

What has the GDA ever done for us?

Tuesday 6th June 2017, Les Cotils 6:30pm

Welcome

Karen Blanchford, Executive Director, GDA

Welcome to the meeting, housekeeping and apologies.

Considering the access requirements for a meeting:

- Physical access and exits
- Hearing loops (if the room does not have a loop consider hiring a portable loop)
- Using microphones for answering questions for anyone hard of hearing
- We will be livestreaming the event so anyone unable to make it can watch it on Facebook and ask questions
- The meeting has been recorded for anyone who missed it (or wants to watch it again!) and will be subtitled

Introductions to:

- Rob Platts – Founder and Equality Adviser of the GDA
- Robin Le Prevost – GDA Chair

Slide GDA Who are we?

I should briefly explain some of the things we do and don't do:

Although the original idea, which eventually led to the creation of the GDA, was that it should represent disability related organisations, our founders realised that individuals must also be represented and, right from the start, the GDA has represented both individuals and groups.

However, the GDA cannot generally help or provide advocacy services to individuals. We simply did not have the resources.

If the GDA ever does get involved with an individual issue it is only when there isn't a member organisation which could help, and then only, if this would have wider implications.

We also decided that we should not generally be a service provider. We decided we must leave that to the States and to our member organisations.

The services we do provide to disabled individuals, and to their organisations, involve being a conduit for their voices to be heard by government.

Our main role is to influence government on behalf of disabled people.

We also help our members to speak to each other, and we consult with members, through monthly meetings, focus groups, through our website and through our campaigns and through social media.

We also empower disabled people, and member organisations, to represent themselves, especially when tackling common issues.

Wigwam's work, representing the interests of children with disabilities in general, within the Children and Young People's Plan, is a good example of this.

When planning for this session Rob sent me an email late one night saying watch this! ... It was the Monty Python – what have the Romans ever done for us? Let's us it, I said, Rob agreed but refused to dress up!

Play Monty Pythons Clip <https://youtu.be/4F99WkhtLQw> 2 mins

Rob Platts MBE welcome

Good evening everyone, I'd like to add my welcome to you all.

Right from the start I should be clear that I'm not claiming the GDA has solved the islands sanitation problems, or indeed brought world peace.

Karen has dealt with the "what we do and what we don't do bit - my job today is to explain some of our achievements.

We have a lot to cover, so I'd ask you to bear with us and to hold questions until the end.

When we talk about achievements today, I am acutely aware that, even after almost 10 years of the GDA being in existence, and four years after the Disability & Inclusion Strategy was agreed, life, and life chances, for many disabled people, have yet to change, significantly, for the better.

What I hope we'll show today is that there is progress being made and that there is reason to expect to see, within this political term, some of the significant promises, made by our government in 2013, becoming reality.

Even so, the current work streams of our Strategy should be seen as only the initial stage.

Realistically, for Guernsey to fully comply with the UN Convention on the Rights of Persons with Disabilities, will, I believe, take several more years.

To get a good handle on all that has happened, we probably need to go back a bit and explain how and why the GDA came into being and, even before that, it's probably worth spending a few minutes talking about what we mean by disability.

Slide of disabled Germans

Attitudes towards people with physical and mental impairments have changed a lot since the last century, when segregation and sterilisation were routine in many countries and even mass extinction was not unheard of.

Before the 1970s, approaches to disability were often, and, sometimes still are, based on charity – and on doing things for disabled people.

But these approaches, although well meaning, can have the effect of being oppressive, and of placing an obligation on people to live in a perpetual state of thankfulness.

These attitudes can rob people of a voice, and may do little to empower them to make a life for themselves, as independently as possible - to participate in society, and to achieve their full potential.

Thankfully, most societies are moving away from attitudes where people with disabilities are seen as objects of charity or pity or as having less worth- or being “invalid”, as my fellow disability campaigner, Aindre, thought provokingly pronounces the word “invalid”. And, disability is no longer being viewed simplistically as a medical issue.

Disability is something which limits a person’s ability to function or to participate.

Slide Disability =

The causes of these activity restrictions are, however, often more to do with barriers caused by attitude and by the design of the built environment and communication and transport systems, than they are to do with the person’s mind or body.

As an example, if a lift isn’t working, everybody is disabled, to an extent, more so if a person is unable to use the stairs instead.

But that disability, or activity restriction, only lasts as long as it takes to fix the lift.

Disability is increasingly understood to be a normal variation of the human condition and there is now worldwide understanding that all people, no matter their level of ability, disability or functionality, or participation have equal rights.

Slide – Disability spectrum

More recently, disability is being explained as being a spectrum or continuum, which every human being is on. There is also an understanding that disability can be permanent, temporary or fluctuating.

Our place on that spectrum. Therefore, changes throughout our lives, even on a daily basis, but generally, disability increases with age.

Reflect for a moment, on the fact that we all start life fairly restricted in our functionality and ability to participate.

The idea that we are all on the spectrum may be an uncomfortable idea for some people, initially at least, especially for those of us who may, in the past, have viewed, and perhaps even used, the word “disabled” as a derogatory term.

It is not surprising, given the history of disability, some voluntary organisations in Guernsey haven’t, in the past, wished to be associated with the word “disability” and indeed, that many individuals may not wish to identify themselves as being a disabled. Hopefully this will change as attitudes change.

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So, moving on to how the GDA came into being: In 2007, two important things happened which led to, and shaped, the formation of the GDA.

Slide: Townsend Report

Firstly, five years after the Townsend Report into Guernsey living standards showed a clear link between disability and social and economic disadvantage, the States decided that part of the solution would be to set up a disability forum, to be made up of various user groups and service providers.

Slide: “The Voluntary Organisations Group”

The States decided that one group should represent all the voluntary organisations which had any connection to disability on the island.

Within a few weeks of the initial meeting in 2007 calling for volunteers, this group was born, with yours truly as the acting Chair of what was then known by the snappy title of the “The Voluntary Organisations Group”. I undertook to devote a year to getting this group set up.

At our first meeting, I remember feeling challenged and a bit deflated by the skepticism and resignation in the room.

There was a bit of a feeling amongst some that it would never work and that we just had to be resigned to being invisible and that the difficulties that many faced were unfortunate, but simply came with the territory.

But I also remember someone sitting quietly at the back, taking it all in, that person was Shelaine Green. That was probably the last time I remember Shelaine being quiet!

Shelaine took over as Chair in the second year and remained in post for 7 years.

Slide: GDA logo

One of the first things Shelaine did was to offer the group a better identity - rebranding it to “The Guernsey Disability Alliance”.

The government initiative, the Disability Forum, never really came to much and eventually fizzled out – but the GDA gathered pace.

The second important thing that happened in 2007 was that I met this man:

Slide: Dave Purdy

Dave Purdy changed my view of the world and my understanding of disability - he did it in a gently challenging and non-judgmental way.

Dave became our first Vice Chair.

Before 2008, the general approach of the 70-odd disability and health related charities in Guernsey was to tackle specific individual projects.

Slide: 70+ Guernsey Health and Disability organisations.

We had a variety of groups or individuals trying to tackle a variety of physical access projects around the island, and then others, trying perhaps to improve access to tailored education services for their child who had high functioning autism, whilst others were trying to sort out speech and language services for their child with learning difficulties.

We had individuals and groups trying to solve the respite gap for adults and yet other groups trying to solve similar gaps for children.

The organisation I had been involved with for some years, the MS Society, was busy tackling, amongst other things, the effects of relative poverty.

– doing basic work, like giving grants, or supplying specific things like incontinence pads to adults with MS so that they could cope with the extra cost of disability, and so that they didn't have to choose between buying such things themselves and foregoing activities which may not be as practically essential, but which we know are essential to our wellbeing –

Things most of us take for granted, like visiting friends or family, enjoying cultural activities, - even something as modest as going to the cinema or having steak, once in a while, for dinner.

But, if you think about it, there are loads of charities, not just the MS Society, which see tackling the extra costs of disability as part of their remit.

However, tackling these extra costs and the effects of poverty, by giving things to disabled people, rather than by tackling the poverty itself, does, of course, tend to re-enforce the unhelpful link between disability and charity.

A time and motion consultant could have a field day and would probably suggest all those charities should pool resources – but actually – that's still not the answer.

Meanwhile, back in 2008, the GDA Exec had a growing feeling it wasn't going to solve much by just being part of the government Disability Forum.

So, how was the GDA going to tackle these issues?

What's the answer to the old question - "How do you eat an elephant? – Anyone? "One small piece at a time".

Actually, the breadth of issues was almost overwhelming and disability in Guernsey wasn't looking much like an elephant. This was a herd of elephants, mixed up with some blue whales and the odd dinosaur.

In the very early days of the GDA, we put together a plan to consult with our members and identify our top priorities. We then aimed to organise separate groups to tackle each one. Those priorities are shown on the slide.

GDA Elephant Slide

Do you see the difference here?

The GDA saw there were efficiencies, and power, in moving away from considering individual projects affecting a particular impairment group in a particular place and concentrating instead on trying to achieve systemic change to those things which are essential for all of us, to live independent, fulfilling and fully participating lives.

It's just as important, for instance, to someone with cancer, that discrimination doesn't prevent them from remaining in employment, or that the extra costs arising from their condition should not unduly effect their wellbeing, as it is say, for someone with learning difficulties, or someone who is a wheelchair user.

We soon discovered however, that the idea of setting up various sub groups was, in hindsight, doomed to failure.

We just didn't have enough volunteers, with enough skills, and of course, much of the work needed to be tackled Mon to Friday 9 to 5 – not the usual hours of the volunteer.

Slide: Then the light began to dawn.

Then the light began to dawn - This enormous and complex issue of disability, this huge elephant, or whatever animal might represent it, wasn't actually ours to eat.

The long-term, rightful and sustainable solution to all of the issues was not charity or pity, no! The solution lies firmly with government which has control over all these things.

Slide: States of Guernsey logo

Oh!, it might seem obvious to you all, sitting here now, but when you've been steeped, as I was, in the service providing charity model and maybe have never even thought there was a possibility of challenging government - let alone that it is our right and, maybe, even our duty, to do so, then you might perhaps see why the penny took a while to drop.

We came too realised too, that, while the Townsend report gave some clues, there was no real data about disability in Guernsey. This was holding things back, because disability was often invisible.

I'm pretty sure I remember one politician saying that there were only 3 wheelchair users in the island – in fact, when Alice Flower's wheelchair report was published, we discovered that there were over 1,000.

We also began to understand there was probably a huge army of carers, even including some children who act as carers, who were unsupported and under-valued - but we couldn't quantify this either.

So, it became obvious that, if the States didn't know how many people were affected, or what those effects were, the States didn't have a hope of tackling the issues.

The GDA's job, it seemed to us, was to help unveil the hidden elephant and guide the government in eating it.

For these reasons, before 2008 came to an end, we decided to seek audience with the States – the following short video from Shelaine explains.

Run Shelaine video 2 mins <https://youtu.be/LVZMO9N8nMw>

Slide: GDA Achievements

I don't know about the brave bit, my legs were shaking all through that presentation.

But, as Shelaine explains, most of the GDA's achievements flowed from that first meeting.

Slide: The Voice of Disabled Islanders

It was that meeting which put disability firmly on the political agenda in Guernsey.

It was that meeting which established the GDA, particularly in the mind of government, as a combined, and representative voice of disabled islanders.

I believe, this in itself, was a significant advance for all islanders affected by disability.

One important point to grasp here, is that in order for the GDA to represent the views of disabled people it must maintain, and consult with, as representative a membership as possible.

Through our regular member meetings, the GDA has, for nearly a decade, provided disabled islanders, and the organisations which represent them, the opportunity to interact with each other, and with visiting experts, and with States Members and Civil servants, and to share views and news and to have their voices listened to.

GDA monthly meetings typically attract 25-40 people and our special meetings have often attracted more than 100.

Slide: GDA attracts high quality speakers

The GDA meetings have also attracted, and funded, a number of expert speakers from Guernsey and from around the world, adding to the local knowledge base and stimulating interest in disability issues.

Slide: Examples of GDA expert contacts:

The GDA has developed useful contacts with a number of internationally renowned experts and with various human rights commissions, many of whom have given generously of their advice and time.

This is important for disabled people, because the advice and opinion given by these experts informs, and adds evidence and authority, to our work to influence the States.

Slide: Government Research 2012 – Front cover of Disability Needs Survey

The research, which the government undertook after that first meeting - the Guernsey Disability Needs Survey, showed, for the first time, the number of islanders affected by disability and how disability affects their everyday lives.

Slide: Guernsey's Disability & Inclusion Strategy - Work streams:

This research led, in turn, to the development of Guernsey's Disability and Inclusion Strategy. The headlines of that Strategy are shown on the slide which we've entitled the State's Elephant.

Slide States' Elephant

One of the principle objectives of the Strategy is attitude change.

The research provided much of the evidence base and the information needed, for the States to priorities the things our government should be doing. I believe this is a better way than simply listening to the loudest voice.

There should be no doubt the GDA was the catalyst for this research, and indeed, for the development of the Strategy which followed.

The GDA realised, however, that another significant piece of research was needed.

Slide: Slide showing front page of GDA report (Ocean)

We knew that one of the work streams of the Strategy would be legislation and that it would be necessary for someone to look at models of legislation around the world, to try to understand what worked and what didn't.

But we also knew there was no government funding or resource available for this research, so the GDA took the pragmatic decision to undertake this work itself.

This research, which took almost two years and ran to 200 pages significantly informed the development of the Strategy.

As well as being directly represented in the development of the Strategy, and then in the Steering Group responsible for monitoring the implementation of the Strategy, the GDA was also a member of the team developing the legislation.

This meant hundreds of hours spent in government offices, but the benefit to disabled islanders is that our voices were being listened to and our views directly reached policy makers.

The GDA research has already benefited disabled people and hopefully it will have a lasting legacy.

Slide: GDA Communication and Partnership Working

During the development of the Strategy, the GDA joined with the States Social Policy Officers, to present the proposed Strategy to all States Departments, through a series of special presentations.

We also presented to various business bodies such as Chamber of Commerce and GIBA.

Slide: Strategy on a page (Framework A4 portrait)

The Strategy was a large and complex document and it was the GDA which helped the States by producing a graphic which, on one page, explained the main work streams. - By the way, we are not expecting you to read or understand the slide – we put it in just to illustrate the point.

We also made sure our members and member charities were kept informed through dozens of other meetings and communiques.

Slide: Montage of fact sheets?

To ensure wider understanding, the GDA developed and published a number of Fact Sheets on key issues.

Because we had changes of government in 2012 and 2016, the GDA, through its unique speed hustings events, made sure that politicians and potential politicians were aware of the issues. This was another of Shelaine's genius marketing ideas.

The effects were amazing — disabled people felt empowered, and politicians started to change their understanding about, and attitude towards, disability.

But this short video explains better than I can

Speed Hustings video

Slide: “Strategy agreed in Nov 2013”

The GDA went on to develop the brand of 'We All Matter, eh? For its member activities.

Slide: “We All Matter, Eh?” logo

This marketing approach was responsible for attracting 200 people to the steps of the States in support of the Strategy.

Slide: Photo of members on steps

We all matter eh? has gone on to become the public face of GDA member activities and the branch of the organisation which tries to change attitudes.

WAME has produced a number of video campaigns, including videos about disabled people's experiences, about transport, hidden disabilities and accessible sports and activities.

These videos were designed to raise and broaden awareness, and to allow individual disabled people a voice.

The videos have been viewed 23,000 times. And the total time spent viewing them equates to 21 days of viewing

We don't have the resources to measure it, but we are confident the GDA has started to change attitude towards disability within the States and, perhaps to a lesser extent, amongst the general population.

Slide: "Everything Guided by the UN Convention"

The GDA has been a direct catalyst for the States commitment to adopting the UN Convention on the Rights of Persons with Disabilities.

It was us who did the research which showed just how unusual it was for any government, let alone a government of a first world jurisdiction, not to have committed to the Convention.

This is, actually, by far, the most important part of the Disability and Inclusion Strategy, as the Convention is designed to guide our government in recognising the rights of disabled people in all that it does.¹

We can't officially get the Convention extended to Guernsey until we have made more progress on the legislation - but this doesn't mean that progress on realising the other parts of the Convention should be held up.

Technically, though, any delay in extending the Convention has the effect of delaying the States' commitment and promise to disabled people.

Slide: Government leadership

Right from the early days, the GDA argued for stronger leadership, recognition and understanding about disability within the States.

We learnt from our research that one of the reasons why Sweden's Strategy, for example, has been more successful than New Zealand's, is because of a difference in political leadership and legal impetus.

Whilst political leadership on disability issues is still weaker here than the GDA has campaigned for, the work of the GDA has led directly to a number of helpful initiatives which have, to an extent help mitigate this weakness.

¹ Jersey Disability Strategy – see link

The GDA's influence led to the Disability strategy including a requirement that anytime a Policy is developed, the relevant committee must include information about how they have considered disability.²

As Shelaine pointed out in the video, our work led to the appointment of the first ever States Disability Officer. A position currently held by Caroline Mullins.

Slide: Picture Caroline Mullins, States Disability Officer

This means that civil servants have an in-house resource to refer to and which guides on disability issues.

The Disability Officer's main roles within the Strategy include project managing lead areas such as improving information and awareness raising, including the launch of the new Signpost.gg website, and working with the Guernsey Employment Trust on information for employers. Caroline is also involved in project managing the States online disability training and the States review of responsibilities.

In addition, our lobbying led to the creation of the political position of States Champion for Disabled People. Currently Sarah Hansmann-Rouxel

Slide: Picture of Sarah & Disability Champions team

There is actually a team supporting the States Champion and that team deals with disability issues raised by members of the public. Their role is to listen to disabled people and to reflect their views in the States of Guernsey.

Slide: access to States debates

It was the GDA which campaigned for, and achieved, access to States' meetings for wheelchair users.

Slide: Right to vote

It was the GDA which campaigned for and achieved changes in legislation which allowed every person with disabilities the right to vote.

Slide "Equality and Rights Organisation"

It was the GDA too, which was responsible for identifying, through its research, the need for getting the States to commit to establishing, subject to business case and funding, an Equalities and Rights Organisation.

² A cautionary note here though, about expectations.

Apart from awareness raising and prohibiting discrimination, which the Convention requires governments to take immediate steps to deal with, most other Articles may be progressively realised taking reasonable account of available resources.

Such an organisation will be valued by many sectors of society but our research highlighted the particular importance to people affected by disability.

Our research shows that, typically, 60% of all enquiries to such bodies, all around the world, are about disability, and that professional guidance and advice is shown to be very effective in preventing and solving disability issues.

Slide: States' Review of Responsibilities

It was the GDA research which highlighted the need for the States to review its responsibilities and services, to quantify what changes and improvements would be needed in order to comply with the UN Convention and indeed with forthcoming legislation. This work is underway.

Slide: Caring for carers and respite service gaps

As we mentioned previously, the GDA recognised there were significant gaps in respite services and, together with the MS Society, we developed and published a report to the States on respite care in Guernsey.

Our work has also helped inform the recent important Community Foundation initiative, looking at provisions for carers in Guernsey.

Slide: Employment and GET www.get.org.gg

The Strategy led to the establishment of the Guernsey Employment Trust. The Trust exists to provide a range of services including support for people with disabilities to find and remain in employment.

The number of people it helps into work has increased each year since 2015 and, so far, the Trust has helped 140 people find employment.

In addition, the Trust has developed an employment best practice guide and is spreading information, and raising awareness, amongst employers.

The GDA has worked with the Trust and has contributed to the guide and to subsequent presentations.

However, the GDA has flagged up that there are disabled people who fall outside of GET's remit and we have requested a review of systems to help these people too.

Slide: Improved information for disabled people

It was the GDA which introduced the idea of the DisabledGo website to the States and our work led to the States contracting with Disabledgo and hundreds of venues being access reviewed.

This means that local people and tourists are better able to plan their trips with confidence. It also provides impetus for our restaurants, hotels and other public venues to improve accessibility.

The GDA and its members were actively involved in the new [Signpost.gg website](http://Signpost.gg) and the free [online disability training](#).

We are pushing for greater awareness of both.

Slide: Access & Access for All www.access.gg

Access, along with rights, was raised as one of the top priorities by our members. Accessibility in all its forms is given high priority by the UN Convention.

The GDA has directly, and indirectly, through its spin-off associate group, Access for All, been responsible for advising on hundreds of access projects, in fact, over 100 in a single year - including physical access projects such as the Rockmount refurb, and access to information, such as website & manifesto design, and access to various services and access to activities and sports.

Slide: Provider of expert opinion and advice

The GDA has provided detailed and expert responses to many government consultations. The GDA's work directly brought changes and improvements in a number of the policies associated with these consultations.

Our work led, for instance, to the four new accessible taxis and to planners taking a more holistic view, within the Island Development Plan, to changes and initiatives involving disability related access.

We have safeguarded the interests of people with disabilities by successfully challenging, and achieving amendments to various government proposals with regard to social security and benefits.

Slide: Legislation: matters challenged by GDA:

- Protection only in employment
- Wholesale import of UK legislation
- Modelling on existing Sex Discrimination Ordinance.
- Introducing fees for complaints heard by the Tribunal
- Medical model of disability,

In a few minutes, Karen is going to talk about the effect of the Strategy work stalling in 2015. Before that, I'd like to briefly explain the progress made on legislation up to that point.

The GDA, as well as the initial large report, contributed many other research papers to assist and influence the work of the legislation group.

By the summer of 2015, the legislation group had developed a draft Policy Letter which was, probably, I don't know, 65% or 70% complete.

At that stage, further work was needed, including wider consultation, to get the draft to a point where it could go to the then Policy Council for approval, before it could finally go on to the States to debate and then subsequent drafting.

The work of the GDA within that development group was immensely challenging but we were able to offer many ideas and concepts which could enhance the legislation.

However, it should also be recognised that resisting certain ideas should be seen as achievements too.

I'm not going to go through the detail of the things we resisted – some of which are listed on the slide.

Instead, I'll briefly describe just the first issue – that of a proposition, which actually came 18 months after the group started its discussions.

The proposition was, that the legislation should, initially at least, only protect disabled people from discrimination in employment and not when trying to access goods and services and education.

This was put forward as a proposition because it was felt to be more achievable and understandable and because Guernsey's current systems and services may be set up more to deal with employment.

Apart from the fact that approaching legislation in this way sends out an unintended, but nevertheless unwelcome message – that the government places a higher priority on protecting people in employment than when learning, for example - Disabled people are getting a little weary, of the delays in respecting their rights, being excused on the basis of having to restrict service delivery to fit current services.

As Martin Luther King observed, "A right delayed is a right denied"

It is the GDA's view there is no real evidence base to the assumed difficulties of covering all the fields.

The GDA produced evidence of need and rights and evidence too, that dealing with discrimination in these other fields is really not very different or onerous.

Many countries, including, for example, the UK, NZ, Northern Ireland, Hong Kong, Gibraltar, Canada, Australia and the USA have had protection against discrimination in the fields of goods and services and education in their legislation for over 20 years.

The GDA resisted this restriction because non-discrimination in the fields of access to goods and services and education is massively important to disabled people. Education is absolutely key to our life chances.

I think everyone here might understand that we were not particularly comforted by suggestions that the States would eventually get around to such protections.

The UN Convention requires governments to take immediate action to prevent discrimination in all these fields. It is one of the few rights within the convention which may not be progressively realised

Because of this, the UK actually won't extend its ratification of the UN Convention until and unless our legislation protects in all these fields.

Slide: Extension of the UN Convention to Guernsey seen as essential

Ratification is really important because, at that point, the Convention moves from being a wish list to becoming a government promise, monitored by the UN.

Experience elsewhere shows that ratification is an important impetus for the real changes we all wish to see.

There is now a new group developing the legislation. Whilst it's a bit frustrating that the new legislation group may well re-visit some of these issues, I believe the new group has a better understanding of what is required by the Convention and also, I believe the new reporting structure will, at least, prevent the discussions from being as protracted.

All of this work by the GDA means that the GDA has protected the development of the legal rights of disabled people and has been directly responsible for, so far, ensuring that the States has not introduced, and incomplete, ineffective and unfair legislation.

The GDA might stand accused of delaying progress, but our resistance was based on, and evidenced by, our research. And actually, the UN Convention gives the GDA a mandate to be in that room, arguing the case for effective legislation to prevent discrimination on the ground of disability.

I'd like to hand over now to Karen, who will spend a few minutes explaining what happened when, and what has happened since, the Strategy stalled in 2015.

Karen to explain from here

Slide: Implementation of Strategy stalled, 2015

By the summer of 2015, the GDA had been representing disabled people, both within the team responsible for overall implementation of the Strategy and within the team working on the legislation, for about 18 months

Significant progress had been made on the legislation and plans were in place to develop capacity legislation and to launch the Guernsey Employment Trust.

Progress on all the other streams, such as information, the audit and the frameworks, however, was slow, and nothing had been achieved as far as the business case for the ERO was concerned.

Basically, the Strategy had been under resourced and also the civil servant leading almost all social policy work left the states in late summer of 2015. But, also, we then had a

change of government and this coincided with the planned substantial changes in the system of government. It took more than a year for momentum to build again.

Slide: GDA not stalled

To be clear, whilst much of the work on the disability strategy work streams, including work on the legislation, stalled for almost 18 months, the GDA was still fully occupied representing the needs and rights of disabled people in all the other strategies which had been cut out from the Disability Strategy. This cutting out of various parts of the Disability Strategy can be seen as a sensible way of eating the elephant.

These included things like the Children and Young Peoples' Plan, the Supported Living and Aging Well Strategy and the Social Welfare Benefits Investigation Committee. The GDA sat in all of these meetings and also ensured the GDA continued contributing to other consultations.

This work now continues with Arrun Wilkie, our Vice Chair, and me covering Social Policy, along with our member organisations.

Also, the work of We All Matter, eh? and Access for All continued.

Slide: Speed Husting photo

The GDA took an active approach to Election 2016 consulting with the Home Department on the right to vote and accessible voting, manifestoes and web design as well holding our Second Speed Hustings Event.

After the 2016 election, responsibility for the Disability Strategy moved from Policy Council to the new Committee for Employment and Social Security.

Ultimately, we believe this will prove to be a good move, but I think we all have to accept the new team needed time to get to grips with eating the various parts of the "Elephant" which still need eating.

We have decided we must move on from the difficulties of 2015.

We're going to put past problems away in a box and look forward with renewed enthusiasm to progressing realisation of the UN Convention.

Slide: Strategy update

The new team is better resourced.

ESSC has established a new Disability and Inclusion Strategy Project Team, and I represent the GDA within that team.

Slide: Picture Ellen Pragnell

Ellen Pragnell is now in post as the lead civil servant on the legislation and ERO projects.

Although not her only responsibility, these are her main projects.

Work has started again on the legislation and work to consider the ERO has also just begun.

As part of GDA push for improved information and transparency ESSC now provides 6 weekly public highlight reports.

Identify Strategy Gap – As Rob has said, most of the Articles within the UN Convention can be achieved progressively but some are meant to be achieved as soon as possible. Two of these things are taking immediate steps to prevent discrimination and the other is awareness raising.

Imagine how much easier it would be to get everyone to agree and welcome the legislation if we had a successful awareness raising campaign was carried out first.

Measuring attitudes.

Karen: That concludes this section of our presentation we'll have questions in a little.....Andy interrupts

Andy, in the audience gets up and says:

Hang on, hang on, this is all very well, but, apart from;

- being the voice of disabled people in all those government meetings and consultations, and,
- putting disability on the political map, and
- raising awareness, and
- the dozens of member meetings, and
- the Speed Hustings, and
- starting attitude change, and
- Access for All, and We all matter, eh, and
- all those videos, and
- raising awareness about carers, and
- the respite care report, and
- the GDA research, and
- better access to voting, and
- access to States' debates, and
- improved information, and
- the hundreds of access projects, and
- accessible taxis, and

- the States disability officer, and
- the States Champion for Disabled people, and
- and the work and influence to achieve:
- the disability strategy designed to;
- safeguard vulnerable children and adults, and
- adopt the UN Convention, and
- build Frameworks for autism, dementia and learning difficulty, and
- establish an Equality Body, and
- Prevent discrimination.
- What has the GDA ever done for us?

Karen to Invite Robin to talk about GDA future risks and challenges.

Funding – Robin (5 mins max)

Slide: GDA Funding and Risk

We'd like to end the presentation by briefly talking about GDA funding and the inherent risks we face.

In the early days, the GDA was established with an unwritten understanding that we wouldn't ask members for a membership fee and please don't worry we are sticking to that.

There were and still are two reasons- many member charities are restricted in what they can spend their funds on and may only fund things which are of direct support to individuals. Also, we could not conceive of asking a fee from individual members, many of whom survive on very modest incomes.

But another issue we soon discovered, was that corporate sponsors were often happy to fund particular projects which can be seen to have immediate benefit to disabled people – the “charity model”, Rob discussed earlier.

But very few companies can be persuaded to fund what is essentially a campaigning organisation – even if the work of that organisation promises to bring more independence and wellbeing and, even, to reduce the need for the traditional charity service model.

So in conclusion the normal routes of funding were out of our reach and remain so.

Now, this next point is important – we've touched on it already but it's worth repeating. When you look at the functions of the GDA, its membership is vital to its work of influencing government and achieving attitude change.

If the GDA doesn't maintain a representative membership, and properly consult with that membership, it cannot claim to represent disabled people.

These two functions, influencing government and representing disabled people are completely different, but absolutely linked, and both require people and money.

The GDA was fortunate to have benefited from a small number of volunteers, most notably Shelaine and Rob, who went on to give many years of more than full time service.

From 2009, Rob was away perhaps 4 months of the year, but, with the wonder of the internet, was able to carry on working, wherever he was.

For the 8, or so, months Rob was on island, Shelaine and he acted as co-chairs and we were both pretty much full time.

Whilst the executive functions of the GDA, the work of influencing Government were being covered voluntarily by Shelaine and Rob, those functions didn't require funding.

However, it's worth reflecting that a conservative estimate of the commercial cost of the time those two have given to the GDA, over the years, is probably nearing a million pounds in terms of consultation services and a massive amount of research which has benefitted Government primarily.

And if you think about when that work begins to be delivered which will provide a substantial and positive improvement to the lives of thousands of islanders, I'd suggest the actual value of their work to Guernsey PLC will be immeasurable.

Slide: Lloyds Bank Foundation CI <http://www.lloydsbankfoundationci.org.uk/>

Fortunately, in the early days, the Lloyds Foundation stepped in to help - providing us with a grant for us to cover the essential membership and communication duties. Rob and Shelaine were focused on the influencing and supporting government part.

The Lloyds foundation has been a fantastic supporter of the GDA, and has understood and supported our vision, almost from the start.

Now – another important point - We thought that by the time the Disability Strategy was in place, the GDA could change from its, "influencing the Strategy", phase 1 if you like, to more of a monitoring role, phase 2, more on that in a minute.

The member communication and consultation roles would, however, largely remain in this second phase.

We thought this phase change might happen within a couple of years of the Strategy having been agreed and the GDA's business plan, developed in 2014, anticipated both Rob and Shelaine's planned retirement.

Slide: Guernsey Community Foundation (GCF) <http://foundation.gg/>

And that we would need an Executive Director to take over as we moved into phase 2, the plan predicted that the Strategy would be delivered, or be well on the way to being delivered, by late 2015.

We are enormously grateful that The Community Foundation agreed to fund the Executive Director position for two years and we embarked on transitioning.

But, as we know, delivery of major parts of the Strategy was slow and then stalled altogether, and, to be honest, this has made a bit of a nonsense of our business plan. In essence, progress has been delayed by, probably, two years.

So in a little more detail what is phase 2?

Slide: UN Convention requires disabled people are consulted and involved.

The Convention requires that:

“In the development and implementation of legislation and policies to implement the Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities”

We might be criticised, perhaps, for not previously including this continuing work within our business plan.

But, what’s the saying, “Plans are useless but planning is indispensable” and, considering the complexity of the issues, and the fact that there are so many factors beyond our control, and indeed, considering all that the GDA has achieved, we were and are open to the challenges of an under resourced and changing government.

The Community Foundation has, thankfully, funded Karen’s position for a further year up to April 2018.

Frankly, without the Community Foundation’s and Lloyds Foundation’s continued support, the GDA and its WAME brand and probably also Access for All, would not exist.

But, relying on the Community and Lloyds Foundations is not a sustainable funding model, and we are seriously concerned about how the GDA, and its essential functions of influencing government to deliver equality of opportunity and of being the voice of disabled people, will continue.

In essence we face a funding gap between phase 1 and phase 2 (which in most other countries is dealt with as a duty of government to provide funding of an independent monitoring and liaison body) due entirely to the extended time that phase 1 has taken, is taking, to come to fruition

The GDA is continuing to explore other avenues for funding, including approaching the States earlier than envisaged, but we thought it important to give a heads up that our vital work faces significant risks.