a person with disability.

We hear some stories about good things happening in the lives of people with disabilities. When we do, you can pretty much guarantee there will be one thing all the stories will have in common. They will have in common a vision.

Good quality of life, in connection with family, friends and community, with jobs and interests and opportunities and variety, does not just happen for people with disabilities by accident. It just does not. It may happen, for particular individuals, as a result of clear vision and determined action.

Some people think the word "vision" sounds a little evangelistic... you know... "Hallelujah I've had a vision" kind of thing. But what I am talking about is having a clear idea and some positive dreams about what we want someone's life to be like. We actually dream all the time about positive lives for ourselves and people we care about. Some of the dreams are so basic and fundamental we hardly even fully articulate them. But when most of us are asked to say what we think are the most basic elements of a „good life“ there is a surprising similarity in what people say...

They generally say things like:

- Relationships: partners, friends, acquaintances; people who care about you

- Home: a sense of security and belonging
- Work or leisure: capacity to pursue skills and interests
- making a contribution
- Enough money to give security/not living in poverty
- Ideally, good health.

If most people come up with these same criteria, we could say these are pretty, ordinary dreams. Everyday dreams. Having a vision for the life of a person with disability is really about claiming for that person the right to the same kind of ordinary dreams. Put simply, having a vision means believing a person with disability can have the same kinds of dreams and will need the same things in their lives everybody else does. And it means thinking about what that might mean in terms of activities, places and people that the person might have in their life.

A vision will reflect a view of what is possible for people with disabilities that represents a completely altered mindset from the common ideas in our society. From birth, the idea of "Separate paths" can become well entrenched for people with disabilities. Other kids go to the park and playgroup; a kid with a disability might go to early intervention and therapy. Other kids go to the neighbourhood school and play in the street or backyards after school; a kid with a disability may be taken across town in a bus to a special school and never see much of other kids in the neighbourhood. Adults might attend workplaces, socialise with co-workers, join sport teams and have people over for barbecues. Adults with disabilities may spend their lives in congregate care facilities; attend work training programs or leisure programs or "independent living" programs.

These essentially separate paths can be maintained throughout life and can be seen by many people to be the inevitable reality for people with disabilities. People with disabilities end up congregated together, and in disability-specific „programs" separate from the rest of the community. All glimpses of what is going on in that other path, in schools, shops, workplaces, clubs, pubs, universities, teams is closed off.

There is something that happens to our thinking where disability is concerned. I will give you an example of how we think differently. I know when my son Alex was young I was urged, again and again, by well-meaning individuals and professionals, to take him to Riding for the Disabled (RDA) as a leisure activity. This was in spite of the fact that I kept repeating that horses terrified him and he was not interested in riding. But people were convinced that "if he got used to it" he would begin to enjoy it. And some were quite determined to change my mind.

Now, I hate flying. I am terrified every time I get into a plane. However, no-one has ever suggested to me that I should join an aero club and that once I "got used to it" I would love

flying. In fact most people are quite at home with the idea that I might submit to whatever flying is necessary for me, but that I am not going to go out of my way to make it a leisure activity.

There is a difference in the way we think about what activities and places are appropriate for people with disability.

Another part of the same story, I think, is the fact that I have had some strange looks from people when I have started telling them that I would like Alex to join some woodworking groups when he leaves school. He loves woodwork at school because of the sound of the machines and has always loved wood and wooden percussion instruments and beating out rhythms. Of course, the strange looks are because people understand that Alex will probably not do much of the actual woodworking. He would probably need substantial support to learn any of the most basic elements of the craft. So they cannot see him being there. I could point out of course that he would not have been riding a horse in RDA without being supported to stay on the horse or without someone leading the horse.

The crucial difference is that RDA is a disability-specific environment so people immediately accept Alex can be there. It certainly would not be a natural environment for Alex as an individual to be in, disliking horses and riding. It would be about as natural as my joining the aero club. The woodworking group is a much more natural environment for him, since he loves the machines, loves the wood. Support can just as easily be delivered there as at RDA, but because that environment has not been specifically set up for people with disability that is much more difficult for people to “get”.

What happens is that society’s expectations about where people with disability can be and will be supported begin to shape people’s lives and experiences. People expect to see Alex, with disability, at RDA where they expect support is provided. They do not expect that woodworking can be a supportive environment. For a lot of people with disability, this thinking just logically leads to horse riding. People’s actual interests or desires become irrelevant when we have already determined the places they can be.

In developing a vision we decide we should try to bring into a person’s life all the basic ordinary good things others value. When formulating a vision with or on behalf of people who are already marginalised by the broader society and expected to be on, (if not already on) a separate path, we need to be extra clear about the vision and extra dedicated in its pursuit.

When we start developing a vision, we should not immediately put limits on a person’s, or our own our dreaming. Most of us do not do that. Our aspirations are limitless when we start out in

life. It is not uncommon to hear kids say they want to be Olympic champions, prime ministers, or the next Johnny Depp. Some of us still have a vague financial plan based on winning the lottery! If we still occasionally buy a ticket it means, that somewhere deep down, we have never relinquished the idea that one day we might actually win, however unlikely that is. It is human to dream sometimes big, unlikely, uplifting or optimistic dreams and all too common to limit our expectations for people with disabilities.

When we start to dream with people with disabilities it is important NOT to say about the things desired, “but I can’t see her ever having a friend” or “there’s no way he could have a job” or “there’s no point in going to woodwork if you can’t use the machines”.

Wonderful things can happen in the lives of people with disabilities. Around the world we are seeing individuals with all kinds and levels of disability having work, living in their own homes, enjoying social connections and the other ordinary things people see as important elements of a good life.

Articulating a vision is the necessary first step. What does this person want? Some people with disability may be able to articulate some of their own goals themselves, with help and support to do so and possibly lots of help to implement these. Others may only need some guidance about how they might live their life.

Others may need us to dream a positive future on their behalf. What do we want for them?

Beginning to flesh out a vision of what a person wants or you want for them could mean, for some people, getting together a circle of support or a „think tank“ to help develop a clear picture of what a person with disability wants in their life. Maybe you can invite others in your life to help you do some dreaming. You could start fairly general with big, core shared issues and/or you could start exploring possibilities in much more individual detail, making a kind of plan of action as well. For many people it could be helpful to write down a vision statement.

We did that in our family. Alex is unable to articulate his dreams so we started with the things we know most people want in their lives. It was surprising what the effect of formalising our thoughts in writing was. It made us clarify our thoughts, it made us check that our ideas were shared ones and it helped us when it came to the next stage of communicating this vision to other people.

When we first did this, when Alex was very little, many of the statements were very general, like: “We want Alex to be involved with lots of different people. We do not want him to be lonely or isolated, but to have friends and acquaintances like other people.”

We wrote things like: “We want Alex to be seen as a person with an individual personality, strengths as well as needs and gifts to bring to others...” As time has worn on, these ideas have become completely internalised; you may never really need to look back at the paper. We kind of make a contract to pursue the things we want in the person’s life. Over time we have worked in things that are a part of what he is able to communicate to us: his love of company, of music, of wood, of water, to the more practical elements of what we do.

I am very grateful that I was encouraged, by other parents, to develop a vision very early in Alex’s life. It helped us reject the ‘separate path’ from an early age. The one thing we knew was that our dream of Alex living a life included in the community and with other people meant that he could not afford to head off on the separate path.

- Early Intervention delivered in a segregated complex? No.
- Early intervention services tailored to Alex getting the best out of his experience of preschool and delivered in the preschool setting in the context of the sandpit or water tray with other kids? Yes.
- Early enrolment in a special school at age four? No.
- Extra days at preschool then a tailored approach to school orientation? Yes.

The choices you make are facilitated by the clarity of your vision.

You need to share the vision with others. Your family, your friends, your acquaintances, the professionals you come into contact with, all those people who are so fond of asking you questions about your family member’s life and future. The more this vision of how someone wants their life to be is articulated, the more it becomes part of a real plan. The more you share it, the more it becomes a part of how others see the person with disability or you and your family. The more consistently it is presented, the more it becomes part of people’s expectations.

After putting our vision for Alex on paper, we began to talk to people we knew about this vision. My parents and parents in law thought we were unrealistic, because they come from a different generation and were still apt to view everything to do with disability as tragic. But people come to understand you are committed to a good life and this is something that, eventually, most people do “get”. You can start to answer the questions people have about a person’s life and future with the consistent communication of the vision. We might quite often have said things like, “I don’t know how we’ll get there yet...” but people have always known what we were aiming for. People may have all kinds of private reactions to that; people might see us as engaging in wishful thinking or developing a head-in-the-sand approach. I am sure many will be sceptical. We have probably all had to justify our choices, sometimes to virtual

strangers, but with a clear vision, it becomes as simple as repeating your vision of what you want and where you are headed.

An interesting thing happens when your vision is clear and consistently communicated. For one thing, it becomes a part of who you all are in the eyes of others. As Alex progressed through school, people began to simply understand the kinds of things we would and would not find acceptable. Some things that involved congregating people with disabilities together or having them go to separate places away from other students were eventually not even suggested for him, as they were routinely touted to other parents. Activities and excursions the kids in ordinary classes went on were also offered to Alex, where they were not always offered to other students with disability. What became apparent is that, while not everyone shared or understood our vision, it was accepted that this was the path Alex was on.

At a recent meeting at the school, the principal asked what we saw Alex doing after he leaves school next year and before we had a chance to say anything, a woman from the Department of Education and Training present at the meeting said something along the lines of... "I assume he'll be pursuing his choice of the things he'd like to do and learn in the community with whatever support he needs to do that". We had not discussed this with her; she was simply saying what she knew would be consistent with our vision for Alex. I do not think she had any idea of how post-school programs work or how we would actually even be doing that; she just said it without really having to think about it.

Another thing that happens is that unlikely people can come on board. Sometimes people you expect to support you do not; but invariably people you never expected get enthusiastic about another way of looking at the lives of people with disability. This can be a really exciting development. As we are doing some more in depth planning of the next phase of Alex's life, we are struck by how it is not necessarily our natural "friends"- the people we choose to socialise with- who are best at helping us with this. Other people we do not necessarily spend a lot of time with, but who value Alex can be really wonderful.

Thirdly, surprising unforeseen things can happen once you get started on pursuing the vision. There can be spin-off effects you were not necessarily expecting. I know of people who belong to a lapidary club where they polish stones, do silverwork, gem faceting and so on to make jewellery. I noticed when I went to one of their shows that there was a woman about my age, who has an intellectual disability. I was told she had been a club member for years. What I discovered about her story is that her parents decided as a young adult she needed interests with other people and brought her with them to lapidary club years and years ago at a time when no services existed for her. There, as it happened, it became immediately obvious that this woman had no interest in lapidary work at all. But she started getting club members cups

of tea and enjoyed the role of providing tea, coffee and, later food. Older members have gone; some younger ones have joined. She makes tea, sandwiches, scones and whatever else she chooses to make for members' contributions. She travels to exhibitions and goes to club social events. She does not need support to go there; other members pick her up etc. She is part of a social group and has a role that has been important in her life. It is probably not what the parents may have originally thought would happen. If there had been some program or service available, they may well have sent her there instead. This is an example of how the vision of a person living in connection with others can have unseen possibilities.

To return to the idea of a compass, once you have created a vision of a positive life and begun to articulate it to others, you also have created a kind of compass for navigating your way to that outcome. The actual navigation can, and probably will, be fraught with difficulties. The compass may point you in a particular direction, but insurmountable obstacles, mountains, gullies, may stand between you and getting there. A parent may know, for example, that they want their daughter in the regular class at school, but they face a wall of professionals continually steering her to a support unit. A person wanting tailored support for a young person to pursue interests and make connections in the community may find the only kind of support arrangement available in a town upon leaving school is a congregated adult day program.

It is vital for us to recognise that if we seek a good life, an ordinary life, for people with disabilities we are moving against a powerful societal current that will constantly try to drag us back to the set path deemed suitable for people with disabilities. This "set path" is limiting, where your vision is enabling. The usual options may be congregated with other people with disabilities, where your vision sees the person with many relationships with people in the community who have the capacity to help stimulate and support the person's life. Services may segregate people from other community groups, where your vision is about being included in the life of the community, in the local music group, library, art class, and workplace.

Clarity of vision allows us to evaluate choices that may be placed before us. You ask a simple question of things: "Will this choice bring the person closer to the desired outcome?" If I was evaluating the option of Riding for the Disabled against my vision for Alex's life, I would ask.... "Does this activity and grouping get Alex closer to the life I want for him, pursuing his interests and making relationships with other people from the community who have the potential to enrich and support his life?"

My answer would be "No".

Could the woodworking group provide him with possibilities to pursue his interests alongside other people who share that interest and can get to know him as an individual? "Yes".

At pivotal points in a person's life it may be a good idea to re-examine and reassess the vision and the paths being planned to achieve it. None of the fundamentals of our vision for Alex's life have changed, but we certainly see areas from time to time where our efforts need to be strengthened, or where we can celebrate unforeseen gains. It helps us strengthen our resolve and keeps us on track. At present, we are thinking seriously about life beyond school. If our vision for Alex is that he have a range of freely given relationships with people and that they get to know him as Alex instead of as a person with a disability, it becomes crystal clear that as he is on the brink of leaving school he must, despite his level of disability, be joining in with other people in ordinary community activities, sharing things that interest them. We will be asking...What does he like? Where will he meet people who share his interests? Would he like to go swimming at the local aquatic centre, to listen to bands at the pub? Join the folk club? If we can bring people into his life through some work role then he needs to have one...what could it be?

These are fundamentally different questions from "What programs exist for people with disabilities?" Our questions are in line with the vision, and are about making the life a person wants. The question about services is common but may be very limiting.

Programs and services are not the answer. Programs and services may provide some funds and supports, but they alone cannot result in the life you want. Unfortunately, for many people with disabilities, programs and services supplant their lives. People end up having nothing else in their daily lives; they have programs instead of a life.

Without a vision as the guide, families can unfortunately misdirect their energies, insisting that more funding, more services, more programs are what is needed for people with disabilities. But, as they are commonly delivered, these things often drive out the person's vision, any hope of dreams, the involvement of family and the building of a natural supportive community around the person. Then, of course, they are seen to need more programs and more services to take the place of other, disconnected areas of their lives. It can be a really vicious circle.

No. It will be what your vision drives you to make of those services, or in spite of those services, or even without those services that makes the difference. Many of the people who have achieved a supported life in the community have done so in spite of services provided rather than as a result of them.

We get loads of 'advice', often loaded with 'professional opinion' and 'limiting statements' about the nature of a person's capacity. The clarity of our vision can allow us to see through some of this. It may help us to see which options will drag us back into the current, and which ideas will allow us to move closer to the desired outcome.

Sometimes, the obstacles in the way are massive and we simply cannot move forward in the direction our compass indicates. It may be forced on us to divert from the path periodically. As my friend says, at times like that, “You may have to simply tie yourself to the mast and ride out the storm until you can make some forward progress again.”

A vision alone cannot guarantee anything. It must be accompanied by constant vigilance and lots of work to keep it on track. In the case where you have been forced to divert, you know you did not want to take this path. Knowing this, you may perhaps be able to put some strategies in place to mitigate some of the negative impact the path might have. For the parent who is more or less forced to place their child in a support unit at school it may be necessary to really step up the effort to increase the connections a child has out of school, through sport or other clubs or by inviting neighbourhood kids in the afternoons. These could be strategies to pursue while you work on getting into the classes you do want. People, who, years ago, had no choice but a congregated specialist day program for a person, may decide to work hard at increasing community connections at other times of the week, while they work out how they may be able to change the support arrangements over time to reflect their vision for the person’s life. We should all expect that there will be obstacles. That does not mean we ditch the vision. It means that we need it more than ever to help us work out other paths to the destination. And it means work.

People with disabilities and families are in the best position to consistently articulate a vision. Others, like workers or professionals are likely to get bogged down in other day to day organisational aspects of the journey. Their loyalties may be divided; people with disabilities and families can have their eyes on the compass. The vision keeps the destination in mind, but the vision alone is not enough. It must be used to examine choices, bring people in to help, provide guidance around barriers, reject inappropriate practices, and work against opposition.

You will be moving against the current. Visions of positive valued lives for people with disabilities are not commonplace. Service systems may operate like the current, channelling you off to the margins. You will definitely need to be determined and persistent. You will probably need to be innovative, apply trial and error, or take a leap of faith occasionally. I have recently had the pleasure of interviewing other parents and reading stories of other families and in many of these stories it became apparent that a better life had been achieved with complete faith in the vision and very little else, other than constant hard work. People without funding had set up small businesses; people decided to set about getting a home for someone with no idea at first how that was going to be achieved. The leap of faith, the trial and error, the thinking differently and the determined pursuit of that got people into better situations where

waiting for a service to provide something better could see you reach 100 years old and still be waiting.

You may receive little encouragement and even some derision. At times of difficulty, the clarity of your vision can offer a source of inspiration and something to steel your resolve. Find others who share your view of what the lives of people with disabilities should be like. Remind yourself to question - what can be so wrong about wanting a good life for a person with disability? Remind yourself that this is being achieved for heaps of people. We know that around the world there are many, many examples of people with disabilities living different kinds of lives, with appropriate support. Richer, more rewarding lives with more varied experiences and more relationships, work, a home and so forth.

If this is what you want and you believe it IS possible, you have yourself real, authentic Pirates of the Caribbean compass - it will point to that which a person most wants and it is a pretty reliable means of charting your course through all weather.

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