



COMMONWEALTH OF AUSTRALIA

Official Committee Hansard

**HOUSE OF
REPRESENTATIVES**

STANDING COMMITTEE ON FAMILY, COMMUNITY, HOUSING
AND YOUTH

Reference: Better support for carers

WEDNESDAY, 25 FEBRUARY 2009

CANBERRA

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HOUSE OF REPRESENTATIVES
STANDING COMMITTEE ON FAMILY, COMMUNITY, HOUSING AND YOUTH
Wednesday, 25 February 2009

Members: Ms Annette Ellis (*Chair*), Mrs Moylan (*Deputy Chair*), Mr Abbott, Ms Campbell, Ms Collins, Ms Livermore, Mrs Mirabella, Mr Morrison, Mr Raguse and Mr Trevor

Members in attendance: Ms Annette Ellis, Mrs Moylan, Ms Campbell, Ms Collins and Mrs Mirabella

WITNESSES

BONYHADY, Mr Bruce Phillip, Chairman, Yooralla 1

Committee met at 10.18 am**BONYHADY, Mr Bruce Phillip, Chairman, Yooralla**

CHAIR (Ms Annette Ellis)—Mr Bonyhady, I welcome you to this private briefing of the committee. Thank you for coming in and giving us your time today. We are very interested in hearing your outline of the whole idea of a national disability insurance scheme.

Mr Bonyhady—I thank the committee for inviting me to present this morning. I really welcome the opportunity. This morning I will take you quickly through the overheads that are part of your presentation pack, to outline the main features of the scheme but also to talk about what I see as the current policy failings. Then I will try and give you as much time as possible for questions.

Let us turn to the PowerPoint presentation and go to the overview. I start from a position which is, I think, similar to where this inquiry starts, which is that people who are carers need additional support. But it is not just the carers who need the support; there is also a need for additional support for people with disabilities. And the issues of carers support and support for people with disabilities are very closely entwined. It is necessary, in thinking about this, to try and untangle that relationship and to try and address the underlying causes rather than the symptoms of the current problems.

The proposal that I am going to put to you this morning is that there needs to be a national disability insurance scheme to transform the landscape for people with disabilities and also for their carers. In putting that case, I think it is important to provide both some background in terms of the theoretical underpinnings for the scheme and some practical examples to talk about the sort of design principles that I think underpin successful social security schemes. I will then talk about the disability insurance scheme in some more detail. If you turn to the page headed 'Background', you will see there is a strong theoretical underpinning to the idea of disability insurance, which really arose out of the ideas around workers compensation in the late 19th and early 20th century and which developed through the 20th century.

It is interesting, when you look at economic theory, that the principal work that was done around health insurance by Kenneth Arrow also identified a group of people who failed to recover—that is, people with disabilities. By the 1960s he was already arguing that insurance should cover not just medical and health needs but also people who failed to recover. Some work has been done more recently, particularly by Brian Howe, on the risks that we all face over the course of our lives and the need to provide insurance for those transitions and those risks. Very importantly, John Walsh, who is a partner at PricewaterhouseCoopers, undertook a detailed actuarial analysis of a long-term care scheme for people who have had catastrophic injuries. He was able to calculate the numbers in that case and, as you will see from what I say later on, it is possible to calculate those risks and to calculate the future costs as they relate to all people with disabilities.

There was a recommendation put to the 2020 Summit—one that I was involved in putting—for a national disability insurance scheme, and it was picked up as one of the big ideas. Importantly, in thinking about this idea, we do have all sorts of practical examples of these schemes operating in the areas of workers compensation and motor vehicle compensation. So, in

terms of our knowledge of whether these things actually work, we have a high degree of confidence that they actually do work, and that they work very well.

There are five social security design principles that I think we need to think about in terms of analysing the issues facing carers and people with disabilities. I have taken these five principles from the 'Pension Review Background Paper'. They are: a basic acceptable standard of living; that the arrangements need to be equitable; that they need to be targeted; that they need to promote participation and self-provision; and that they need to be sustainable.

In terms of a basic acceptable standard of living, there is considerable evidence—that I do not need to tell you about—that both many carers and people with disabilities do not have an acceptable standard of living. There are many examples of unmet need. If you look at a number of indicators on carers and their financial position, according to the Australian Institute of Family Studies, they are almost twice as likely to be in financial crisis as the general population. Their physical health is about half the national average, and 50 per cent of female carers and 30 per cent of male carers have suffered a mental illness for six months or more since becoming carers. So there is enormous evidence that there is enormous strain on carers and also on people with disabilities.

In terms of equity, the current arrangements are inequitable in a number of respects. Importantly, there is an enormous difference between those who receive compensation because their injury was as a result of a fault and the person or the organisation that was negligent is well insured, and all those people who are not eligible for compensation. There is also enormous inequity in terms of the impact that then has on carers and the informal care system because the carers are expected to provide care to the level that is necessary. So if you have a child who is profoundly disabled and needs close to 24-hour care then that is what you are expected to provide. If you have a child who has a much more moderate level of disability then that is the level that you are expected to provide to them. So there is enormous inequity in the current arrangements, and I think that is inconsistent with our sense as a community of what a fair go might look like.

In terms of participation and self-provision, there is now considerable evidence that people on disability support pensions stay on those pensions for very long periods of time—they cannot break into the workforce—and that carers, because of their requirement to provide constant care, become alienated from the workforce and are not able to participate thereafter. So, in terms of promoting participation both in the workforce and the community more generally, current arrangements fall a long way short of what I think is desirable.

Mrs MIRABELLA—Can I just ask a question about those disability support pensions. That is a huge diversity of people—from your bad back to your severely disabled person. Have you actually done a breakdown of those figures?

Mr Bonyhady—I have not seen an exact breakdown of that but, from the anecdotal evidence that I have, most people with severe and profound disabilities start on the disability support pension and they stay on it. The barriers to them entering the workforce are enormous. And there are numerous barriers too, including how they get to work and access in the workplace. There is a whole series of things. But, also, in terms of the way the current system promotes self-provision and self-sufficiency, there is not the emphasis on training and development and

engagement that there needs to be and that there could be. You can contrast that with what happens with workers compensation. When someone is injured in the workplace, there is enormous effort put into getting them back to work—if not at the job they had, then at another job: ‘What is the training they need? What is the assistance they need to do that?’ We can contrast that with what happens to people who are born with a disability, who just do not get that sort of support.

CHAIR—Thank you. Keep going.

Mr Bonyhady—In terms of sustainability, I think there is, again, considerable evidence that the current arrangements are not sustainable. We only have to look at what is happening to carers and how exhausted many of them are to recognise that the current arrangements are not sustainable. There is enormous conflict for families about whether they should fulfil the role of informal carer or try and remain in work and the impact that has on other members of the family. The demographics mean that the situation will get worse. We are seeing more people being born with disabilities than we previously did. We are seeing people with disabilities living longer and we are seeing the propensity to care declining—in part because carers are ageing and in part because household structures are changing. As we move towards more single-person households the propensity to care declines. One is much more likely to provide care to someone who is living in the same dwelling as oneself than to provide care for someone who is living two or three kilometres away—let alone in another city.

As a result of these trends, we are seeing very rapid growth in the need for disability services—rising in real terms to between five and seven per cent per annum—that is, rising faster than GDP. So we face a situation where there is significant unmet need today, and where, on current policy settings, that unmet need will continue to grow. There are a number of other dimensions to the current arrangements which would suggest that arrangements are not sustainable. We are not undertaking the sort of research into best practice that we should be doing, there is not the emphasis on access that there should be, there is not enough thought about prevention, and we just do not collect the data that we need in order to provide for both current and future service needs.

As a community and a government we face a choice. We face a choice between trying to improve the current system—and I would suggest that that amounts to putting band-aids on a system that is failing—and thinking about more transformational reforms that will really lead to much better outcomes for people with disabilities and carers. In saying that, I recognise that governments already spend a lot of money in this area but they are spending a lot of money for what are really very poor outcomes. So the question is: can we take the funding that is currently provided, add to that funding and then provide for much better outcomes over the long term? In a sense, I believe we face a situation that is not dissimilar to the one that we faced in the 1980s when we started to think about retirement incomes and said, ‘How do we deal with the fact that the baby boomers are going to retire? When they retire there will be a very large number of people on the old age pension and we need to prepare for that now, so start to meet the current need but also prepare for the future need.’

Essentially, with retirement incomes, we said that we had the old age pension. At that stage we had a number of pension schemes and superannuation schemes mainly in the public service but to an extent in the private sector, but in the private sector mainly providing retirement incomes

for more senior executives and no real additional voluntary contributions to retirement incomes. So we said, 'Let us build a three-pillar policy,' and compulsory superannuation was going to be the central pillar of that new arrangement. The National disability insurance scheme would work like that. It would essentially provide that second pillar that would then augment the existing accident compensation schemes and provide comprehensive insurance for all Australians. Then we would be in a position to add additional voluntary contributions, if we so wish, so things like the special disability trust would sit within a context of a comprehensive scheme rather than in the context of a system that is failing at the present time. Just as we have seen with additional voluntary contributions and superannuation, I think the potential to tap those additional resources is considerable.

A National disability insurance scheme would provide care and support to those people who suffer permanent disabilities before the age of 65. I draw the distinction here between a disability insurance scheme and an aged-care insurance scheme. It would provide, as we envisage it, care to people after the age of 65 who incurred their disability before the age of 65, so they would not need to transfer from the disability support environment to the aged-care environment, because we already know from current arrangements that there is a clear disjuncture at that point and it can be avoided. It would therefore cover people born with disabilities. It would cover people who acquire disabilities through an accident, through an injury. It would cover people who acquire a disability through a progressive medical condition, say, motor neurone disease or MS, and it would also cover people with a mental illness.

The concept would be based on need and it would be no-fault, so if you have a need for care and support or for the services that are within the scheme then you would be eligible for those benefits. The benefits would principally be care and support, including therapy. It would not include income support, so the basic income support would be provided by the Disability Support Pension as it is at the moment. That is the first pillar. This is about the service system being reshaped to provide those additional needs of both carers and people with disabilities. There would be access to equipment. There would be access to building modifications. There would be access to community inclusion and that would include access to education, access to training and access to the community more generally.

I estimate that there would be about 600,000 people covered by this scheme, so it is a big scheme. When I say 600,000, they are the people with severe and profound disabilities under the age of 65. People with mild and moderate disabilities—the people who do not have a need for care and support—would be eligible for things like equipment and minor needs that they might have, but the primary focus of this scheme would be on those people being supported by carers. So what it would do for carers is it would enable them to make the choices that all other Australians make today. They could make the choice between whether they provide care or they provide support.

Ms COLLINS—Are you suggesting that everybody that works pays for the insurance? Are you suggesting that everybody universally pays, even if they are on income support?

Mr Bonyhady—Let me get to the—

CHAIR—We have not got quite to that point yet.

Mr Bonyhady—I will deal with that now. The idea would be that we would continue with the current levies as they apply to workers compensation and as they apply to transport accidents and so forth but that you would put in place a universal levy. That could either be taken as a share of general revenues or it could be a specific levy like the Medicare levy.

Mrs MIRABELLA—But are you suggesting state or federal, because workers compensation and accident—

Mr Bonyhady—It would need to be a Commonwealth levy. I think national standards and national consistency is something that is really important.

Mrs MIRABELLA—How do you resolve the issue that this sort of scheme effectively takes over a role that is provided by state governments in many key areas? Do you tell them, ‘Don’t provide it anymore because there is duplication’? Or do you tell them, ‘We are taking it over because you cannot do the job’? Or do you just leave it there and not say anything? If you are advocating this sort of scheme, I think it is essential that you resolve the question of how you manage that interface between the Commonwealth and the state governments. It is the states who have primary responsibility for a lot of this resourcing at the moment.

Mr Bonyhady—You are absolutely right. The proposal is that there is a national governance framework which would set eligibility standards and benefit standards. The overall governance of the scheme needs to be national because one of the current issues we have is the great inequity between different states and the great problems people with disabilities have in moving from state to state. They might have a service in Victoria but will they get it in South Australia? I think it is vital that there is a national governance framework. That is the first point. The second essential point is that the current service delivery system should be moved into this framework because an insurance framework creates an alignment of interest, I think, that the current welfare framework does not.

Mrs MIRABELLA—So in other words it is provided through the federal government?

Mr Bonyhady—Can I come to that issue of whether the federal government provides it, because I think the question of the costs and benefits of alternative structures is something that needs to be worked through in a very detailed way.

Mrs MIRABELLA—Sure.

Mr Bonyhady—I think it is essential that the services that are delivered today come under this system, because the current services are delivered in a welfare mind frame. The welfare mind frame says: ‘How do I minimise my cost today?’ An insurance framework says: ‘This person has a disability. Chances are that they are going to have this disability for life. How do I maximise their opportunities over their lifetime and how do I minimise the cost to them and the community over their lifetime? If I need to provide early intervention—because I know it has long-term benefits—I provide it today. I do not say: it costs too much. I say: there is a huge cost-benefit in providing that today.’

The second point is that the existing service dollars—the cost—need to be brought in and managed under this scheme. I think the question as to whether the Commonwealth becomes

totally responsible for disability or whether it remains a state responsibility should be tested. In that context, I think it is very interesting that Brendan O'Reilly, the retiring Director-General of disability services in New South Wales, said last week that he would support the introduction of the national disability insurance scheme. He thought it should happen within four years and the Commonwealth should take it all over. I am not sufficiently familiar with the costs and benefits of that, because it would require the development of a whole Commonwealth infrastructure that does not exist today; it would then enable some dismantling of state infrastructures. I think that is something that could be tested within a COAG framework.

Mrs MIRABELLA—Because that is fundamental. If you have identified these problems in delivery at the state level, the universal aspect of this—having a Medicare type levy, having effectively an additional federal tax to set up this scheme—will not change what happens on the ground, if that is not reformed. It just means that there is more money, that it comes from the federal government and that it is allocated.

Mr Bonyhady—I think what I am suggesting is that there needs to be fundamental reform. There are all sorts of arguments about how state public servants can be closer to the action than people based in Canberra. I am arguing for fundamental, total reform, but the detail of just what gets delivered—to what extent states are responsible for service delivery and to what extent the Commonwealth is responsible for service delivery—should be tested on the basis of what is the most effective way of doing this, recognising the current failings.

Mrs MIRABELLA—Your organisation has extraordinary experience at the coalface. I would be interested to know—if there are problems and this system is supposed to fix them—if you can provide that analysis of what the problems are, because it is a bit difficult to say, 'We need this scheme and it needs reform, so we will have this funding arrangement at the federal level', without actually explaining. Some of us are a bit nitpicky, I suppose. We know there are problems—we know anecdotally and we know from some facts—so why is there not some comprehensive analysis now? These are what the problems are. That is the main issue we are concerned about—and, by the way, the process. Because the national insurance scheme you are proposing is the mechanism for solving the problem, and I think some of us need to know the details of the problem.

Mrs MOYLAN—But, if you draw on the analogy of the delivery of healthcare services, you can have a national program—

Mrs MIRABELLA—It is hardly edifying, though, to draw on the Nationals and say: 'The federal government collects Medicare and gives it to the states.'

Mrs MOYLAN—No, but I—

Mrs MIRABELLA—That is not working.

Mrs MOYLAN—But just let me finish. There are schemes in other parts of the world where there is a national framework or there is a framework under one umbrella for the delivery of a care model. I think this is what you are really getting at: that we need some kind of national framework and some kind of benchmarking in relation to the early intervention and delivery of services. In some of the national care models that I have seen—I am not talking about

nationalised medicine; I am talking about schemes actually driven by health insurers—they have set down parameters of care for people with certain types of chronic illness, who are then managed by the medical practitioners. But there is a protocol to work to, and it is clearly demonstrated, from some of the models I have seen, that those protocols have made an enormous difference to the health of the individual. I do not see why you cannot apply that, but you need to start with the framework that you are talking about. I do not see that you cannot apply that model to the national scene, still having your service delivery as close to source as possible. But you have to have clear benchmarks.

Mrs MIRABELLA—It is chicken and egg. I am asking which one comes first. Do you take the money and say, ‘Okay, we’ve got all this money; let’s work out what to reform,’ or do you say, ‘This is what has to be reformed; therefore this is how much money we need.’

CHAIR—With the greatest respect, I think we know what needs to be reformed—that is, the absolutely clear failure of every level and every colour of government to adequately address the growing unmet level of need in disability and chronic illness services. It is already evidenced there.

Mrs MIRABELLA—That is great, Chair. That is a great statement but the details of it—

CHAIR—There is a lot of detail around.

Mrs MIRABELLA—That is motherhood. We all know that.

CHAIR—No, it is not motherhood at all, Sophie. It is based on fact, as you will see if you read the reports done by UC here—what are they called? I mean the national modelling. There is a heap of information around and the point is that I am personally of the view that the notion of a national disability insurance scheme in itself as a principle should not get bogged down at this point—even though they are justifiable questions—with the issue of who will be hammering the nail in the ramp in the house.

Mrs MIRABELLA—No, it is not that. You are misinterpreting what I am saying.

CHAIR—No, I am not suggesting that you are saying that. But there is an absolutely fundamental financial failure in adequately addressing the needs of people with disability in this country, and this is an alternative model that deserves to be looked at in full to see whether it can work.

Mrs MIRABELLA—What I am saying is that looking at it in full necessarily requires looking at the fault.

CHAIR—That is fine. Mr Bonyhady, please just keep giving your information at this point. I am of the view that the fault is already quite clear.

Mr Bonyhady—Sophie, I would be happy to provide you with information on current failings. There are numerous studies that have been done, most recently by the Australian Institute of Family Studies, looking at the impact of caring on families and at the impact of disability on families. If I can be so bold as to suggest it, I think there is a lot of time being spent

on describing the problem. I am taking the point that the problem exists and is very significant and then saying, 'How would one deal with it in a systemic way?'

Mrs MIRABELLA—The problem exists, and I have asked these questions because it would be irresponsible not to be prudent in asking those sorts of questions.

CHAIR—There is no problem with you asking the questions. It is perfectly fine.

Mr Bonyhady—As I say, I would be happy to provide you with additional information.

CHAIR—That would be a good idea.

Mr Bonyhady—One of the aspects that is critical in the design is the governance arrangements, which we have just recently alluded to. Insurance schemes are governed in very different ways to welfare schemes. With insurance schemes, you think about what the assets of the scheme are, you think about what the liabilities of the scheme are and you look to balance them up in a way that a welfare system does not. A welfare system just continues to make calls on revenues.

One of the important issues with a scheme like this would be whether it is what is called a pay-as-you-go scheme. For a pay-as-you-go scheme, the costs of supporting carers and people with disabilities this year is met from this year's revenues. The alternative is a fully funded scheme, which sets aside this year the monies that will be needed to meet the future liability for all those people who incur a disability or are born with a disability in the current year. Given where we start today—which is with a huge unmet need—I would suggest that the national disability insurance scheme would need to be a mixture of pay-as-you-go, so that it meets the current unmet need, and also an element of meeting the future liability as well, so that over time the cost of this scheme would tend to decline because you would be putting aside monies for those future needs. Just as with superannuation, where we progressively build up assets to meet future liabilities, this scheme would do the same.

Importantly also, it would collect data not just on the incidence of disability but around the results of different types of treatment. One of the things in a scheme like this is that you are always driving for more effective therapies and treatments to maximise opportunities and minimise costs. So there is an inbuilt mechanism here which I think aligns the interests of people with disabilities and carers and also the scheme, and hence the public.

In conclusion, I believe that we need to set a light on the hill for people with disabilities and their carers so that they can have an expectation that, when they are no longer able to care for a family member with a disability, there will be public support and that that is done in a planned and structured way rather than in the current crisis way. Today, to be eligible for a service, the way that you get it is that you are in crisis. On the one hand we say to people with disabilities and their families that we want to uphold and build their self-esteem but on the other hand we have designed a system in which the only way they get access to a service is to describe their situation in the most abject terms. I believe that a national disability insurance scheme would enable that transformation to take place. It is obviously a major reform. We have alluded to the need for a really close examination of Commonwealth and state responsibilities under such a scheme. In my view, it would rank equal to Medibank, Medicare or compulsory superannuation

in terms of its significance as a social and economic reform. It is a reform which I hope this committee will see fit to make a central recommendation of its findings.

Ms COLLINS—You have talked about a fully funded scheme and possibly funding it through a Medicare style or superannuation style levy. How much do you think that levy needs to be to adequately cover the scheme? What sort of figure are we talking about?

Mr Bonyhady—I think you will find that the numbers will be less than most people expect. Most people have assumed that the scheme is going to cost a huge amount. I note that Brendan O'Reilly last week commented that it is likely to cost less than people think because of the efficiencies that are likely to be generated as a result of the comprehensive review that it would involve. I am a member of the Disability Investment Group that Bill Shorten has established. It is doing some work on this and it will be reporting to government. There will be an estimate in that report.

Ms COLLINS—So we do not know at the moment?

Mr Bonyhady—No.

CHAIR—Is the work that the national investment group is undertaking in relation to this, or is it a general thing about what costs would be involved?

Mr Bonyhady—What it has been asked to do is examine how we can boost investment in services for people with disabilities. In a sense, part of what it is designed to do is encourage families and organisations to invest in this area. But a critical thing that we have concluded is that, in the absence of a strong central pillar like a national disability insurance scheme, it is impossible to get any meaningful, significant additional investment. Look at the examples that exist today. There are many families who have said they are prepared to provide for the housing of a disabled son or daughter but only if they get care and support. But they cannot get the care and support because they are not in crisis, so they do not make the investment in housing.

CHAIR—Are you finding in that same investigation that there are also tax and other implications for the parents in those cases that need to be clarified?

Mr Bonyhady—Yes.

CHAIR—So the whole thing needs to be looked at?

Mr Bonyhady—Essentially, the investment group is identifying the need for a second pillar and the need for reform of savings and tax structures to ensure that there are no unnecessary impediments to those private contributions. They will be reporting to government in the next little while and that report will then provide you and others with an estimate of what the cost will be.

Ms COLLINS—Is there any ballpark or rough estimate? Are we talking one or two per cent, or are we talking 20 per cent?

Mr Bonyhady—I feel constrained in what I can say. I am really here in my capacity as Chairman of Yooralla and while I think that it is reasonable for me to refer to the work that is being done by the Disability Investment Group because that is on the public record—

Ms COLLINS—My concern is that if you are advocating that we as a committee put in our report that we support this type of scheme, how can we do that not knowing what it might cost people?

Mr Bonyhady—I understand the dilemma that you have got and so there is probably a timing issue in terms of when you report and when the Disability Investment Group reports that would need to be clarified.

CHAIR—Without pre-empting what we are going to consider in our report, because we have not got to that point yet, it is always possible for a committee to use language that says we are aware of and we encourage further work on it, because there appears to be a need for examination of alternatives. You can say that without saying go ahead and do it. There are ways of talking about these things in a report if in fact we do not have sufficient information at that point.

Mr Bonyhady—When are you hoping to finalise your report?

CHAIR—We are hoping to report by April—maybe out of session if need be. It depends on our handling of the draft. In concluding, the comments you just made about the pressure that families in particular find themselves under in trying to grab that rare dollar for services for their cared-for person have come through constantly, loudly and clearly in our current inquiry. Without wishing to misquote, one of the points of evidence that came to us, which I will paraphrase, was: how bad can it be when you are fighting as an individual to make your case sound worse, or be worse, or be considered as worse, than anybody else in the same queue? What a terribly distressing position to find yourself in. That is the position a lot of families are finding themselves in. In one particular jurisdiction where they line up for the packages, or accommodation particularly, the battle is: ‘I have to stand up as a parent,’ they said, ‘and convince the authorities that I am worse off than everybody else who is the same as me.’ That is the distressing part of the process for them.

Mr Bonyhady—I absolutely understand that and I know from personal experience of many cases like the one you are referring to. I think that one of the attractions of a scheme like this is that it shifts our thinking away from a particular type of disability or a particular cause. For too long the disability sector has advocated on that basis and, as a result, has really been in competition with other parts of the sector.

CHAIR—Exactly.

Mr Bonyhady—By moving to a needs based system the cause or the name is irrelevant—

CHAIR—It matters not what—

Mr Bonyhady—Let us put the person at the centre and meet their needs. Let us make sure that the family is best supported to provide those needs and then let us build the system from

there. I also think that because that is the way it is framed it will have very broad appeal to the Australian public. We then say that disability is a risk that we all face and in the event of a disability that results in a significant need you are covered.

Mrs MIRABELLA—Would it be means tested?

Mr Bonyhady—No. A need is a need.

CHAIR—That is logical as well. It does not matter what your circumstances are, if the services are not there you cannot even buy them. That is the point. That is the distressing end of this. Thank you very much, Bruce, for coming today. It is really great to have you here and we appreciate very much the time you have taken. If you think of any other information, as per the earlier discussions, that you want to send through to the committee, please do and we will distribute it accordingly. We would be very happy to get it.

Committee adjourned at 10.59 am