MEMORANDUM

MACOMB-OAKLAND REGIONAL CENTER

MT. CLEMENS, MI.

TO C. Patrick Babcock DATE December 23, 1986

FROM Nancy Rosenau

SUBJECT Special Assignment on Children's Placements

In August 1984 I was asked to work on a special assignment for the east and southeast sections of the state. As project leader I was to address strengthening of efforts to assist families in maintaining or returning developmentally disabled children to their homes or to develop residential opportunities for those where that is not possible.

With two years of history on our special efforts to reduce the use of institutional care for children, it is a good time to draw some conclusions and make some recommendations. The effort over the past two years has been primarily in two directions: 1) closing the last pediatric facility in the state, and 2) assuring that sufficient alternatives are offered on a timely basis to prevent the development of another facility care system for children. The major accomplishments of the past two years are outlined. Also given is some data regarding the potential magnitude of the need and finally some suggestions are made about systems modifications that are necessary to maintain the new direction we have clearly set.

NR:mk

cc: Ben Censoni

	Warren Village		Other Nursing Homes	Hospital Referrals	DD Facilities	TOTAL
	Prior to Announced Closure	After Announced Closure				
PLACED						
Return to Natural Home		9		25		34
Foster Care	7	43	4	14	3	71
Group Home	5	17	1	2	4	29
TOTAL	12	69	5	41	7	134
Still Waiting		50*	26 11 Taylor TLC 3 Wayne TLC 1 Greenbrook 6 Willowbrook 1 Oakland Medical Care* 1 Oak Hill* 3 Southfield Rehab*	11 6 SRC 1 MORC 4 Oakdale	12	99
Died		16		10		26
Went to Nursing Home				(11)*		
Number Children Known to Project	12	135	31	73	19	259

I. Major Accomplishments

In a relatively short period of time a very large number of severely multiply impaired children and young adults (134) have been moved from or have been diverted from entering large facility based care alternatives in favor of families or small group homes. The group homes have been used almost exclusively for youngsters over 16 years of age. For a few youngsters under 16, Mulberry, a small group home licensed for respite only, has been used as a transitional setting into family care.

Our experience with hospitals who had previously referred to nursing homes is that a referral to a nursing home setting was too quick and easy a discharge for a child with multiple problems or a family with multiple problems. Once in the nursing home no one looked at any assistance to resolving the family's situation or advising the family that multiply impaired do not necessarily need nursing home care. With the option to refer to an easily accessible nursing home removed, we have had an opportunity to work with families. The result has been return home as the most utilized option. In many cases the deciding factor was simply information and discussion about potential positive futures and resources.

II. Magnitude of Problem

Interactions in the southeastern area have included 18 counties and three DD facilities. Of the 18 counties Wayne (expectedly) had 60 referrals from hospitals while 12 counties had only 1. For the fifty youngsters remaining in the Transitional Units used to phase out of the Warren Village situation, matches exist for all but five. Only 12 youngsters remain in the DD facilities (SRC, MORC, & Oakdale). Only one of these is from Macomb or Oakland county and only five are from Wayne. From the three counties that represent 2/3 of

the state's population, there are only six youngsters remaining in DD institutions which has moved us well toward the 1986 goal outlined by the Governor.

While there is cause for optimism, there also needs to be caution raised about the risk of "losing" small numbers of children scattered throughout the state in adult long term care settings. We have found several through our informal networks who have not been identified by the interagency agreement. A tightening of the procedures in that agreement needs to occur to prevent children getting lost in the system.

One of the implications of the efforts to make family life a reality has been the need for extraordinary resources to some families. While the Medicaid waiver is beginning to address some situations, it is now clear that the needs of this population and their families outstrips the dollar ceilings of waivered services. I believe the waiver was written before we had much experience with children with very challenging medical needs. A few families will require as much as $50,000 per year. While the number of families requiring this level of support are not great, the use of that kind of resource for one family raises questions when set against the needs of families at poverty level incomes (who do not necessarily have developmentally disabled children). In order to keep perspective on the relatively small number of families needing that resource, of the 34 children who went to their own homes, only one utilized that level of funding. In fact, 17 appear to have gone home using only already existing resources, that is, private insurance covered services, "standardly" available CMH respite, Crippled Children's services, and natural supports.

Part of the fear behind use of such expensive resources is the "floodgate" myth that many new families and children will come forward. A look at data from the R-19 process (Public Health level of Care approvals for nursing home care) is instructive. From R-19 data prior to the closure of Warren Village,

for the twelve month period from May, 1984 - May, 1985, 40 children were admitted to nursing homes (on an average of 3.3 per month.) For the twelve month period from July, 1985, to July, 1986, we dealt with 29 hospital referrals and 12 community referrals at risk of entering nursing homes for a total of 41. Because of the similarity of these numbers, I am confident that our informal contact process is bringing to our attention this previously nursing-home-bound group of children.

III. Recommendations for Systems Modifications

We have made a great deal of progress, but as always, have a great deal yet to do. A number of problem areas could benefit from attention as outlined below.

A. Service Caps

#1 CMH Response Time to Intake and Assessment

Early in the project I initiated contacts to all the major referring hospitals to explain alternatives and the CMH process to access services. My ongoing role has been to be available to hospital social workers on a timely basis with directions about who to call and what to expect. Equally important has been the role of problem solving when the hospital social worker received a less than acceptable response. In some cases this meant additional direction. In other cases it required direct intervention to Community Mental Health on my part. I think CMH's are learning but this is a relatively new population to many and the time pressures of hospital discharge planning do not often fit the waiting list status of many CMH responses. It would be helpful to organize a training session for CMH intake workers specifically addressing responses to hospital discharge plans. One mechanism to do this would be through the CMH family support coordinators and intake workers for a special training session. Another effort in the

planning stages is a conference being planned with Tony Kim specific to discharge planning for infants. The audience would include the health care professionals in addition to mental health staff.

Lastly a protocol for dealing with these referrals is suggested and attached.

#2 Transition Capacity

A key factor in the ability to prevent nursing home referrals has been the capacity to provide meet "high consumer" need on a short term notice. In some cases this has only been possible through utilization of Mulberry, a six bed child caring facility operated as an off shoot of a home care agency.

The availability of Mulberry has proven to be enormously important for a number of reasons:

1) It allows relief of hospital discharge pressure when another alternative is not yet ready.
2) It is able to accept virtually any medical problem (except CNC by prohibition).
3) The commitment to short term placement is real so that we don't create a long term group home.
4) The commitment to family care is clear and aids in the transition plan to family placement.
5) Because it is not a DMH contracted home, we pay only for the beds we use. Other funding sources also purchase beds.
6) Because it is expensive, a CMH that chooses to use it as a transition to foster care or return to natural family is automatically pressed to do so in a timely fashion.

While there have been some problems in operation they are clearly worth fixing rather than discontinuing use of this home. The home is most frequently used as a transitional setting rather than its original intent to do respite.

We would very clearly be hard pressed to prevent nursing home admission if we did not have Mulberry, and experience has shown no transition from nursing homes. If we could use nursing homes in this way, it is very difficult to get out once having granted permission for admission.

To improve the larger system I think we may need one other Mulberry type home.

#3 Foster Care Capacity

A major drawback in the development of alternatives to institutional placements for kids is CMH capacity to recruit specialized foster care. Many counties do not have child placing licenses. Rather than having a truly useable relationship with a child placing agency, there is often a response that simply negates foster care placement. Some activity to assure either child placing license or contractual relationship with a child placing agency is a prerequisite to avoiding institutional admission.

#4 CMH Nursing Assessment Capacity

A second major drawback is the poverty of nursing input available to CMH's. Frequently no nurse is on staff and no clear relationship exists with a contract agent. Where contract capacity exists it may involve a nursing service which may not have pediatric and/or DD expertise. It seems to me we need to beef up this discipline's input to CMH's so that there is readily accessible nursing input for decision making/planning purposes.

B. System Coordination Needs

#1 DMH/DSS/DPH Agreement

The DMH/DSS/DPH agreement does not work with fool proof surety. We know of youngsters who have gone to adult nursing home settings where we have not received referrals from DPH. Consistently we have had better luck with "networking" approaches with hospital staff. Hospital staff have come to see us as helpful and call for that reason rather than because required to

do so. However this is not sure enough. I am fearful that we may lose track of a few youngsters and end up several years from now with a hidden population of children. We need to establish a more secure tracking system of children.

#2 DD Facilities

With regard to DMH "inpatient" kids we have reached a point where the numbers are small enough to track by name. A published list of kids would keep them visible and could be reviewed regularly at CMH area manager meetings, Ben's community placement meetings and facility director's meetings. I believe the high visibility would accelerate their prioritization for movement.

C. Service Realignment

#1 Definition of DD

There has been some question raised by CMH's about the definition of developmental disability. It is not possible nor desireable to predict "substantial impairments that will continue indefinitely" for a two month old infant. However, failure to be able to do that has led some CMH staff to question ability to serve. Clear direction from the Department is necessary.

#2 Continuous Nursing Care

I believe it is time to take on the CNC agreement especially as it regards child caring facilities. It would be very helpful if we could reach some sort of agreement to allow a Mulberry type operation to care for CNC children.

A case in point is a vent-dependent child at Hurley Hospital. Mulberry would take and could take him while we recruited a very special foster home except for the prohibition against CNC. The alternative that the hospital is pushing is an available bed in Grand Rapids in a vent-dependent unit in a

hospital across the state away from his family and the folks who will be recruiting for foster care. The use of Mulberry would be preferable.

IV. Conclusion

The reality of this two year intensive effort is that we have changed the way in which services are provided to developmentally disabled youngsters and the place where they are provided. The effort has gone hand-in-glove with the permanency planning efforts to challenge previous practice and attitudes. With continued attention to some gaps in services and some coordination problems this momentum can continue. The effort has resulted in two important events: 1) Most children are going to a family home from acute care settings who heretofore would have been placed in facility care, and 2) the actual number of children cared for in facilities vs. non-facility care has decreased significantly and we are moving quickly toward the elimination of utilization of institutions for DD children.

ADDENDUM

PROTOCOL - NICU/PICU Discharge Planning Inquiries

On receipt of phone call from hospital social worker

ESTABLISH

-child's disability

-potential discharge date

-natural family situation

-insurance coverages

CHILD'S DISABILITY

Does the child have a developmental disability?

If denied by CMH alert area manager for review.

POTENTIAL DISCHARGE DATE

Timely response is needed even when discharge date is not yet being predicted.

NATURAL FAMILY SITUATION

Many families have had a one-sided presentation. The following areas may not have been covered by the hospital:

-family support services available such as respite

-parent to parent initiatives

-life consultation and planning

-possible interventions with assertive medical practices (unfortunately still negative presentation from physicians)

-permanency planning

INSURANCE

Careful review of coverages with an eye toward waiver coverages - MA Model I, II; BCBS Waiver