Guidelines for Practice with Parents with Intellectual Disabilities and their Children

The following material was developed by Megan Kirshbaum, Ph.D. Executive Director of Through the Looking Glass, Co-Director of the National Center for Parents with Disabilities and their Families, and has been distributed in training since 2004. For additional information, please contact Through the Looking Glass (contact information at the end of this Fact Sheet).

- Disability accommodation needs should be clarified from the outset of involvement with CPS, so that the communication process, case plan, evaluation and reunification efforts are appropriately adapted. Reports for court should reflect attention to these issues. It is not appropriate or feasible to address disability issues only at the end of the process.

- Translator/interpreters/advocates should be available during, prior to and after court so that the parent understands the process.

- Public defenders serving such parents will need lower caseloads and awareness about the particular accommodation needs and issues.

- Evaluators need adequate expertise re the parent's disability, children the age of this child, interaction and relationships relevant to parents and a child or infant of that age, appropriate accommodations for evaluation; disability resources and solutions.

- Expert consultants should be used to fill in gaps in knowledge of evaluators and workers. Evaluators should elicit input from involved intervention providers in the community who are familiar with parent and child.

- It is poor practice to use a categorical diagnosis of "mental retardation" or “developmental disability” rather than evaluating actual functioning of parent in relationship with child.

- It is poor practice to use psychological tests or measures to infer parenting capability without any or adequate observation of parent with child.
• It is poor practice to use cognitive dependent measures which preclude success.

• Observation of parent and infant/child should be in the natural setting (a combination of home and community is optimal).

• Observation should occur over a period of time, e.g. a minimum of 6 to 8 weekly two-hour visits.

• One should observe all aspects of basic care as well as play.

• Appropriate conditions for evaluation need to be utilized. Inappropriate conditions for evaluation include: Observation only in office setting Too many people present Someone present who alters the situation-- foster parent/someone with hostile relationship

• These same conditions should be considered for visitations. Adequate and appropriate visitation needs to be established so that a parent/child relationship can be developed or sustained.

• Evaluation should take into account the adequacy of the preceding contact between parent and child and the impact of this on evaluation data.

• Evaluation should assess the adequacy of services that have been provided, including the appropriateness to the parent's disability. Duration of disability appropriate services should be assessed.

• It is poor practice to assume that generic, unadapted reunification services have been adequate.
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• Evaluation should be done promptly and be specific enough that it can include recommendations to guide adaptations needed in future communication and services.

• To determine the potential effectiveness of intervention appropriate and adapted intervention should be provided promptly, evaluating its impact and the responsiveness of the parent.

Guidelines for Improving Practice In Intervention with Parents with Intellectual Disability and their Children

• Very early intervention, preferably beginning in pregnancy • Individualizing/tailoring services

• Flexibility of services

• Cultural appropriateness of services

• Staff with diverse expertise

• Strength-based, empowering and respectful approach

• Incorporating adaptations specific to diverse disability issues

• Infant/parent and family system relationship-based

• In-home using "real time coaching", responding to concrete interaction and issues as they are
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raised • Intervenors with expertise regarding infant mental health, infant/parent interaction, and family therapy

• Intervenors with diverse infant development expertise

• Minimal # of intervenors--consistency • Long-term intervention

• Small caseloads, with frequent and regular home visiting

• Teamwork between intervenors

• Play therapy for older children, as needed

• Clinical supervision, support and training for staff

• Group and networking opportunities for parents

• Tutoring opportunities for older children