

The CHOICES Project

(Choosing How Our Investments Create Enabled Supports)

Draft Monograph

**Submitted by The Arc of Ohio
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I. General Overview

The CHOICES project began in early 1999 to assist 25 residents in large congregate settings make a smooth transition into community living by December 2003. Approximately 10,000 people with developmental disabilities are living in large congregate settings in Ohio. These setting include developmental centers, ICF/MRs, and nursing home facilities. The CHOICES project is following the increase shift in the provision of long-term support for people with developmental disabilities, which would allow for community integration, self-determination, and individual choice. The continued need for sufficient resources, experience and expertise are being addressed to allow those in large congregate settings to move successfully into homes of their choice.

The Arc of Ohio has been collaborating with People First of Ohio and Independent Living Centers throughout Ohio to form two self-advocacy teams to work with individuals in large congregate setting who have expressed an interest to move into the community and choose other life choices. Each self-advocacy team is composed of 12 to 14 members and one team leader who are self-advocates with a background in the social service system. Team members are trained in relationship building, choice making and services offered by governmental agencies. Team members provide information and training on aspects of community living as well as, identifying and addressing the concerns of family members. Each team meets regularly to discuss information and issues that are of concern to all individual team members and other participants.

During the first two years of the project, the Project Director and Project Coordinator have utilized the skills and resources of many organizations and individuals. The CHOICES project has cooperated with the following organizations: People First of Ohio, Capabilities Unlimited, Ohio Statewide Independent Living Association, the Ohio Developmental Centers Superintendents, the Ohio Department of Mental Retardation and Developmental Disabilities, the Ohio Association of County Boards, the Arc of Ohio local chapters and individual members of the Arc. The collaboration with these organizations has included general presentations on the CHOICES project, training to the staff members of these organizations and advocacy groups, and to encourage active participation to ensure and expand the goals of the Project, especially in the State Developmental Centers.

The Choices project will continue to work with all stakeholders and teams to assure that individual choice is honored, respected and implemented. The staff and team leaders have identified several areas that ongoing training, support and advocacy are needed to assist individuals, family members and concerned

parties make informed decisions about where people live and will be supported in the decision and the eventual move.

II. Position on the Role of Large Congregate Settings

The Arc of Ohio and the CHOICES project has held the belief the every individual should be given the opportunity to make choices about where they want to live. If any individual decides to change their living arrangement or would like to experience community living, the CHOICES team will make every effort to link individuals to resources in their community. The CHOICES staff believes that in order for individuals to make informed choices about where to live, it is necessary for them to experience what community living is all about. The congregate settings will need to share the core beliefs of self-determination and choice for staff to engage in and participate in community activities with team members. Team members will assist people with disabilities develop the skills necessary to live in the community.

The CHOICES project will work with large congregate setting to identify individuals expressing an interest to live in the community. The focus of the CHOICES project will be on individuals and their families seeking assistance in choosing and moving into their communities, not the impact on the large congregate settings as a result of individuals moving. The CHOICES project staff is fully aware that individuals will benefit if their current residential provider is included in the transition into the community. Furthermore, collaboration with large congregate settings will continue so that self-determination and choice are fully realized by people currently residing in congregate settings.

III. Lessons Learned

A. Team Information: Roundtables and Meetings

Team meeting have been held to review the goals of the project and discuss personal stories of team members. Some of the discussions have been held regarding the Ohio Department of Mental Retardation and Developmental Disabilities project entitled Self-determination in the Developmental Centers, and how it relates to the Ohio service delivery system. The Self-determination program will support individuals with funding their community support that will enable them to move into the community.

Approximately fifty individuals have attended the roundtable discussions. Invitations have been extended to professionals, self-advocates and parents that have an interest or knowledge in assisting us in reaching the CHOICES project goals and to discuss areas of concern. The CHOICES staff will invite

and encourage more involvement of all stakeholder and advocates so that additional expertise is given to make the teams operate more successfully. The team members will continue to share successes and failures to assist one another in working with individuals looking for community supports.

B. Personal Profiles

The team meetings have allowed members to discuss personal stories of their direct involvement with individuals expressing an interest to move into the community. The stories range from the very successful cases and the not so successful cases. At the March 2001 Developmental Disabilities roundtable meeting, two friends will discuss their involvement in the CHOICES Project. We have outlined two stories in which a friendship was developed and that friendship assisted the person into moving into a community setting of their choosing.

A team member befriended an eighteen year old woman that had been living in a nursing home for two years. The friend was not attending school. The team member and the friend discussed future plans and goals. The friend was informed the process to move might take four to six months. The friend indicated she wanted to be part of the CHOICES project. The friend was not a participant in the MR/DD system and was unfamiliar with supported living and other services to assist her in moving into the community. The team member set up a PAS-R evaluation in which the friend completed. The State gave MR/DD sixty days to give the friend a supported living slot. The friend was granted a supported living slot. The friend currently lives with a roommate and has begun to go to school.

In another case, a man was living in a nursing home because his wife had left and he could not physical care for himself without assistance. His goals were to become waiver eligible, secure accessible housing, purchase a new wheelchair, and to find a bed and other items. The team member arranged transportation and went with the friend to fill out a waiver application at the Department of Jobs and Family Services. At the same time, the friend needed a wheelchair because the nursing home owned the one he was using. The team member assisted the friend with acquiring a doctor's prescription for a wheelchair. The team member assisted the friend in applying for and securing accessible subsidized housing through HUD. The friend was able to get hospital a bed with a doctor's order at no cost because the friend had Medicare. The friend also secured a new medical team (outside of the Nursing Home) that helped with prescriptions and other medical needs.

C. Self-Advocates

The team members for the ICF/MR and Nursing Home are all self advocates, as well as the two team leaders. Both teams have been successful in reaching people in the congregate settings.

The Nursing Home team has been extremely successful in training and helping individuals move into the community. The training is ongoing at the various Independent Living Centers and with new team members. The Nursing Home team has experienced some turnover, but has been able to recruit new members relatively quickly. The project staff will assist in looking for new team members familiar with the Nursing Home setting. In early 2001, the staff will be meeting with four independent living centers to conduct training and possibly add additional team members.

The ICF/MR has been working closely with the People's First organization in developing their team. This team has identified individuals for community living, but face more obstacles due to health and safety concerns of parents and the close relationship individuals have formed with their congregate setting personal care staff. Also, the ICF/MR team has experienced some challenges in physically reaching all the locations due to proximity, geographic locations and the fact most individuals do not drive.

The project staff is currently working with the Superintendents of six developmental centers to address the issues of promoting the project within their organizations and identifying individuals that may be interested in the project. The project staff will help better facilitate and coordinate transportation for team members. The assistance may include linking Nursing Home and ICF/MR team members to work together when meeting individuals interested in the project. Furthermore, it has been suggested that more one to one community activities with individuals living in the ICF/MRs need developed to ensure friendships can be formed. The large group activities have not produced strong personal friendships needed to support a transition into the community. Team members will be working with Developmental Center staff assigned to the State Self-Determination Project.

D. Parent Involvement and Collaborators

Family members have been involved in the CHOICES project due to the fact that The Arc has traditionally been a parent-based association. The project staff will need to better cultivate the relationships between the Arc members and family members with concerns about relatives who may leave the congregate settings. The project staff has already began to reach out to parents not currently associated with The Arc of Ohio. Arc members will also

act as self-advocates to educate the general assembly and other policymakers about the value of choice in deciding where people want to live.

The project staff is currently setting up meetings with family members of individuals in the Developmental Centers. The CHOICES project has experienced some resistance in the Developmental Centers among family members. The staff will work diligently to build relationships in and out of the Developmental Centers that will encourage community living.

The project staff and team members will also redirect some efforts to work with local communities to better facilitate the community options for those individuals choosing to move into the community. Once an individual has expressed moving into the community, staff and team members will work with civic organizations and community service providers to help make the transition feasible and possible. This will also include working with personal caregivers and the staff of congregate settings to develop a dialogue that will encourage community living.

E. Training

The CHOICES project staff and team leaders continue to provide training and information sessions to team members, community advocacy organizations, professionals and provider associations. The trainings have acted as a marketing and referral source for new team members and individuals interested in moving out of a congregate setting. The team leaders have continued to make presentations at conferences, public policy forums, and to professional associations. The team leaders will continue to participate and be active with other organizations working to facilitate choice and self-determination.

Team members have been receiving training on various aspects of community living that includes housing issues, Medicaid waivers, advocacy, and training from representative of the Ohio Department of Jobs and Family Services on the Medicaid programs. An ongoing effort will be made to develop and educate team members on community resources available that promote choice.

F. Public Policy

The CHOICES project has been viewed as a positive component toward Self-Determination. The Ohio Department of MR/DD and several Superintendents of Ohio Developmental Centers are actively working with the CHOICES project, and have verbally committed time and resources to work with staff and team members to assist individuals develop natural supports in the community and to make the transition to other housing alternatives. The

Developmental Superintendents have linked their staff with advocacy groups (i.e. People First) and the CHOICES staff to assist in the project. The Superintendents have expressed a desire to link the CHOICES project in conjunction with their self-determination initiatives.

The CHOICES project will continue to work with the Ohio Department of MR/DD and other decision-making bodies to encourage policies that support people with disabilities develop the skills and support networks necessary to live in the community. Also, the CHOICES project will continue to work with the Ohio Association of County MR/DD Boards to ensure legislative budget proposals encourage financial support to individuals and families wanting to move into the community from congregate settings.

G. Progress

The progress and support for the CHOICES project has been remarkable. As of December 2000, thirteen individuals have moved from the congregate setting into the community. The majority have been individuals from the Nursing Home team. Both teams have worked extremely hard to cultivate relationship as well as express commitment and enthusiasm in the their community. The opportunity to work more aggressively in the ICF/MR settings is promising with the commitment by the Developmental Centers and the Ohio Department of MR/DD. The ICF/MR team is expanding the CHOICES project to include an additional four Developmental Centers for 2001. The team leader will be assigning a team member to each of the Developmental Centers.

The teams continue to provide follow-up support to individuals who have moved into the community. The supports consist of regular communication and to plan activities with other self-advocates or support groups in the community. These team member activities include assisting friends with community networking with local churches, civic groups, and other community organizations.

The CHOICES project sees the commitment and dedication by individual team members as a great success of the project. This dedication has enabled thirteen people to move into the community. The self-advocacy of the team members creates a positive impression for individuals in the congregate settings, and allows individuals to learn by example from the team members in terms of expressing ones desires and goals for life.

Another success has been the development and ongoing experiences of individuals toward self-determination. The CHOICES project has allowed team members and individuals choosing to live in the community to experience the hands-on successes and failures everyone faces when enabled to make decisions. Those involved are learning to be resourceful and demanding when choosing and selecting where they want to live. Each

team has been required to use different skills and abilities in communicating and carrying out the goals of the project.

The resources available to the project have been utilized. Teams are using the transportation and community activities reimbursements toward community activities with individuals in large congregate settings. The project has also used reimbursements for the trainings, roundtables, and workshops involving issues related to the CHOICES project. This has allowed the team leaders and members gain valuable skills and acquire the knowledge of resources to assist the individuals they serve.

IV. Barriers and Challenges

A. Obstacles and Opposition

The aspect of developing friendship and making contact in the large congregate has been challenging due to the fact that creating friendships and establishing trust takes time. The project will continue to promote and collaborate with these setting to encourage relationship building. The staff of Developmental Centers believe more one-to-one activities would be more productive. The Nursing Home team has experience roadblocks from nursing home staff, and will need to engage the nursing home operators to open communication and dialogue.

Team members have run into challenges of community supports such as funding, community residential options, lack of attendant care, lack of training of professionals in order to support individuals to move. The expressed desire of individuals does not translate into definite ability of the system to support community living. Especially in rural areas, the local provider networks have expressed a lack of resources as the main obstacle to community living.

The CHOICES project staff needs to work closely with team members to develop a better tracking system on contacts and activities. The reporting of activities could be seen as a challenge because much of the work of team members is verbalized to the team leaders. Team leaders will be asked to ensure "data sheets" and monthly activities are recorded for reporting purposes. These items will be addressed at the January 2001 team meetings.

B. Opportunities

- Through future trainings and team meetings, expand the knowledge and expertise acquired by the team leaders and members during the first two years. The project will encourage seasoned team members to work with new members on activities that have proven to be

successful. This will include examples and outlines for members to use to provide team leaders with data on their activities.

- The CHOICES team will develop and cultivate the commitment expressed by congregate settings, especially the Developmental Centers and the Ohio Department of MR/DD; and translate this commitment to other large residential settings (Nursing Homes and Private ICF/MRs). The team leaders will be part of this process to help team members engage in strategies that will facilitate the goals of the project.
- The CHOICES project will focus on connecting with the Self-determination programs at the State Developmental Centers and through the County Boards of MR/DD. The team leaders will encourage team members to connect with those staff in the congregate settings responsible for self-determination. Each team member will be given the contact person at each Developmental Center.
- The CHOICES staff will continue to promote the project goals and individual demand for choice through trainings, publications, and one-on-one contacts in local communities. Team leaders will ask their members to share their contact information with other members so that they may build these relationships in their communities.
- The CHOICES staff will try to build upon the success of the first two years of the project. The team leaders and members can demonstrate and outline to individuals wanting to move the real cases of others that have successfully moved out of the congregate setting.

V. Advocacy Plan

1. Team members will work with individuals and staff members in large congregate settings. Team members will be encourage to work one-on-one with individuals that have expressed interest in moving, this includes social activities, training on community resources, and participation with family members and/or guardians.
2. Team members will gather information and guides to community resources that can be given to individuals and their families to better help individuals in congregate settings make informed choices.
3. The CHOICES staff will work with Developmental Center, Nursing Home, and ICF/MR staff to train them on the CHOICES project and to gain a commitment to the principles outlined in the project.
4. The CHOICES project will continue to promote and enhance the relationships with the Independent Living Centers and the People's First organizations throughout Ohio.
5. CHOICES and The Arc of Ohio will maintain active in public policy forums addressing choice and self-determination. The staff will present the

CHOICES project to private providers of services, government entities, and other interested stakeholders.

VI. Summary of Activities and Action

People are choosing to live in less restrictive settings on a monthly basis with the support of friends, team members, and team leaders made through the CHOICES project. The Arc of Ohio has been amazed at the CHOICES Project's success during the first two years. The project will work more closely with Nursing Home Administrators, Developmental Center Superintendents, public and private ICF/MRs and the League for the Mentally Retarded during 2001 to secure their support of Choice and Self-Determination. The CHOICES team members believe individuals will be encouraged to experience community living if we have the commitment of their families, guardians, and current personal care staff.

The initial response to the CHOICES project has been positive. The project has had a lot of support from the People's First Movement, the Ohio Department of MR/DD, the Ohio County Board Association, the Ohio Supported Living Association, Advocacy and Protective Services and County Boards of MR/DD. The project will continue to work with those representing the Developmental Centers, public and private ICF/MRs and Nursing Homes. People in the congregate settings are expressing an interest in experiencing community living and involvement. Success will depend on the commitment of management and direct staff in these congregate settings, as well as family members and guardians, to the belief that people should have choice and opportunities to live in the community they desire.