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ABSTRACT

This module presents the philosophical perspective that the fostering of family/professional partnerships is an integral part of effective service delivery to young children with disabilities. The module addresses the issues involved in nurturing the development of dynamic working relationships with families. The issues include: (1) understanding the impact of the child on the family; (2) establishing trusting relationships with families; (3) recognizing and utilizing parental expertise; (4) understanding the impact of intervention on the family system and individualizing family involvement; and (5) facilitating "parent to parent" and "family to family" support. Appendices contain a "wish list" of what parents want from early intervention professionals and a list of 17 suggested readings. (JDD)

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FORGING PARTNERSHIPS WITH FAMILIES

Module 3

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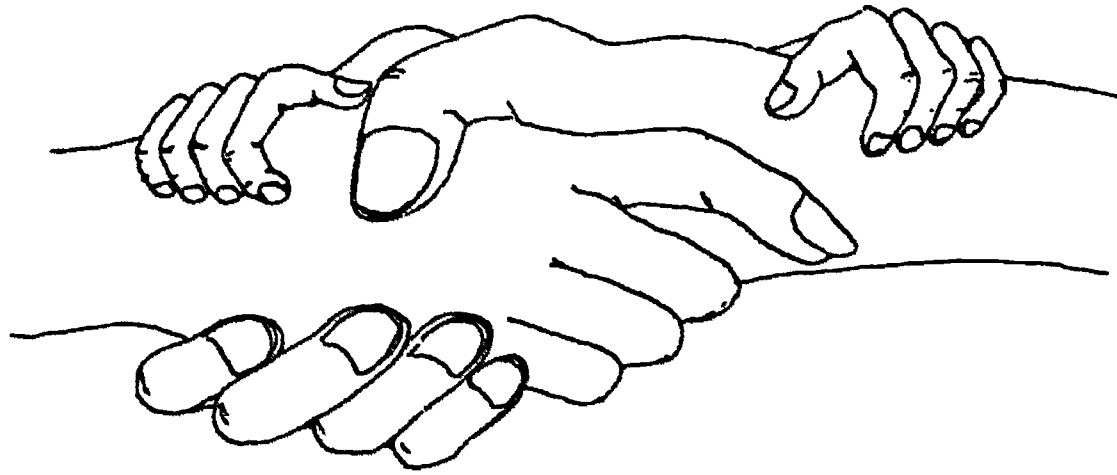
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Module #3: FORGING PARTNERSHIPS WITH FAMILIES

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and
Susan Harper-Whalen**

**Illustration:
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FORGING PARTNERSHIPS WITH FAMILIES

Philosophy and Purpose

Our purpose as early intervention professionals is to help young children with special needs to reach their full potential, not just inside the walls of our preschool classroom and in their eventual transition into elementary school, but within the broader contexts of family and society. Early intervention professionals have recognized for many years that families, and most particularly parents, should be an integral and equal part of the team which provides services to young children with special needs. Forming effective, working partnerships with families not only brings valuable information to the early intervention team, but within teams which view families as important and equal partners "empowerment occurs...that avoids the paternalism of the client-professional relationship" (C.J. Dunst, 1985).

Within the traditional "medical model" approach to the early intervention process, the child or family is seen as having deficits which the professional can "cure" or fix in some way. In contrast, the evolving philosophy of early intervention is based on an approach which integrates parents, other family members, and professionals as counterparts on the early intervention team whose function it is to design and implement plans which work toward achievement of specified child and family goals. Within such a model the professional is not someone who does things to or for a family, but someone who works with a

child and his/her family to help them acquire the skills they will need to make a healthy adaptation to the circumstances which shape their lives.

The existence of family/professional partnerships enhances the ability of the early intervention team to achieve the goals of each individual child and family. And, although developmental progress can and does happen for children enrolled in early intervention programs without extensive family involvement, the partnership of families in that process provides optimal, higher-order results which have broader impact not just on the child, but on his/her family and their adaptation to social systems.

It is, from the philosophical perspective of the CO-TEACH Preschool model, a "best practice" for early intervention professionals to foster the growth of such alliances with families.

Overview of the Module

The sections of the "Partnerships with Families" module which follow address the issues involved in nurturing the development of dynamic working relationships with families. Those issues include 1) understanding the impact of the child on the family, 2) establishing trusting relationships with families, 3) recognizing and utilizing parental expertise, 4) understanding the impact of intervention on the family system and individualizing family involvement, and 5) facilitating "parent to parent" and "family to family" support.

The Impact of the Child on the Family

For almost all families, accepting the fact of their child's disability will be the most difficult and complex issue they will ever face. Research tells us that the presence of a child with a handicap within a family is a stressor which places all family members at risk for psychological problems. Having knowledge of the stresses which are an everyday part of life for such families can help early intervention professionals to understand the needs, feelings and life perspectives of the families with whom they work.

When a child with a disability comes into a family the impact is broad-based and overwhelming. Fundamental change of any sort in our lives (i.e., moving to a new city, getting a divorce) is stressful. This particular "change" (assimilating a child with a handicap into a family) causes nearly every aspect of family structure and interaction to be altered substantially. (K.A. Crnic, et al., 1983) Emotionally, the family as a unit and each of its individual members must come to terms with what has "happened" to them. That process of coming to "acceptance" is very similar to the process of grieving which accompanies any large loss in our lives (the death of a loved one, etc.). The process includes experiencing the many stages of the grieving process: shock, denial, anger, chronic sorrow, reorganization and equilibrium. Those phases in the process of "acceptance" are not often passed through sequentially; each may resurface repeatedly and in no orderly fashion. In addition, the wound opened by the

initial diagnosis is reopened each time a "new" complication or problem with the child is uncovered. Since early intervention professionals are often the very people doing the "uncovering" of further needs, an acute awareness of the sensitivity with which families receive "more bad news" is required.

The birth and diagnosis of a child who has a disability is indeed a loss - the child whom the family wanted, anticipated, dreamed about and planned for is replaced with a child who brings with him/her fear of the unknown and a future in question. For most families there are soon difficult decisions to be made on a daily basis, endless rounds of therapy, appointments with medical and educational professionals, medical crises, surgeries (usually in out-of-state hospitals for families who live in rural states), looming financial burdens, advocacy work, and literally no "free" time. The physical demands of caring for a child who is medically fragile are massive and exhausting. Socially, families with children who are developmentally delayed are more isolated than families with non-disabled children. Lower levels of self esteem and higher levels of depression among parents of children with disabilities have been documented. Divorce and suicide rates for parents of children with disabilities are well above the national average.

When significant changes take place in our lives (i.e., we move to a new city to take on a new job) it is stressful, but almost always by our own choice. The changes which take place

for the family of a newly diagnosed child are, for the most part, out of their control. Families often remember those first few years as a time when "everyone" but them was making suggestions, referrals, and decisions about what was best for their child. Such removal of control is disempowering for families and often leaves them living day to day "waiting for the other shoe to fall."

Since families have said that early intervention programs may act as a source of social support or they may add to the stress already being experienced by the family (S. Duffy, et al., 1984) professional sensitivity to the life situation of each family is an essential component of any early intervention program.

Establishing Trusting Relationships with Families

Historically, teacher education programs have not included a strong focus on working with families. Except for parent/teacher conferences and "open house" evenings, communication with families is often limited to phone calls or notes from the teacher when something is amiss at school. The lack of close ties between family and school often leaves teachers believing they ought to be able to "do the whole job themselves" and families feeling that they are not to "intrude" in what takes place behind the brick walls of the school each day. Yet, particularly in the case of service delivery to families who have children with special needs, the family/school link is vital. No one person will ever be able to meet all the the needs of a child

with disabilities; partnerships between families and schools are the mechanism through which such a child's needs can be optimally served. Yet, breaking down the family/professional barriers is not easy. Often teachers need to take the first steps.

Primary among the catalysts which facilitate the development of family/professional partnerships is trust. When a family feels trust in the professionals who serve their child, it does much to diffuse the confused emotional reactions that parents often face as they go about seeking and implementing services for their child. For a parent to seek help for their child is an admission that help is needed. The very act of soliciting aid requires the parents to admit to themselves and "the world" that their child has a problem. For most parents that admission is an excruciating step. Simply picking up the phone to make the call asking for help is an act most parents recall as painful. Many admit to avoiding it as long as they could.

In some ways the traditional service delivery system seems to set up families and professionals in antagonistic roles from the very beginning of the relationship. Since the "system" usually begins service provision with a formal developmental evaluation of the child, what parents immediately face after seeking services is a team of professionals likely to give them even more dismal news. They have already experienced a trauma most of us only know in our nightmares. They know a depth of sorrow few of us will ever fully understand. They are trying desperately to recover from the initial diagnosis and to shield themselves and their families from more pain. And, any

evaluation, unless it totally contradicts the original diagnosis, will inflict more pain. However, if parents can perceive, when they first meet with professionals, that the professional is a human being who clearly cares about and has their child's best interests at heart, it does much to dismantle all the "defense shields" that are in place. It lays the foundation for establishing a trusting relationship in which families and professionals alike know they are members of a team with a common goal: to nurture the child's development.

From a parent's perspective the first meeting with professionals would ideally happen in a relaxed and comfortable setting. (For some parents, that means having the professional come to their home; for others that situation seems intrusive. It seems reasonable to ask the family what would be the most comfortable for them.) There would be few, if any, forms to fill out. They would simply talk to the professional about their child; they would air their concerns and be asked for information. Their words would be listened to with a great deal of attention. The professional would play with and get to know their child. By their actions and responses to the child, the parents would be able to see that the professional sees the child "first" and the handicap as secondary to the human being. (Modeling this attitude of "acceptance", by the way, is seen by parents who have "been there" as the single most effective helping strategy in aiding the parents themselves to accept their child's disability.) Filling out the forms and scheduling any formal evaluations would happen only after the parents

establish some rapport with the people who will, literally, be helping them to raise their child.

Thus, a situation which has the potential to seem very intrusive to the family can be made to feel less so. It can be, instead, the foundation on which an effective partnership is built. A most common comment of parents who have had extensive experience with early intervention programs goes something like this: "If I see acceptance of my child in the teacher or other professional, if it is obvious that they like my kid and that my kid likes them, then I will do everything in my power to make the relationship work. We may have to "agree to disagree" on some issues, but if I know the people truly care, that's what is most important to me."

Perhaps the best way to learn what fosters effective partnerships with families is to listen to what "veteran" parents have said. The comments below are the combined thoughts of families who belong to the Western Montana Support Group for Parents of Children with Special Needs.

Marge: "Please understand that we experience conflicting emotions when we meet with you (through no fault of your own). Simply talking about our child is painful, and we are usually frightened about any transition our child and family is about to make. We also feel great relief because we know you represent hope and help for our child. It helps a lot if you find positive things to say about our child's potential, or even if you comment on long eyelashes and pretty hair. That helps us to know you see

our child as a human being, as opposed to a "problem."

Lynette: "We need to feel that professional members of the team which serves our child value our input. Parents who are treated as equal and essential members of the team are much less likely to become defensive or hostile. Parents usually get that way when we think no one is listening with any attention to what we say."

Judy: "We know that you cannot "eliminate the negative", but we need you to "accentuate the positive" when you are assessing our child's development and potential. We need to understand that evaluative testing and "labels" are just tools we all use to make decisions and obtain services; that IQ numbers and diagnostic labels do not define who our kids are as human beings in your eyes or in our own."

Susan: "Complex diagnoses and educational strategies need to be explained to us in language a lay person can understand. Don't talk down to us, just routinely offer explanations of technical language, and don't forget - what may be everyday language to you is often technical jargon to us."

Kathy: "We need to be given continuing encouragement to ask about things we don't understand. Our emotional vulnerability does not always allow us to grasp what you say to us the first time we hear it. We can assimilate only so much information

before the defenses protecting us from "more hurt" automatically snap back into place."

Marge: "We need to feel that adequate time has been allocated for the meetings in which decisions about our child's life are made. One frequent and major complaint of parents who have been through early intervention programs is that meetings are often hurried or scheduled "back to back" with other meetings, so there is pressure to "get it done quickly." We see the decisions that are made in these meetings as momentous in our child's life, and we require time during and after the meetings to consider the consequences of what is decided. If papers need to be signed, please let us take them home to read and to consider their impact on our family in a less pressured atmosphere."

Jan: "More than anything else you do, we need you to be an enabling and empowering force in our lives. If you can help us to be aware consumers of services and good advocates for our child, you have given us skills we will need and use for a lifetime."

Qualities of professionals and programs which foster trusting partnerships. There are several qualities of early intervention programs and the professionals who deliver early intervention services which serve to develop trusting partnerships with families. Foremost among those qualities is

the ability to nurture open communication with families. Professionals who serve families effectively are usually "approachable" people who listen closely and make eye contact. Their classrooms are always open to parent observation and family participation. They foster communication by being "available" and welcoming both incidental conversations (as often occur when a child is dropped off or picked up from school) as well as more formal meetings. They use notes, phone calls and school-to-home notebooks to keep the lines of communication open not just when there is a problem, but all the time. They adapt to the communication system which seems to work best for each individual family. They keep the tone of communication positive by using language which focuses on the "strengths and needs" of a child rather than on "deficits and weaknesses." Though the semantics may seem trivial, it is not. The manner in which we speak about people often determines how we think about that person:

"Sara is a child who has a disability" rather than "Sara is a handicapped child".

"Johnny has many needs in the gross motor area which we can work on improving" rather than "Johnny's gross motor skills are very weak".

"The Benson family has a need to work on how they function as a family unit" rather than "Our clients, the Benson's, are a dysfunctional family".

Putting the child (or family) before the disability in our spoken and written language helps us to focus on the individual

and it helps families to see that we always think about the child first as simply a child.

Recognizing and Utilizing Family Expertise

Families have a depth of personal knowledge about their child simply by virtue of how much time they spend with the child each day. Their insights are one of the most valuable resources of the team which serves a child's needs. Information about learning styles, behavior patterns, and a child's likes and dislikes are readily available knowledge to parents but may be not as clear to other members of the early intervention team, particularly if the child is "new" to the program. Sharing that kind of parental and family expertise with all team members allows the team to implement an Individualized Education Plan which is based on a broad spectrum of information about the child. It also empowers the family with the self confident feeling that they can contribute useful information to the team and thus to their child's well being. In return, the family may garner knowledge from the early intervention team about behavior management techniques and learning strategies which broaden their base of expertise and make their own lives less stressful. Professional recognition of a family's expertise also helps families to retain a sense of control over lives which often seem to them to be driven by professional advice and yet "one more referral."

Tapping the resources that families bring to a program.

Tapping the asset of family expertise is not always an easy task. Parents often think of themselves as "just moms and dads", and do not fully recognize the depth of knowledge that comes to them naturally in the process of parenting a child every day. The members of the early intervention team can help parents to realize their expertise in many ways; the easiest and most effective strategy is simply to ask for parental input often, listen to what parents have to say and then validate their information by putting some of their suggestions into practice:

Four year old Jacob, who has Down Syndrome, routinely crawls under a small table at preschool when asked to do things he does not like. The early intervention team members are spending lots of time crawling under the table to physically assist his removal and compliance. When asked what he does to address this problem at home (where the behavior also occurs), Dad gives the team two practical suggestions: 1) Jacob loves to play with cars and trucks. Since he is working on understanding when/then consequences, Dad says to tell Jacob "when you come out and do your work, then you can play with the cars and trucks." He says this idea works most of the time. His alternate suggestion: "Don't move Jacob, move the table." Team members implement the suggestions, and though the problem does not "disappear", there is significant improvement. Team members remember to tell Jacob's dad that his suggestions were used and have helped a lot.

Results: 1) Jacob complies more frequently, 2) team members

learn which verbal cues are good motivators for Jacob (and they spend less time under the table), 3) Jacob's dad gains empowering confidence in his ability to problem solve to meet his son's needs, and 4) there is consistency in behavior management across the home and school environments.

The Impact of Intervention on the Family System: Individualizing Family Involvement

For all special families the ultimate goal must be to balance the needs of all family members with those of their child with disabilities. For professionals who address the needs of those children, an awareness of individual family dynamics can help them to choose a style of service delivery which has its primary focus on the developmental needs of the child, yet is also supportive of the broader goal of family equilibrium.

Because children with disabilities, like all other children, exist within a family system, any intervention affects all members of that family in some way. For example, the scheduling of home or center based early intervention programs or therapies may infringe on a brother or sister's activities. Most families feel great pressure, especially when their child with disabilities is very young, to "do everything" they can to help. Thus, dancing lessons and soccer games for siblings may be viewed as "not as important". Though the denial of one recreational activity may seem unimportant at the time, a continual pattern of such "sacrifice" leaves siblings feeling "less important". It may set up a pattern of family functioning that is damaging to family

relationships and sibling self esteem.

Professional sensitivity to the needs of all members of a family simply means thinking about what each family's life situation is like, and then taking the time to make a comment or an adjustment in schedule that will mean a great deal to that family; since professionals must guard against personal "burnout" and cannot be reacting to the needs of every family they serve all the time, it also means being aware of which families may be in need of a little more support at any given point in time:

"Is this three o'clock meeting time okay for your family now that you are both working, or is there a better time of day?"

"Johnny will learn so many things and have so much fun camping with your family - don't worry about him missing two days of school!"

"Please bring John and Mary (siblings) to our open house so we can meet all of Jessie's family."

"I know a neighbor girl who is great with kids. Bet she'd baby-sit if you and your husband/wife would like to get away for a few hours."

The need to individualize. Families are partners in providing early intervention, but the level of involvement is (and should be) as varied as the families early intervention

programs serve. Just as individualized education plans address needs specific to each child, so should the amount of family involvement in a program be dictated by the individual family's overall needs.

Continuum of involvement. A continuum of involvement which provides families with options may be the best way for families to find a level of involvement which is comfortable for them. Such a continuum also allows families to change their level of involvement as their life circumstances and their child's needs dictate. In addition, it allows the parents and family to make decisions about what works best for them (the beginning of family empowerment). Though the level of involvement for each family served may vary substantially, working partnerships with all families are possible no matter how little/how much involvement a family chooses.

Such a continuum of involvement may include many options which the early intervention program offers to families:

1. Having parents or other family members bring and/or pick up their child.
2. Keeping a home/school notebook as a means of daily or weekly communication.
3. Sending progress check sheets or mini award certificates home, especially when the child has had a good day (see pg. 26).
4. Phone conversations with parents.
5. Inviting parents/families to observe and/or participate in activities within the program day.
6. Inviting parents/families to come along on field trips.

7. Inviting parents/families to assist in staff training.
8. Inviting parents/families to receive staff training.
9. Sending a weekly newsletter home which tells families what's happening at school that week (see pg. 25).
10. Holding parent/staff meetings to share informal progress reviews of child and family status.
11. Having parent/family meetings to discuss family issues and goals.

By offering a continuum of options for parent/family involvement, the element of family pressure is lowered and families are able to choose the level of involvement which best suits their individual circumstances. The best way to ensure that early intervention results in a family that is stronger and better able to cope in the long run is to provide a good match between the needs/strengths of the family and the services offered by the program.

Facilitating Parent-to-Parent and Family-to-Family Support

One of the most valuable incidental services that early intervention programs can provide is the facilitation of parent-to-parent and family-to-family support. For parents and other family members, talking with people who live within similar life circumstances is invaluable. Such mutual support, whether informal (as at a potluck dinner) or formal (as in an organized support group meeting) serves many functions:

1. It provides emotional support and lessens the isolation that parents and siblings of children with disabilities

experience. ("Do people stare at your sister in the supermarket like they do my brother?")

2. It provides a forum for sharing information and knowledge. ("Who's the best pediatrician in town for our kids?")

3. It provides a forum for group advocacy to begin. ("If we go to the legislature as a group, maybe we can make some changes.")

4. Formal support groups allow families more access to professional expertise for which they may have a common need. ("There's a genetics specialist who is willing to speak to our group and answer our questions.")

Though the primary focus of early intervention programs is addressing the developmental needs of young children, there are many ways in which such programs can foster the legitimate family need for parent-to-parent and family-to-family support:

1. Introducing parents/siblings/families to one another. (Confidentiality is not breached if you have received permission from families ahead of time. "Would you like to meet Jacob's mom?")

2. Hosting school functions (open houses, family nights, potluck dinners) which allow families to meet each other and talk in relaxed social surroundings.

3. Making available a bulletin board and/or resource shelf which features items of interest to parents/families (i.e. notices of parent or support group meetings, sample copies of magazines or newsletters which focus on family interests). Let

parents know they can bring in items to share and borrow what information they want.

4. Encouraging parent/family support groups by advertising, sponsoring, or providing a meeting place for them.

5. Assisting support groups by offering to be a resource for needed information, speakers, training, etc.

6. Advertising and supporting appropriate activities (i.e., local hospitals often keep a list of "veteran" parents who are willing to talk to families with newborn or newly diagnosed children with special needs.)

Summary

Families of children who have special needs are as individual as the children early intervention programs serve. The service delivery system works best when professionals and families alike recognize that we need each other in order to provide optimal services for children with disabilities and their families. The fostering of family\professional partnerships is an integral part of effective service delivery to young children with disabilities.

APPENDIX

WHAT PARENTS WANT FROM EARLY INTERVENTION PROFESSIONALS

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The following "wish list" was compiled by ten families, all of whom have children with handicapping conditions, and all of whom have had extensive experience with home-based early intervention programs.

*Help us to see our child as a valuable human being who has a contribution to make to this world. (The best way to help us is to model that attitude yourself.)

*Whether we are single parents trying to cope with our kids, or couples facing our extraordinary circumstances together, help our families to stay together and function as a unit. Understand that whatever work you do with our child has an impact on ALL members of our family.

*Help us to see that personal and family happiness does not end with the diagnosis of an imperfect child.

*Help us to meet other parents who have stood in our shoes, survived, and gone on with their lives.

*Help us to nurture learning in our children, but do not strip us of our parenthood by asking us (or allowing us) to become therapists or behavioral researchers.

*Tell us when we are doing good things. Tell us often.

*Help us to see the difference between problems we can overcome and problems we must learn to cope with.

*Help us to see the need for respite time BEFORE a crisis happens.

*Help us to be effective advocates for our child. (For all of us, there have been times when we couldn't be good advocates, for whatever reason. Be an advocate for us at such times, or help us to find someone who can fill that role.)

*Know that parents are ALWAYS vulnerable people, because of the emotional stake we have in our child. Understand that emotion as a natural feeling for a parent to have about any child. Don't write us off as neurotic or hysterical parents because we have those feelings, and may sometimes have trouble keeping them in check.

***Understand that, for many parents, there are times when, for various reasons, we will chose not to follow some recommendation you have offered. Saying "no", selectively, to things which will not work in our lives right now is not an indication of lack of faith in your abilities. Most of the time saying "no" is a short term matter of survival. Don't take offense.**

***Know that there are times when asking us to do one more thing that "only takes five minutes a day" is NOT a good idea. Be alert for signs of "burnout" - exhaustion, lack of ability to concentrate, apathy. When a parent says, "I don't know how much longer I can do this," what they probably mean is, "I CAN'T do this anymore!"**

***There are parents who know the law, who are effective advocates, who have become de facto early intervention professionals. We all need to remember, however, that the best resource parents can bring to any parent/professional relationship is their intimate, day-to-day knowledge of their child. USE THAT RESOURCE.**

**SUGGESTED READINGS FOR PROFESSIONALS AND FAMILIES
SEEKING TO FORM EFFECTIVE PARTNERSHIPS**

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FAMILIES AND DISABILITY NEWSLETTER, Ann and Rutherford Turnbull, editors, Beach Center on Families and Disabilities, University of Kansas, Bureau of Child Research, 4138 Haworth Hall, Lawrence, KS, 66045.

EARLY CHILDHOOD UPDATE, Susan M. Thornton, editor, University of Colorado, Health Sciences Center, 4200 E. Ninth Ave., C223, Denver, CO, 80262.

P.L.U.K. News, Katharin Kelker, editor, published by "Parents, Let's Unite for Kids," Montana Center for Handicapped Children, Billings, MT 59101-0298.

Selected Bibliography

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Crnic, Greenburg, and Slough (1983) Adaptation of families with mentally retarded children: A model of stress, coping, and family ecology. American Journal of Mental Deficiency, 88, 125-138.

Duffy, McGlynn, Mariska, and Murphy (1984) Finding and Founding Support Groups. Acceptance is Only the First Battle: How some parents of young handicapped children have coped with common problems, 6-11.

Duffy, McGlynn, Mariska, and Murphy (1984) Things some professionals did that drove us nuts and made us crazy. Acceptance is Only the First Battle: How some parents of young handicapped children have coped with common problems, 19-23.

FALL HARVEST

P.M. CLASS

OCT. 17-19

Monday, Oct 17 : Vegetables



Where do vegetables come from?

Easel paint vegetable shapes

Play food bingo

Pick brussel sprouts from the stalk for snack

make invitations for Family NIGHT ★



TUESDAY, OCT 18 : Apple Days

TELL THE APPLE STORY

Make Apple cinnamon toast for snack

Create apple prints

Play Worm Through the Apple

Sand in the trough



WEDNESDAY, OCT 19 : Apple Days FIELD TRIP

We will be going to the Fort Missoula Museum

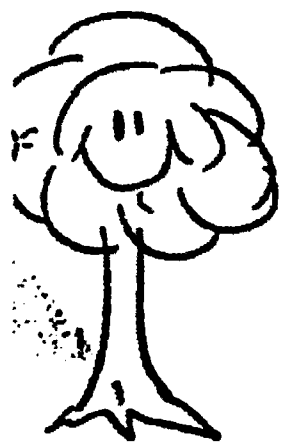
to press apples and make cider. We will

leave the preschool at 1:10 and return

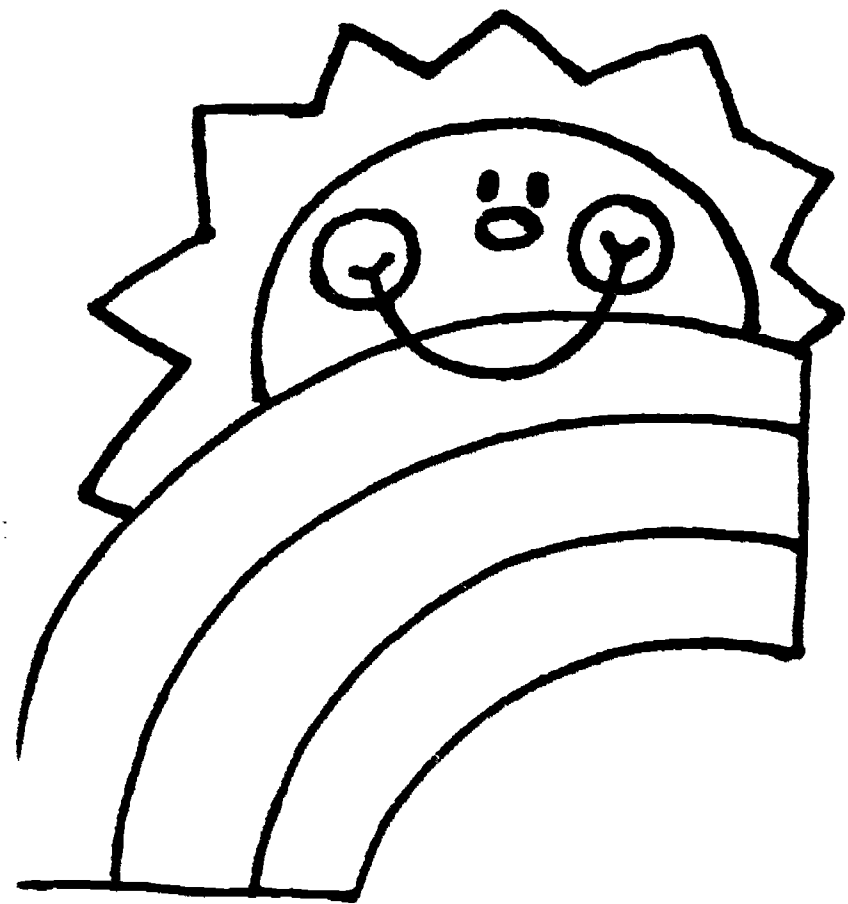
at 3:00. Each child must bring one

apple and dress appropriately for the weather.

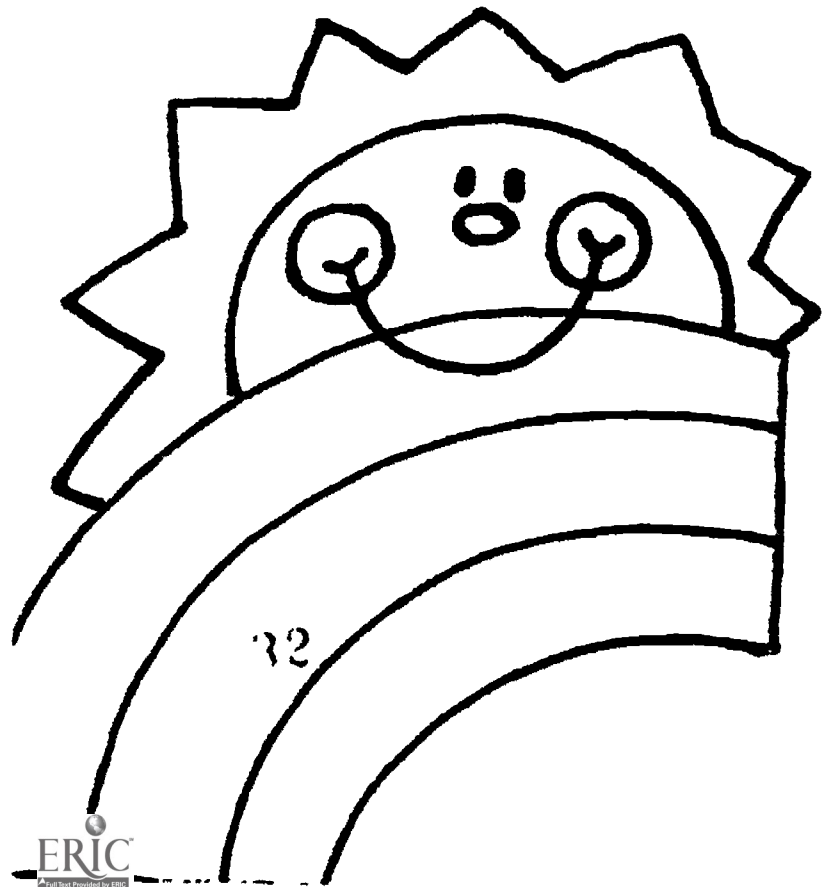
Please sign up if you can help us by driving on the field trip.



★ Remember: no school Thursday, Oct 20 (MEA) AND ○○○○
FAMILY NIGHT WILL BE HELD NEXT
THURSDAY, OCT 27 FROM 6:30-7:30 PM!



Something GREAT happened
at school today!



Something GREAT happened
at school today!
