

## **Health-care Management Service Pilot Launched**

*By David Forney*

After more than two years in the planning, a pilot study of the Down Syndrome Association of Minnesota Health-care Management Service has been initiated.

A nurse consultant, who brings us decades of experience working with adults with Down syndrome, has been retained by the Association. She is working with several families to help them define the health-care needs of their adult sons and daughters with Down syndrome.

The needs of those participating in the pilot study range from families in need of validation that the services they currently access are appropriate on to those who have been badly frustrated in securing a wide range of services.

The goal of the six-month pilot is to determine if the service is of value to our families; early indications are that it is surpassing expectations.

Each participating family has been asked to complete a questionnaire detailing the health-care history and needs of their adult son or daughter with Down syndrome. That is followed by a meeting with the consulting nurse which includes the parents or guardian and the self-advocate. At the conclusion of that meeting, each family is provided with a detailed health-care management plan, complete with referrals to health care providers for follow up. The nurse-consultant will stay in contact with each family to answer questions, deal with problems and document the effectiveness of plan implementation.

Our nurse-consultant is working closely with the Adult Health-care committee to gauge the value and effectiveness of the service. All participating families have agreed to complete an evaluation questionnaire and we intend to follow up with other techniques. The current plan is to complete the pilot study and evaluation early this fall and launch the service to all Association members soon thereafter.