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Computers, Law and a National Register of the Handicapped

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When I was approached and asked about the idea of formulating a national register of the Handicapped, I replied that it was a positive thing; rather, it was essential to have one. Without information we would not be able to analyse and plan effectively so as to ensure that the limited resources at our disposal are put to use in the best way possible for the benefit of the handicapped and Maltese society. However at the same time I warned that any register which would eventually be compiled - be it national or otherwise - must incorporate all the necessary measures needed for the protection of fundamental rights as enshrined in the most progressive and modern laws formulated during these last twenty years. Nowadays, when someone wishes to gather any information in a systematic way, it is normal practice for a computer to be used to store and analyse the information gathered, and I am in no doubt that if we are to start a project on a national register we will perforce be using a computer to assist us in our work. What should we do to ensure that the information collected for the national register is in fact collected, stored and used only by those authorised to do so?

International legal machinery has developed a number of principles and methods to achieve these aims. Let us glance at those developments-both local and foreign-which can bear on the manner in which we compile a national register of the handicapped. But first let me clarify some points. Perhaps somebody amongst you is asking himself: "What prompted the organisers of a seminar on the handicapped to invite someone who specialises in computer and the law? With so many

problems to discuss are we going to waste our time talking about legal intricacies?" And in actual fact, when we talk about the law with regards to the handicapped, we normally refer to the 2% of total staff complement which the law lays down must be employed, or to the pension and so on, but actually I am not going to waste my time on legal niceties but shall only mention certain legal aspects which normally are not mentioned with regards to the handicapped. Not only, but more importantly, for once we are not going to ask if society can or cannot enact a special law for the handicapped, but on the contrary we are going to ask if society should not ameliorate the law for each and everyone of us, the handicapped person in this case serving as a "catalyst", that substance which in chemistry starts a reaction and helps change one substance into another. In relation to the matters with which I shall deal, I will be asking you all, whether handicapped or in any way interested in the handicapped, to help me change the law-and above all the attitude of Maltese society-to avoid making a mess in the case of the handicapped, as, I am sorry to say, happened in other spheres of Maltese life. When, round about seven years ago, I became interested in the subject of computers and the law, I initially started examining the possibility of using the computer in matters legal, in the Law Courts, at the lawyers or notary's office, for research and other purposes. Even here at the University of Malta we are presently working on a research project (similar to those in other countries) on how to design computer systems which would provide, for example, legal or medical advice.

This is known as "The Computer as a tool for the lawyer", (I would like to add something here-with reference to the subject broached yesterday during the workshop-that a need is felt to investigate the computer's potential as an aid to the handicapped). However I soon realized that there is another aspect: "The Computer as a subject of the Law." In this sphere of study there exist various distinct fields, like for example copyright of computer software or contracts relating to purchase and maintenance of computers. But what interests us today in this Seminar is the effect of the computer in relation to privacy, or rather how the use of the computer can affect our private lives as a whole. Now why are we posing this question? First of all, for example, when a census is organised or when information is being gathered to produce a national register (in this case we are talking about a national register of the handicapped) each one of us who offers information is offering it for a specific purpose: It is given so that it can be used to achieve the purpose mentioned by Professor Cuschieri - we can analyse it, learn from it, and it will help us to plan ahead better and make a better use of our resources. Therefore, if anyone suspects or fears that this information is not going to be used as it should be, the effect and effectiveness of this register can be undermined. However-and this is something which I am going to keep stressing this morning, this is not something which will affect the handicapped only. In fact it affects each and everyone of us.

When we enter a bank and request a loan, either for business or to buy a house, the bank authorities enquire about our income, about our bank accounts, what property we own

and other things. Normally we don't go out into the streets and tell everybody how much we're earning or what income we have or what property we own. This is not only confidential information but concerns our private life. When I receive the income tax form and I fill it in and send it back, I am doing all this to observe the law and at the same time do my duty as a normal citizen. However I would be resentful if I were to find out that some information that I had given in my income tax return is passed on to a third party. As you may notice these things apply in all cases where the gathering of information is concerned, be it for the handicapped, income tax purposes or medical records. Therefore the legal principles which we are going to discuss today are the concern of each and every one of us. I am saying this because, if we are going to start gathering information about the handicapped person in a scientific way - as Profs. Cuschieri rightly expects - the same handicapped persons acting as catalysts in this exercise as I said earlier - we should go about it in the right way. Why? Because up till now, here in Malta-unfortunately (perhaps with some exception here and there)-we have proceeded haphazardly and erred in many ways with regard to the collection and protection of information. I am not implying that blame attaches to the various persons in Government employment, but the blame lies rather with the system within which these work, and also with education. If you will bear with me I can offer you some examples as proof that what I am saying is not idle talk but is something which happens in everyday life. This type of information debate, (commonly referred to as the "Computer versus Privacy Debate") initially started recently in 1966 in the U.S.A. In fact the U.S.A. was the first country to use computers extensively. (The first computer ever sold in fact was to the U.S. Bureau of Census in 1951). However in 1966 the U.S. president set up a so called 'task force' consisting of a group of experts who were to make a joint study regarding the best way how to collect information without incurring heavy expenses. They spent nine months studying this specific problem and came out with a practical proposal which reflected their brief. Their instructions were as follows: tell us how to collect the required information in the most effective and efficient manner and-naturally, as this is a case of typical American management mentality- "the most cost-effective way possible." As stated these experts came back after nine months and said:"Mr.President, we think that the best thing to do to attain your objectives is to set up a super computer data bank, centralise everything, store all Government information and other data in one place and thus you will be able to collect and analyse the information you need in the most effective manner."

The report provoked fierce reaction on the part of Congress and the American press who between them waged a royal battle against the very idea it mooted, and the reason for all this was because they (as those who had read the famous book by George Orwell "1984" are aware of), were afraid of the symptoms or the possibility of a "Big Brother", where the state would know everything about every citizen. In fact there was such a furore raised in the U.S. that a special sub-committee from the Senate was appointed: this sub-committee submitted its report in 1972 and in 1973/74 the famous

U.S. Privacy Act was passed. It was in fact due to this uproar that this new attitude was conceived with respect to the effect of computers and the gleaning of information which can be learnt about the private life of an individual. Maybe you would ask: Admittedly we are going to gather information and store it in a computer; but if, after collecting the information required we do not make use of the computer, would not an abuse of the information so gathered still be possible?

In fact there are two factors-historical and sociological-that affect our analysis of this comment. First of all, if we were to check, we would find out that up to the last World War we gave very little information to the State. We were duly registered in the Public Registry and that was that, apart from the Parish register kept in the office of the parish priest. However after the 2nd World War there was a complete change. Due to the fast emerging concept of the "Welfare State" we introduced the income tax system and set up National Insurance, while insurance companies started dealing with an increasing volume of work, and banks were more and more being made use of. As you may notice, for each and every one of these cases (income tax, banks, insurance) the private citizen gives out information. He is not giving it capriciously, because nobody likes to give away information on his private life. But he is giving it because he expects something in return. If he offers information to the Bank it is perhaps because he is expecting to be given a loan.

Now when one notices these changes one is constrained to say that the developments in the legal sphere during these last twenty years did not come about because the computer in itself is something bad, but because its use made people realize the importance of information. Today we do not say anymore that we are living "in the post industrial revolution age." In fact there are some who in relation to this classification, refer to it as the "information age", or the "computer age". What about the stage reached by the law? Unfortunately, the Law does not always move with the times. It takes years in order to change the law and bring it in line with the changed situation. I will just give you one example: in our Criminal Code you are still liable to be prosecuted and fined if you drive a horse across a drawbridge at a fast pace (I will bet that you won't find one single drawbridge which is still functioning in Malta and on which you can drive a horse). On account of its own technical intricacies the Law cannot keep abreast with technology. If you were to try and copy a computer software programme you would encounter great legal difficulties in order to protect the rights of those having an interest in the computers' software. At the same time the Law had to race against time to try and cope with the implications of computers and private life. Because let's make it clear, it is true that before the advent of the computer we used to collect information, but if you went to ask for a particular file-with all due respect to the Civil Servants here present-in a Government Department, or at times even a private company, they might find it for you in 3 minutes (a rare thing I am assured), but it might take them 3 days, three months, 3 years etc. and sometimes in some places files actually disappear. The good or bad fortune of computers is-if they

function well and the right information fed-just press a button, say “Joe Cannataci” and in a few seconds you can collect all the information you need regarding that person. Not only that, but if someone went to Prof. Cuschieri and spoke to him professionally, Prof. Cuschieri is bound by his professional secret. If somebody comes to me I am bound in the same way. But you don’t have to be bound by a professional secret in order to use the computer, and therefore there is room for abuse. Before proceeding further I would like to read to you a short passage by the famous Russian author Alexander Solzhenitsyen, which has much in common with the idea and concept of private life. It goes thus: “As every man goes through life, he fills in a number of forms, for the record, each containing a number of questions. There are thus hundreds of little threads radiating from every man, millions of threads in all. If these threads were suddenly to become visible, the whole sky would look like a spider’s web, and if they materialise like rubber bands, buses and trams, and even people, would lose the ability to move, and the wind would be unable to carry torn-up newspapers or Autumn leaves on the streets of the city”

It is true that Solzhenitsyen is describing the situation in a poetic manner but when you come to think about it, you would resent it if the type of information which you gave regarding yourself was not used properly. I will describe to you briefly what happened in International Law in Europe to date: At the same time that the Americans were trying to solve their problems-as I already mentioned-from 1966 to 1973, the Europeans were beginning to stand on their own feet. The first special law on “data protection”-as it is called-was enacted in Hessen, Germany in 1970. From then onwards nearly all the countries of Europe enacted a special law regarding this situation. Sweden was the first in 1973, then after Sweden came Germany in 1977, in 1978 came Denmark, Norway; in 1979 Luxembourg (a small country like Malta) in 1984 the English followed suit, as did the Irish in 1987; Holland have just done so in 1988. Almost all the countries of Europe have enacted a specific law on how to protect private information on the individual. Not only that, but also-and very important-in 1981 the Council of Europe launched an international convention on the protection of Data. Since then, this convention has been signed by 19 countries out of the 23 member-countries of the Council of Europe and has been ratified, coming into force in 1985. Malta is one of these countries - along with Switzerland, Finland and San Marino - which has yet to sign this convention. Which is no surprise, because Malta is not usually the first and in the forefront in many international situations. However this state of affairs must be rectified. In the European Convention-with special interest to the handicapped-it is clearly laid down that a certain type of special data is not to be given. Article 6: “Special categories of data. Personal data revealing racial origin, political opinions or religious or other beliefs as well as **personal data concerning** health or sexual life may not be processed automatically unless domestic law provides appropriate safeguards. The same shall apply to personal data related to criminal convictions.”

This principle was not only included in International Law by means of this convention but is protected by laws enacted by many countries throughout Europe. Besides all this, the special committee of the Council of Europe, the Committee of Experts on Data Protection (on which committee I have the honour of representing Malta) issued a series of recommendations on how to protect these principles. The first recommendation was that of 1981 regarding the protection of Data given for medical purposes, and that of 1986 regarding data given for Social Security Purposes; Another refers to data given for statistical purposes. The interests of the handicapped are protected under each of these three headings, qualifying under "medical records", "social security records" and "statistical records". Unfortunately, we in Malta did not register the same progress like other countries did.

During these last seven years, I discovered that unfortunately in the majority of Government Departments concerned-including the Hospital Health Information Centre and the Swatar Computer Centre-most of the staff are not even aware of these laws, let alone putting them into practice. And these are laws which affect each, and everyone of us. Someone might make a wrongful use of the information on the handicapped. This can happen in my regard and in yours. And not only do we have no knowledge of these laws, but there are certain things which are not being done in a professional way and are not done the right way. It is not appropriate at this moment to go into details, but one must mention that we in Malta are acting and doing things that in other countries are considered gross errors in as much as the use of I.D. Numbers is concerned. For example in Portugal it is absolutely forbidden to use a National I.D.No. or that only one number for I.D.purposes is used. Now what actually happened on the quiet-and here some civil servants were involved-the number issued by the Public Registry to each and every one of us at birth became-as the Americans call it-"your womb to tomb number". Why? If you remember rightly, your I.D. Card number was different from what it is today - it has been changed. Why? So that the number will be the same. Now your income tax number as from this year is the same as your I.D.Card number. Your I.D.Card number is being quoted in your passport and is being used for medical records. This is something which could, in some countries, qualify as a sort of blasphemy in the field of data protection, something which should be remedied. It is true that it is much easier for whoever is using them to have first one number and to know who that number represents. But if you happen to know that that particular number "one" is mine you would find it much easier to obtain information about me from the Social Services, income tax, Banks, and various other places. I will conclude by saying that there seems to be a ray of hope. It consists in the fact that the two major Maltese parties, Labour and Nationalist, in their electoral manifesto of 1987, both expressed their opinion about this subject: both said that they would like to have privacy protected. Both said that they would like to do something tangible about it. In fact, during the recent debate about the Parliamentary Select Committee regarding changes to the Constitution, in the first report-the preliminary report approved by both sides of the House, - it emerged that there should be changes

made in the Constitution to protect privacy per se. I must state that not only are there problems with regard to privacy where computers are concerned but even your own private life is still not explicitly protected by the Constitution of Malta. Unfortunately from the legal standpoint, the only reference to private life and privacy that we find in the Constitution as it is at present is in Article 32, and Article 32 is not enforceable in the Constitution, that is, it is there, we have a principle, but I cannot apply to the Constitutional Court and get any remedy in respect of that article. One of the first laws passed by the present Government was the European Act of 1987, and in article 8 of this Act we find the right to private life, which means that recently we have incorporated something in the law. But this situation must be rectified. This should change not only at the Constitutional level, that is at the highest level of the Law of the country, but it must be accompanied by the enactment of special laws on data protection on similar lines adopted in other countries, and particular regulations that cover and ensure the confidentiality of information regarding each and every one of us when collecting information.

I will conclude by saying that yesterday in this Seminar we often mentioned the word “integration”. In practice, are we really integrating the handicapped in our society? I think that this is an excellent case for the handicapped to prove that they really form an integral part of Maltese society. Instead of serving only as a lobbying group for the specific interests of the handicapped, they can also help in the struggle to ameliorate the law which provides not only for them but for every member of Maltese society. They can be the ones to say “Look here, we want to have a register for the handicapped, but it must be done in a proper way, in a way which will safeguard our rights.” And thus the handicapped will have given an example to each and every one of us who form part of Maltese Society.