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- ▶ Good afternoon. Thank you for coming to this session.
 - ▶ My name is Maree Ireland. I work as Project Co Ordinator with field, furthering inclusive learning and development.
 - ▶ Today I am fortunate enough to have two assistants, Breeanna Dahl, who is field's Assistant Office Manager and who is helping me with the I T side of my presentation, and Karishma Bagiam who is my work based assistant.

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- ▶ Today I am looking at the development and management of disability support services within the last 10 to 30 years.
 - ▶ **I'll start by posing this question. Have people with disabilities and service providers come full circle over the control or management of the delivery of disability support services in the last 10 years? Can we stop this circle and learn and develop an up-ward spiral of co-operation?**


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- ▶ Is there some learning and development that can occur to assist people with disabilities and service providers to work together so people with disabilities can manage their disability support services to the extent that we want?
 - ▶ I will explore these questions now

- The year 2000.


- ▶ In the year 2000 we watched the first reality TV show “Pop Stars”. Then we experienced the Super Star Reality of the Sydney Olympics, and the introduction of the GST. The “super reality” for people with disabilities, however, was “back to the future” in “new institutions” after the promising start to attendant care in-home support in the 1980’s




By the year 2000, the development and management of attendant care from the mid 1980's was slowly being eroded from people with disabilities. Why did this loss of management happen and why are we now trying to regain control of our support services but maybe not with the same impetus of people with disabilities in the 1980s.


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- ▶ Disability support workers are the cornerstone of my life, as they are for many people with disabilities. I doubt that I, or other people with disabilities, could live meaningful lives without our disability support workers.

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- The question, for me is, then, how much “control and management” do I want to have over these services? I started using attendant care in 1994. At that time, I was able to interview and choose new workers, and vary shift times, through my co-ordinator which worked well for a few years.


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- ▶ Then around the late 90's, early 2000's a number of issues began to occur, like not being able to choose workers; shifts not being filled or being filled with strangers etc.
 - ▶ Further issues, such as shortage of workers, and the impact of the blanket interpretation of O H & S rules which impacted on the rights of people with disabilities have been explored and discussed over the last few years, in forums and research undertaken by *field*.


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- ▶ This has led to some people with disabilities, advocating for total control of the provision of their disability support services. Some people with disabilities have taken Self Directed Approaches (SDA's) on successfully, while many appear to be reluctant to take on the responsibility of self directed approaches.

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- ▶ The question, now, is what does “control” of your disability support really mean? Is it the actual, physical work, that is, managing salary related duties and costs such as timesheets, work cover, O H & S requirements etc. or is it being able to delegate those tasks and being the one who decides how one’s hours are used to





make one's life more meaningful? Is the meaningfulness of self directed funding in the actual doing of the management of such tasks, or is it the delegating of those tasks, and being able to direct how you use your hours and choosing your own workers in co-operation with a service provider.

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- ▶ I wonder if this question was ever thought about, or needed to be thought about in the 1980's when attendant care was a new concept between people with disabilities and support workers with no third party. A group of people with disabilities first came up with the idea of attendant care, or disability support, as it is now called.


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- ▶ This leads me to the question; what is the difference between the 1980s and the present day that people with disabilities are perhaps less inclined or motivated to take up self directed approaches.

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- In my research for my blog this year, some observations have been made that some people with disabilities and their supporters are reluctant or scared to take self directed approaches due to the responsibilities of it.


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- ▶ I will now look at the circumstances between the original development and establishment of attendant care in the mid 1980s by people with disabilities themselves, and the present establishment of self directed approaches, which is being led largely by government policy.





The question for me is, with change, does the ownership of the impetus for change, influence the degree of control people with disabilities will take on? In the 1980s the drive for the establishment and control of disability support services came from people with disabilities themselves,



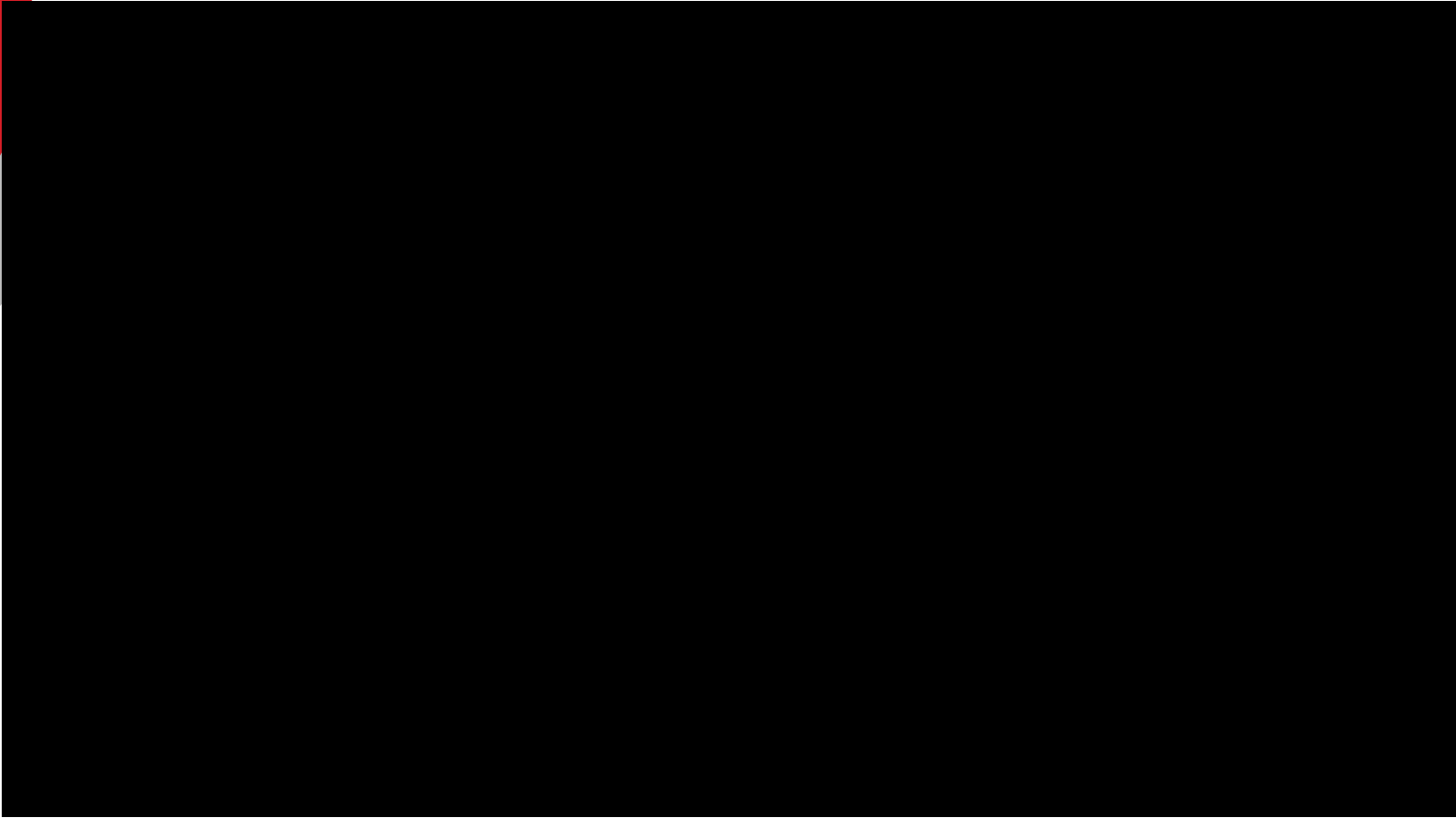
through using employment initiative project funds within a tight knit, co-operative environment, Whereas with self directed approaches, does the fact that the impetus, which has come from a policy directive and within an environment of many and diverse service providers, result in not so many people with disabilities having the desire to take on SDA's?


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- ▶ So is there some kind of learning and development (i.e. for people to regain the same impetus similar to the 1980s), that needs to occur to ensure that the idea behind self direct approaches can stay with people with disabilities within an environment of co-operation between people with disabilities and service providers?


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- ▶ I now want to take us back to the 1980's to see if we can explore what happened then, and avoid a repeat of the loss of management of disability services that had been established by people with disabilities.




I will now play a video of a conversation I recently had with Cath McNamara who was involved with the setting up of attendant care in the 1980s. Here are some of her thoughts on what drove people with disabilities to establish attendant care in Victoria in the 1980's



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- ▶ The concept of attendant care / disability support evolved in the mid-1980s which was a radical” idea, then and now, was for people with disabilities to have more control of their lives and live in natural communities. But what is it about self-determination, that is so radical?

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- ▶ Being in control of one's disability support is important, as it enables us to be independent and to pursue our lifestyle interests, in a way that suits us, as well as be a part of natural and reciprocated networks of support and interest.


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- ▶ Attendant support, as it was then called, was first thought of, and advocated for by a number of forward thinking people with disabilities, including Rob McNamara, Geoff Bell, Frank Stephens, Margaret Cooper and Mary Reid. These people had strong views about the way they wanted to live in the community, and saw types of institutionalised accommodation and support, that was being offered in the 70s and 80s as inappropriate.

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- The aim of attendant support was to find, advertise for disability support workers within their local area, to work and assist them to live their lives as community members. These workers would then form a team for that person. They then formed co-operatives that operated in a manner of respect and mutual co-operation.




▶ Different type of disability support.


- ▶ People with disabilities felt that this type of disability support gave them more control over their lives; more choice over the people who supported them and the type of relationship they could have with their workers.


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- ▶ Obviously the people who advocated for this type of support were people who were, and had been living in the community with the support of family and friends. They believed they had a RIGHT to be a community member and did not believe or thought they should be pushed into segregated or “institutionalised type” accommodation and support.


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- ▶ This group of people came up with the idea of being able to employ unemployed people through applying for employment initiative, project funds which were available at that time. They then established the Disability Attendant Study Incorporation (DASI)
 - ▶ This group was able to secure funding to set up the Personal Care Workers Study in 1984

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- ▶ They were able to set up a small organisation, with two guiding principles: consumer control and consumer participation. As Rob McNamara states in his book, *Touching the Corners*; I quote,
 - ▶ “The aim of attendant care is to enable people with disabilities to live in the community in their own homes without relying on an institution or family for our care.


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- ▶ It also gives us the unique opportunity of controlling our own lives by giving us the power to decide who will work with us. With attendant care we are no longer patients or clients, passive or grateful recipients of care or service. We are employers, with the power to hire and fire and the right to choose how our care is provided.” End quote.

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- ▶ This group developed an organisation called DASSI and after continuous struggles to maintain funding for the on going delivery of attendant care, they were involved in the establishment of the National Attendant Care Scheme.

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- This is a very brief summary of how this group of people established attendant care in Victoria.
 - The full story is in Rob's book, *Touching the Corners*.




There were many people involved and I think because people with disabilities were involved, there was a strong movement and impetus for the establishment of attendant care. People with disabilities had initiated this concept and wanted it for themselves to be able to live their lives the way they wanted

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- ▶ However, there were also other people with disabilities, who, due to their circumstances or the effects of their disability, were unable to remain living in the community and were living in segregated accommodation. There were also people who, because of their life experiences, did not know the difference and who thought they would always be dependent on segregated services of which they had little control.

Attendant care in the 1990's.


As the concept and demand for this type of attendant support grew, support agencies came into existence, to supply disability support workers and do the management side of it. This introduced a third party to the equation. As time has progressed, people with disabilities felt their control of the management of their disability supports, was slowly eroded.

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- ▶ This occurred through introduction of certain legislation; competition between agencies, and the depleting availability of workers. The concept of “consumer control” through being on committees of management of these services became popular in the 90’s



Although it was developed with good intentions, often, it became a tokenistic gesture, rather than meaningful management.


▶ During the 1990's and this decade there were many issues around the provision of attendant support such as stated above





All these issues slowly changed the character of the relationship between support worker and the person with a disability. Rules and regulations impacted on the underlying relationship of support worker and person with a disability.


Mid 1990's to mid 2000 – the concept of “attendant care” turned into a “business” -

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- Service providers were set up to provide “support workers” to people with disabilities in all situations. This led to quality standards; block funding to service providers; development of O H & S regulations, whose conservative, risk averse” interpretation

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- ▶ by service providers, impinged on the rights of people with disabilities. The “choice and control” by people with disabilities was slowly being “eroded” by regulations and control of service providers.


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- ▶ One example of this is illustrated by a woman with a disability, who was in a relationship, was asked to get a single bed so that workers could assist in turning her over during the night. How can you have a relationship in a single bed?
 - ▶ It felt like the main aim of service provider agencies was getting workers to fill shifts and people with disabilities could only get what was available.

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- ▶ We knew workers' conditions were not fair or equitable, but we had to live. It could be said that both people with disabilities and workers, could potentially have had “cost efficiencies” applied to them for the sake of profits. This led to shortages of workers and people with disabilities further losing control over who assisted them in their daily life.

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- ▶ It appears what we gained in size and systems providing attendant care, we lost in contact, management and comfort with our support workers within a close knit environment. We went from a “work colleague” situation, where there were workers interested in their position, to situations where workers in the 90s who were not as motivated;

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- ▶ **had issues around communication; and who had been “trained NOT to have a relationship with the person with disabilities.**

- ▶ There were also people with disabilities still using “segregated services”; nursing homes because of lack of funding for them, to be able to use “support services within the community”. What made these people with disabilities different from people with disabilities who had initiated and developed the concept of attendant care?





Did this lack of funding and “dependency on services” disengage and disempower people with disabilities from believing in themselves and their ability to live and participate in community life.





Is the tide now turning?

With the ongoing use of segregated services, (through no fault of their own doing), and the slow erosion of the control of attendant care by people with disabilities, it is little wonder that many people with disabilities have become dissatisfied in the delivery of disability support services.


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- ▶ Today people are once again trying to take back control of their lives through the opportunities afforded by the Self Directed Approaches to funding in Victoria. There are people who have successfully taken on Direct Payment and Direct Employment packages to gain control of their disability supports and their lives.


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- ▶ However, these are the minority and the reasons more people don't take up this opportunity are of particular interest and examined later.
 - ▶ It appears, that controlling one's own disability support service is seen as "a new and innovative:" step which started in the U.S.A, UK and other countries.


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- ▶ It was an idea that people with disabilities and their supporters started to advocate for again in the early 2000s. However, there is little mention or recognition that this type of delivery of support services was first thought of and established by the impetus of people with disabilities themselves in the mid 1980s.




Does the fact, that the push for self directed funding has come from an external source, that is, policy directives such as the Disability State Plan and other government policies, of which people with disability had indirect influence, rather than the impetus of people with disabilities themselves in the 1980s,


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- ▶ **explain the slow acceptance and uptake of SDA's by the majority of people with disabilities.**
 - ▶ **Can people with disabilities go through a process of learning and development to regain the drive of the 1980's, as well as skills and knowledge to take this step? What would this process look like? that can occur to strengthen people's meaningful choices?**


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- ▶ Does there need to be a process of “personalisation” of what it will mean for me; what will it enable me to do. Maybe this would “lessen” the perception of the enormity of the operational tasks of self directed approaches.

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- ▶ As well, perhaps with self directed approaches and the personal approach, the focus may be restored to the relationship between the person with disabilities and the support worker. During the 1990s there was a tendency to dissuade any notion of “personal relationship” forming between people with disabilities and their




▶ workers. This notion was conveyed in the professional training of disability support workers and by agencies who supplied workers. Inevitably though, there were relationships that did grow.

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- ▶ This was the topic explored in *field's* Learning Partnership Project. Participants in this action learning group – people with disabilities and disability support workers - focussed on exploring the relationships between support workers and people with disabilities.

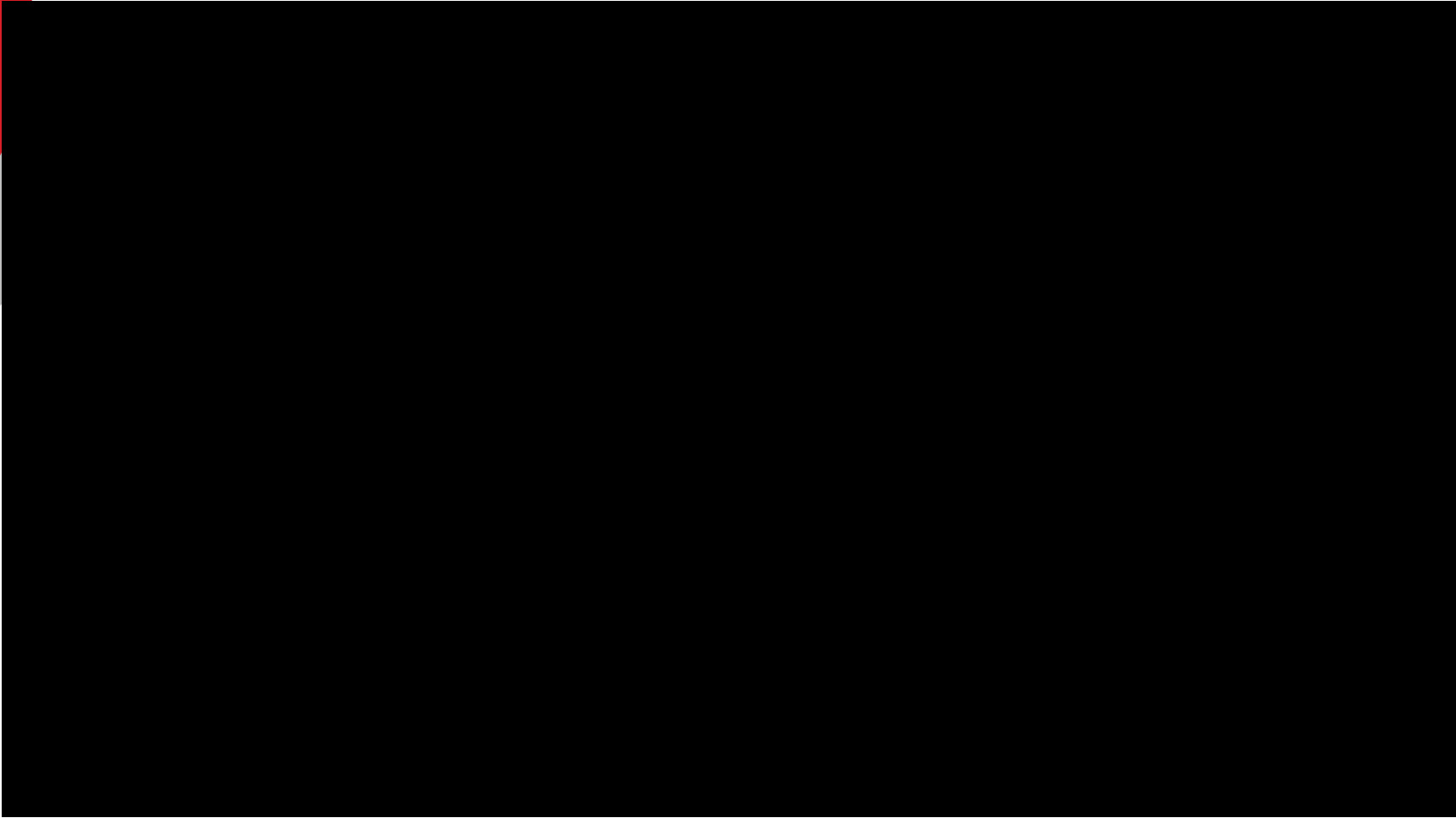



What is needed, so that today's people with disabilities, can have the "impetus" to take self directed approaches on? Perhaps there needs to be some action learning around the real meaning of self directed approaches? Not only by providing learning opportunities around the theory behind it, but also reasons why you should take it on, (that is, have the impetus).

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- ▶ Learning Focus should on the skills, knowledge you need to decide whether you can take on a type of Self Directed Approach, and the skills; knowledge; motivation that you need to then do it; that is, learning focussed on the needs of the people with disabilities rather than the provider.





I will go back to my conversation with Cath Mcnamara to share her thoughts on what needs to happen today to get people with disabilities more enthused about self directed approaches





Field's efforts are focussed on providing learning space for both service providers and people with disabilities and begin to give practical answers to questions and allay the uncertainty that currently exists. I would encourage you to visit our website; www.field.org.au, and my blog at http://www.field.org.au/blog/maree_ireland to make a contribution to this.

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- ▶ Together we can strive to evolve into an up-ward spiral of co operation, between people with disabilities and service providers, in the spirit of the concept of attendant care, introduced in the mid 1980's by people with disabilities..
 - ▶ Thank you.



I am happy to take any questions or comments, if time permits.