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Speech delivered by Professor Adam Graycar, Social Welfare Research Centre, University of New South Wales:

"Who are the carers ; what are their needs?"

Sydney, 10th March 1982

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10/3/82

(19)

WHO ARE THE CARERS - WHAT ARE THEIR NEEDS

can do/ teach - appropriate ahead
appropriate feedback
~~could put in~~
Sir Henry Parkes fact -

both fact (facts) + direction
SPEAKING NOTES

ADAM GRAYCAR

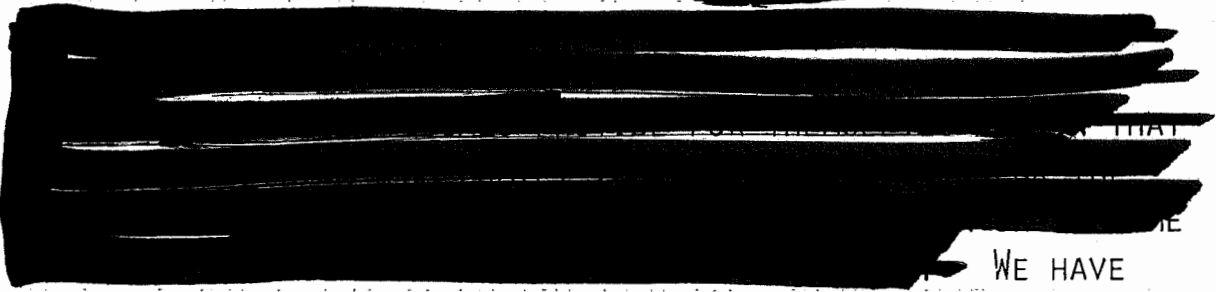
100 YEARS AGO LIFE EXPECTANCY AT BIRTH WAS 47 YEARS FOR MALES AND 51 YEARS FOR FEMALES. TO-DAY IT IS AROUND 70 FOR MALES AND 77 FOR FEMALES. THESE OF COURSE ARE AVERAGES AND MANY PEOPLE LIVE BEYOND THESE YEARS. IN SOME CIRCLES THIS INCREASE IN LIFE EXPECTANCY IS SEEN AS A CALAMITY FOR SOCIETY - BUT I THINK IT WOULD BE MORE REASONABLE TO REGARD IT AS A MAJOR ACHIEVEMENT. THERE IS, HOWEVER, A PRICE TO BE PAID FOR THE PRIVILEGE OF LIVING LONGER AND THAT PRICE IS PAID IN TERMS OF AN INCREASE IN DEGENERATIVE DISEASES. THE RATES OF CHRONIC ILLNESS IN ALL INDUSTRIAL SOCIETIES ARE VERY HIGH AND AUSTRALIA IS NO EXCEPTION. WHAT BECOMES IMPORTANT IS TRYING TO UNDERSTAND THE NETWORK OF THE SERVICES - STATUTORY AND NON-STATUTORY - FORMAL AND INFORMAL - WHAT CAN BE BLENDED TOGETHER TO IMPROVE THE QUALITY OF LIFE OF THE PERSON SUFFERING FROM CHRONIC ILLNESS, AND TO ENSURE THAT THOSE WHO CARE FOR THESE PEOPLE HAVE THEIR NEEDS MET AS WELL.

NOT SURPRISINGLY, CHRONIC CONDITIONS INCREASE IN INCIDENCE, WITH AGE. FOR EVERY 100 AUSTRALIANS 45 EXPERIENCE SOME SORT OF CHRONIC CONDITION. FOR EVERY 100 AUSTRALIANS OVER THE AGE OF 65, 77 EXPERIENCE SOME CHRONIC CONDITION. WHAT IS EVEN MORE INTERESTING IS THAT THESE 77 ^{elderly} PEOPLE EXPERIENCE BETWEEN THEM ABOUT 180 CHRONIC CONDITIONS.

NOT ALL CHRONIC CONDITIONS ARE THEMSELVES LIMITING AND NOT ALL CREATE SOCIAL PROBLEMS. THE AUSTRALIAN BUREAU OF STATISTICS SURVEY WHICH IDENTIFIED THE EXTENT OF CHRONICITY IN AUSTRALIA, CLASSIFIED ANY PERSON AGED 65 OR MORE WHO WAS CONFINED TO BED, CONFINED TO HOME, OR NEEDED HELP IN GETTING OUT OF THE HOUSE, AS SOMEBODY WHO WOULD HAVE AN ACTIVITY LIMITATION. FOR EVERY 100 PEOPLE OVER THE AGE OF 65 IN AUSTRALIA 13 WERE

REGARDED AS HAVING AN ACTIVITY LIMITATION - 15 OUT OF EVERY 100 FEMALES AND 11 OUT OF EVERY 100 MALES.

ACTIVITY LIMITATIONS MEAN THAT PEOPLE WITH CHRONIC CONDITIONS NEED SOME FORM OF SOCIAL AND MEDICAL SUPPORT. IT IS NOT KNOWN HOW MANY PEOPLE WITH ACTIVITY LIMITATIONS LIVE IN INSTITUTIONAL CARE, HOW MANY LIVE ALONE, OR HOW MANY LIVE WITH RELATIVES. WHAT WE DO KNOW IS THAT MOST ELDERLY MALES - ABOUT 60% - LIVE WITH THEIR SPOUSE WHILE VERY FEW ELDERLY FEMALES LIVE WITH A SPOUSE - ABOUT EQUAL NUMBERS LIVE ALONE AND WITH RELATIVES. THE IMPORTANT POLICY QUESTIONS ARE TO TRY TO DETERMINE WHAT SORT OF SUPPORT MECHANISMS ARE FEASIBLE TO ENSURE THAT QUALITY OF LIFE IS ENHANCED AND THAT ADEQUATE CARE IS MADE AVAILABLE. IN RECENT TIMES WE HAVE SEEN ATTEMPTS TO LIMIT THE GROWTH OF THE PUBLIC SECTOR - FUNDS ARE NOT AS READILY AVAILABLE FOR SUPPORT SERVICES. AT THE SAME TIME THERE HAS BEEN A WORLDWIDE EMPHASIS ON FAMILY POLICY - THE ARGUMENT BEING THAT FAMILIES OUGHT THEMSELVES TO TAKE CARE OF THEIR DEPENDENT ELDERLY.



WE HAVE HEARD A LOT LATELY ABOUT FAMILIES ABDICATING THEIR RESPONSIBILITY TO CARE FOR THEIR ELDERLY MEMBERS. WHAT EVIDENCE THERE IS SUGGESTS THAT THE FAMILIES ARE NOT AT ALL ABDICATING THEIR RESPONSIBILITY, BUT RATHER THEY ARE UNDER ENORMOUS PRESSURE BECAUSE THEIR CAPACITY TO DEAL WITH AND PROVIDE ADEQUATE CARE FOR ELDERLY DEPENDENT RELATIVES IS DIMINISHING. TO ARGUE THAT THE FAMILY IS THE BEST CARE AGENT IS ONLY TO TELL PART OF THE STORY. IT IS IMPORTANT TO ENSURE THAT FAMILIES WHICH FIND THEMSELVES IN A CARING SITUATION ARE PROVIDED WITH ADEQUATE SUPPORT. IT IS NOT MY TASK TO-DAY TO CANVAS THE VARIOUS POLICY OPTIONS BUT RATHER I WOULD LIKE TO SHARE WITH YOU SOME OF THE FINDINGS FROM A RESEARCH PROJECT THAT WE HAVE PRESENTLY UNDERWAY IN THE SOCIAL WELFARE RESEARCH CENTRE AT THE UNIVERSITY OF NEW SOUTH WALES.

Don't photograph speakers at any address audience when or where appear on platform

RESEARCH THAT WE HAVE BEEN DOING INDICATES THAT AGED PEOPLE IN THE FUTURE WILL PROBABLY LOOK MORE TOWARDS THE FORMAL SYSTEM OF CARE AND LESS TO THEIR FAMILIES. MANY FAMILIES WANT TO LOOK AFTER THEIR ELDERLY RELATIVES BUT THEY ARE NOT EQUIPPED TO DO SO NOR DO THEY HAVE THE SOCIAL SUPPORTS THEY NEED. WHAT HAS COME THROUGH OVERWHELMINGLY IN OUR SMALL SURVEY IS THAT MOST FAMILIES ARE RELUCTANT TO COMMIT THEIR ELDERLY RELATIVES TO THE CARE OF A NURSING HOME ~~_____~~ THE STUDY ALSO SHOWS THE EXTREME DIFFICULTIES THAT MOST CARERS OPERATE UNDER.

OUR STUDY WAS OF A SMALL NUMBER OF HOUSEHOLDS ^{in a w/c area} WHICH HAVE LIVING IN THEM AN ELDERLY PERSON PRESENTLY RECEIVING HOME NURSING. MOST OF THE PEOPLE BEING CARED FOR WERE WOMEN - THREE QUARTERS WERE EITHER MOTHERS OR MOTHERS IN LAW OF THE PERSON DOING THE CARING. MOST WERE OVER THE AGE OF 80. MOST HAD QUITE A RANGE OF CHRONIC ILLNESSES AND DISABILITIES. IN ALL CASES THE PERSON PROVIDING THE BULK OF HOME CARE WAS A WOMAN. IN A QUARTER OF THE CASES IT WAS A WOMAN LIVING ALONE WITH THE PERSON BEING CARED FOR. IN OTHER CASES THE SITUATION VARIED, TO FAMILY SITUATIONS WITH YOUNG CHILDREN PRESENT. IN ABOUT 40% OF THE CASES THE CARING SITUATION HAD BEEN GOING ON FOR SOME SIX YEARS OR MORE AND IN THE MAJORITY OF THE CASES THE ELDERLY PERSON BEING CARED FOR HAD MOVED INTO THE HOUSEHOLD OF THE PEOPLE PROVIDING THE CARE. PRIOR TO THAT THEY HAD LIVED EITHER ALONE OR WITH A SPOUSE AND OBVIOUSLY FOUND IT IMPOSSIBLE TO CONTINUE. OF THOSE WHO HAD MOVED, ONE QUARTER WERE UNWILLING TO HAVE MOVED AND WERE NOT HAPPY AT ALL ABOUT IT.

IN DECIDING ABOUT WHETHER A MOVE OUGHT TO HAVE TAKEN PLACE, THREE QUARTERS OF THE HOUSEHOLDS CLAIMED THEY HAD NO OPTION BUT TO TAKE THE COURSE OF ACTION THEY DID. MOSTLY THEY DID SO ON THE BASIS OF A DECISION TAKEN ENTIRELY WITHIN THE FAMILY, THOUGH IN A VERY SMALL NUMBER OF CASES DOCTORS OR SOCIAL WORKERS WERE CONSULTED. WHAT CAME THROUGH OVERWHELMINGLY WAS THE REJECTION OF ANY FORM OF INSTITUTIONAL CARE AND ONLY TWO OF OUR SAMPLE HAD EVER SPENT ANY TIME IN A NURSING HOME, AND THE OVERWHELMING ATTITUDE WAS THAT ^{permanent} NURSING HOME CARE SHOULD BE AVOIDED AT ALL COSTS. THERE WAS HOWEVER A RECOGNITION AMONG

HALF OF THE RESPONDENTS THAT THE TIME MAY COME WHEN SOME NURSING HOME CARE MAY BE REQUIRED FOR A PERIOD.

IN LOOKING AT FUNCTIONAL ABILITY OF THE ELDERLY PEOPLE IT WAS FOUND THAT BY AND LARGE THEY REQUIRED A GREAT DEAL OF ASSISTANCE AND SUPPORT. JUST OVER HALF WERE ABLE TO FEED THEMSELVES AND JUST UNDER HALF WERE ABLE TO GET ABOUT THE HOUSE A BIT, AND WHEN THE OCCASION REQUIRED, GET TO THE TOILET ON TIME. MOST WERE NOT ABLE TO GO TO PLACES OUTSIDE WALKING DISTANCE, MOST WERE NOT ABLE TO PREPARE THEIR OWN MEALS, THEY COULD NOT DO LIGHT HOUSEWORK, MOST WERE NOT ABLE TO GET UP AND DOWN STAIRS, BATHE THEMSELVES, CUT THEIR TOE NAILS, TAKE THEIR OWN MEDICATION OR HANDLE THEIR OWN MONEY. THE MOST COMMON ^{Medical} CONDITION EXPERIENCED BY THE ELDERLY PEOPLE WAS ARTHRITIS BUT ALMOST HALF HAD HEART PROBLEMS, JUST UNDER HALF HAD FAILING SIGHT OR HAD HAD FRACTURES, WHILE ABOUT A QUARTER HAD NERVOUS CONDITIONS, WERE RECOVERING FROM STROKES OR PARALYSIS, OR HAD RESPIRATORY PROBLEMS.

THE CARERS THEMSELVES FELT A STRONG SENSE OF OBLIGATION TOWARDS THEIR ELDERLY RELATIVE AND ACCEPTED THE CARING TASK, BECAUSE BY AND LARGE THEY BELIEVED THE FAMILY HAS RESPONSIBILITY TO CARE, AND ^{furthermore} THAT THEY LOVED THEIR PARENTS. WE ALSO IDENTIFIED A LOT OF PRESSURES ON THE PEOPLE WHO WERE PERFORMING CARING FUNCTIONS.

FAMILY CARE IN REALITY IS CARE BY WOMEN. WHEN I SAID EARLIER ON THAT PEOPLE WERE LIKELY TO LOOK MORE TOWARDS FORMAL CARE SYSTEMS THAN INFORMAL CARE SYSTEMS I WAS THINKING OF THE FACTS THAT THE POTENTIAL POOL OF CARE TAKERS IN AUSTRALIA - THOSE UNMARRIED WOMEN NOT IN THE LABOUR FORCE WHO ^{formally} SAW IT AS THEIR ROLE TO LOOK AFTER ELDERLY PARENTS - IS RAPIDLY DIMINISHING. THERE ARE FEWER NEVER MARRIED WOMEN IN MIDDLE AGE TO-DAY THAN THERE EVER HAVE BEEN. THERE ARE ALSO MORE WOMEN IN MIDDLE AGE IN THE LABOUR FORCE THAN THERE HAVE EVER BEEN. THE SITUATION HAS BEEN CHARACTERIZED BY AN AMERICAN SOCIAL SCIENTIST, ELAINE BRODY WHO IN DESCRIBING THE PHENOMENON OF

"THE WOMAN IN THE MIDDLE" WROTE "

"SUCH WOMEN ARE IN MIDDLE AGE, IN THE MIDDLE FROM A GENERATIONAL STANDPOINT, AND IN THE MIDDLE IN THAT THE DEMANDS OF THEIR VARIOUS ROLES COMPETE FOR THEIR TIME AND ENERGY. TO AN EXTENT UNPRECEDENTED IN HISTORY, ROLES AS PAID WORKERS AND AS CARE GIVING DAUGHTERS AND DAUGHTERS IN LAW TO DEPENDENT ELDERLY PEOPLE HAVE BEEN ADDED TO THE TRADITIONAL ROLE OF WIVES, HOMEMAKERS, MOTHERS AND GRANDMOTHERS. MANY OF THEM ARE ALSO IN THE MIDDLE IN THAT THEY ARE EXPERIENCING PRESSURE FROM TWO POTENTIALLY COMPETING VALUES - THAT IS THE TRADITIONAL VALUE THAT CARE OF THE ELDERLY IS A FAMILY RESPONSIBILITY, VIS-A-VIS THE NEW VALUE THAT WOMEN SHOULD BE FREE TO WORK OUTSIDE THE HOME IF THEY WISH."

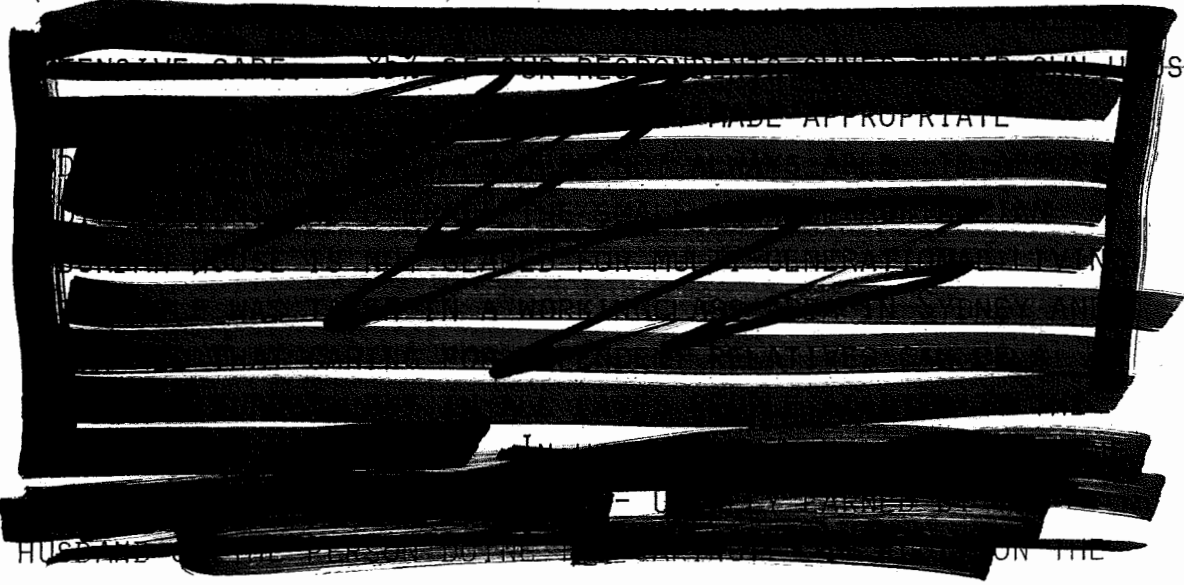
THE WOMEN IN OUR STUDY FOUND VERY OFTEN THEY COULD NOT MANAGE ALL OF THESE COMPETING VALUES AND IN FACT MORE THAN HALF OF THEM HAD STOPPED PAID EMPLOYMENT IN ORDER TO CARE FOR THEIR ELDERLY RELATIVES. IN MANY CASES THERE WAS SOME CONSIDERABLE RESENTMENT AT HAVING TO LEAVE A PAID JOB - THERE WAS NOT RESENTMENT AT CARING FOR THE RELATIVE.

THE CARERS BY AND LARGE FELT THEMSELVES FAIRLY ISOLATED. FEW HAD ANYBODY TO PROVIDE ANY PERIODIC RELIEF WHEN IT WAS REQUIRED. THOSE WHO HAD HUSBANDS AND CHILDREN FOUND THEM GENERALLY SUPPORTIVE, BUT VERY OFTEN THE SUPPORT WAS ONLY VERBAL AND DID NOT TRANSLATE INTO ACTION. MANY OF THE CARERS THEMSELVES HAD HEALTH PROBLEMS. WHEN ILL THEY HAD NO OPTION BUT TO CONTINUE OFFERING CARE. MOST HAD NOT HAD A HOLIDAY FOR YEARS. THEY RESENTED THEIR LOSS OF INDEPENDENCE AND THE DECLINE IN THEIR HEALTH WHICH WAS CAUSED BY STRESS. ALSO THEY EXPERIENCED GREAT ANXIETY - ON THE ONE HAND THEY FELT

THEY COULD NOT LEAVE THEIR ELDERLY RELATIVE FOR ANY LENGTH OF TIME AND ON THE OTHERHAND SOME FELT THAT THEY WERE NEGLECTING THEIR FAMILY RESPONSIBILITIES. SOME FELT A TREMENDOUS EMOTIONAL DRAIN ON THEMSELVES AND ONE SAID TO US "AT 80 I'M GOING OVER THE GAP - I COULDN'T PUT MY KIDS THROUGH THIS".

ALMOST HALF OF THEM HAD NOT HAD A HOLIDAY FOR OVER 2 YEARS. ONLY ONE THIRD HAD RECEIVED ANY HELP FROM PEOPLE OTHER THAN THEIR OWN FAMILY. THERE ARE MANY REASONS FOR THIS, A QUARTER SAID THEY FOUND IT DIFFICULT TO ASK FOR HELP, A VERY SMALL NUMBER DID NOT KNOW WHO TO ASK, ALSO A VERY SMALL NUMBER ASKED FOR HELP BUT WERE REFUSED. BUT ABOUT HALF FELT THEY COULD MANAGE IN THEIR OWN WAY AND DID NOT WANT ANY HELP. GETTING THE ELDERLY RELATIVE OUT OF THE HOUSE WAS NOT AN EASY THING. MORE THAN HALF OF THE CARERS DID NOT HAVE THE CAPACITY TO TAKE THE ELDERLY PERSON ON AN OUTING. EITHER THEY DID NOT HAVE ACCESS TO A CAR OR IT WAS NOT POSSIBLE TO GET THE ELDERLY PERSON INTO THE CAR. THIS IS VERY IMPORTANT WHEN ONE CONSIDERS THE OPTIONS IN COMMUNITY SUPPORT. IT IS NOT ALWAYS POSSIBLE TO TRANSPORT DISABLED AND DEPENDENT PEOPLE TO SERVICES AND IT IS OF GREAT IMPORTANCE TO BRING THE SERVICES TO THE PERSON.

Among our sample, home ownership was high, but income was low.



EL [REDACTED] RECEIVED THE AGE [REDACTED]
SIMILAR PENSION SUCH AS A [REDACTED] PENSION. THE [REDACTED]
NURSING CARE [REDACTED] RECEIVED IN [REDACTED]

S [REDACTED] INCOME AND SALARY EARNER [REDACTED]

ON [REDACTED] IN ROUGHLY ONE HALF OF THE HOUSEHOLDS THE ONLY INCOME COMING INTO THE HOUSEHOLD WAS IN THE FORM OF GOVERNMENT SOCIAL SECURITY BENEFITS WHICH COULD NOT BE DESCRIBED UNDER THESE CIRCUMSTANCES AS GENEROUS IN ANY WAY. MY COLLEAGUE DAVID KINNEAR WHO DID MOST OF THE INTERVIEWS IN THIS STUDY IS, AT THIS MOMENT, CONDUCTING INTERVIEWS TO BROADEN OUR SAMPLE. WHEN HE RETURNS TO SYDNEY WE WILL BE ABLE TO WRITE UP OUR STUDY FROM A BROADER PERSPECTIVE.

*change
class. S
- Churchill
drunk/
sobs*

OUR RESPONDENTS REPORTED A RANGE OF DIFFICULTIES THEY EXPERIENCE IN PERFORMING CARING FUNCTIONS. ABOUT A QUARTER FELT THAT THEIR FAMILY COMMITMENTS WERE BEING NEGLECTED, ABOUT THE SAME NUMBER RESENTED THEIR LOSS OF INDEPENDENCE, AND ABOUT THE SAME NUMBER REPORTED FEWER OUTINGS. ABOUT THREE QUARTERS FELT THE TIME AVAILABLE FOR RECREATION AND LEISURE ACTIVITIES HAD JUST ABOUT DISAPPEARED. ABOUT HALF FELT THEY WERE NO LONGER ABLE TO GET THEIR HOUSEWORK AND CHORES DONE IN TIME. IN ABOUT HALF THE CASES HEALTH AND PHYSICAL STAMINA WAS SEEN TO HAVE DECLINED AS WAS THE GENERAL STATE OF RELAXATION. ABOUT HALF THE PEOPLE WERE LESS ABLE TO RELAX AND SLEEP THROUGH THE NIGHT THAN THEY HAD BEEN BEFORE TAKING ON THE CARING FUNCTION. ABOUT HALF REPORTED A DECLINE IN THE RELATIONSHIP WITH THEIR FRIENDS AND ABOUT THE SAME NUMBER A DECLINE IN THE RELATIONSHIP WITH THEIR BROTHERS OR SISTERS. ABOUT A QUARTER EXPERIENCED A DECLINE IN THE RELATIONSHIP WITH THEIR SPOUSE AND ABOUT THE SAME NUMBER FELT A LOSS OF SELF ESTEEM SINCE ENTERING A CARING SITUATION. OVERALL ABOUT 40% FELT THAT THEIR GENERAL EMOTIONAL STATE HAD DETERIORATED SINCE TAKING ON THE CARING FUNCTION. IN ADDITION MANY FELT THAT THE PLANS THEY HAD MADE FOR THE FUTURE WERE NO LONGER OPERATIVE. THE SITUATION ADDS UP TO THE FAIRLY COMPLEX SITUATION OF CONSIDERABLE SACRIFICE BEING MADE IN THE ABSENCE OF WHAT MIGHT BE REGARDED AS A BROAD RANGE OF COMMUNITY SUPPORT SERVICES.

THIS IS NOT TO SAY THAT THE SERVICES WERE TOTALLY NON-EXISTENT. OUR SAMPLE WAS BIASED TO THE EXTENT THAT ALL PEOPLE WERE RECEIVING OR HAD RECEIVED HOME NURSING SERVICES. WE ASKED PEOPLE ABOUT A FAIRLY BROAD RANGE OF SERVICES AND WHAT WE FOUND WAS THAT MORE THAN THREE QUARTERS WERE NOT AWARE OF SERVICES WHICH COULD POSSIBLY BE OF ASSISTANCE. (THIS IS NOT TO SAY THAT ALL OF THESE SERVICES WERE READILY AVAILABLE). FOR EXAMPLE MORE THAN THREE QUARTERS HAD NOT HEARD OF THE HOME HELP SERVICE, SHOPPING OR DELIVERY SERVICES, HOME VISITING SERVICES, GRANNY SITTING SERVICES, DAY CARE CENTRES, RESPITE BEDS, HOME PEDIATRY SERVICES, WHILE TWO THIRDS HAD NOT HEARD OF MEALS ON WHEELS. THERE IS A PARTICULAR DILEMMA RELATING TO SERVICE KNOWLEDGE AND USAGE. MOST SERVICES ARE ALREADY STRETCHED TO THEIR LIMITS AND IF MORE PEOPLE WERE AWARE OF THE SERVICES AN EVEN GREATER CRISIS THAN PRESENTLY EXISTS COULD EXIST. SERVICE PROVIDERS HAVE A RESPONSIBILITY TO LET THE POTENTIAL CLIENTELE KNOW OF THE SERVICE, BUT THE CATCH 22 IS ONCE THEY INFORM PEOPLE OF THE SERVICE THE CHANCES ARE THEY WILL NOT HAVE THE CAPACITY TO DELIVER THE SERVICE ADEQUATELY. THIS POINTS TO A SITUATION THAT REQUIRES VERY CAREFUL BOLSTERING AND SUPPORT.

In conc'

THE DEPENDENCIES OF OLD AGE ARE CHRONIC RATHER THAN TRANSITIONAL AND MAY FORESHADOW CONTINUING OR INCREASING DEPENDENCY. THE DEPENDENCIES ARE EXPECTED AND ACCEPTED AND WHEN WE HAVE COMPLETED OUR STUDY WE HOPE TO BE ABLE TO PROVIDE MORE INFORMATION ON HOW THESE DEPENDENCIES CAN BEST BE DEALT WITH IN TERMS OF THE PROVISION OF SUPPORT AND SERVICES FOR FAMILY MEMBERS AND ELDERLY DEPENDENT PEOPLE.

In developing policy we need to blend expertise with humanity - remember - an expert is a person who avoids the small errors while heading towards the grand fallacy

Electrician - commonsense a rare God-given gift - I only have a technical education.

For the rest of the day I hope we can blend our technical