

Date: 2/6/13

Title: Adding home based services to complement center based intervention for children with autism

Clinical Question:

- | | | |
|---|-----------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------|
| P | <i>(Population/Problem)</i> | Among children under the age of 6 years old with autism spectrum disorder (ASD) or pervasive developmental disorder - not otherwise specified and their parents |
| I | <i>(Intervention)</i> | does home based developmental intervention in addition to center based developmental intervention* |
| C | <i>(Comparison)</i> | compared to center based developmental intervention* only |
| O | <i>(Outcome)</i> | improve child and/or parent outcomes*? |

[Definitions for terms marked with * may be found in the Supporting Information section.](#)

Target Population for the Recommendation:

Inclusion

- Children under the age of 6 years old with ASD or pervasive developmental disorder – not otherwise specified
- No exclusion criteria for children with dual diagnosis

Recommendations:

1. It is strongly recommended that home based developmental intervention in addition to center-based developmental intervention be provided to children with ASD or pervasive developmental disorder- not otherwise specified to improve:
 - a. child IQ in families with high stress (*Rickards 2007 [2a]*)
 - b. communication (*Oosterling 2010 [2a]*)
 - c. gestures produced (*Drew 2002 [2a]*)
 - d. play skills (*Ingersoll 2007 [5a]*).

2. It is recommended that home based developmental intervention in addition to center-based developmental intervention is provided to children with ASD or pervasive developmental disorder-not otherwise specified in order to:
 - a. reduce parental stress (*Drew 2002 [2a]*)
 - b. reduce parental depression (*Küçüker 2006 [4a]*)
 - c. increase parental satisfaction with child outcomes (*Ingersoll 2007 [5a]*).

Discussion/Synthesis of Evidence related to the recommendations:

There is high quality evidence to recommend that home based developmental intervention in addition to center based developmental intervention is helpful in improving parent (*Drew 2002 [2a]*, *Küçüker 2006 [4a]*) and child outcomes (*Oosterling 2010 [2a]*, *Rickards 2007 [2a]*, *Drew 2002 [2a]*). Improvement in child IQ levels in the Rickards study were maintained at one year per a follow up study (*Rickards 2007 [2a]*).

Several studies directly address the addition of home based developmental intervention to center based developmental intervention exclusively for children with ASD (*Oosterling 2010 [2a]*, *Drew 2002 [2a]*), while others included children with ASD as well as other developmental disabilities in the study (*Rickards 2009 [2a]*, *Rickards 2007 [2a]*, *Küçüker 2006 [4a]*).

Children from highly stressed families benefit the most from the addition of home based developmental intervention and were able to maintain significant gains in IQ after one year (*Rickards 2009 [2a]*, *Rickards 2007 [2a]*). Drew revealed that the addition of home based developmental intervention significantly improved words understood, words said and

gestures produced (Drew 2002 [2a]). Additionally, Oosterling determined that over time, home based developmental intervention significantly improved words understood and words said (Oosterling 2010 [2a]). Ingersoll & Gergans reported significant improvements in the generalization of spontaneous object imitation and gesture imitation into the home setting for young children with autism (Ingersoll 2007 [5a]).

Some parental outcomes were reported to improve as a result of home based developmental intervention. Drew found that parent stress was significantly decreased over time when compared to the control group (Drew 2002 [2a]). Küçüker revealed that the intervention significantly decreased depression in both mothers and fathers (Küçüker 2006 [4a]).

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IMPLEMENTATION

Applicability Issues:

When considering home based developmental intervention, it is important to consider the cost and reimbursement for the service. Many payment sources fail to cover the cost of community-based care and will only reimburse for direct patient care not parent-only training or coordination of family services (*Hanft 2000 [5a]*).

Other variables to consider are the staff that will be providing the service and if the same clinician would be able to provide both center based and home based developmental intervention. If more than one clinician is providing treatment, it is important to consider close collaboration between these professionals as to preserve the fidelity of the treatment.

Current literature supports that children from highly stressed families have achieved better outcomes with IQ following home based developmental intervention (*Rickards 2007 [2a]*). Therefore, it is important to establish a screening process to identify which families will benefit from this specialized service.

Relevant CCHMC Tools for Implementation:

None

Outcome and Process Measures:

Outcome Measures: Individual treatment goals will serve as a primary measure of both child and parent outcomes. These goals will be established in collaboration with the client and family. The Canadian Occupational Performance Measure is an occupation-based tool that is frequently used to assess parental perception in the area of performance and satisfaction and is used as a means of establishing goals. Parent satisfaction surveys may be used to gather information on the parent's perception of the intervention provided and their satisfaction with outcomes. IQ testing studies support gains in IQ. Measuring stress would not be recommended as an outcome measure due to the chronic nature of stress in parents of children with ASD (*Küçüker 2006 [4a]*).

Process Measures: Screening center based clinicians should use their clinical judgment to identify families whom they feel may need additional support implementing strategies in the home setting. Indicators for further assessment include, but are not limited to: plateau in progress of the child toward therapeutic goals including communication, gestures produced and play skills, increase in cancellation of appointments, drastic shifts in parental behavior or engagement in services, and information from a learner assessment that a parent has psychosocial barriers to learning. The clinician may utilize one of the following tools to identify a parent's baseline stress level as a further indicator of the need for developmental home based intervention:

- Questionnaire on Resources and Stress-F (QRS-F) - A score of greater than 160 is considered high stress (*Rickards 2007 [2a]*). This can be used as a screening tool for families who have been identified as "at risk" for high stress and therefore may benefit from the addition of home based services.
- Parenting Stress Index (PSI) (*Abidin 1997 [5a]*) - There are no reported thresholds for this measure. Clinicians will need to interpret the results as instructed in the testing manual.

Informal screening for a history of depression should be completed during the interview process. Referrals to social work should be made when appropriate for families who report a history of depression.

Intervention: Upon identification of appropriate families, a home visit may be made available. The clinician can use clinical judgment to determine the frequency and duration of additional consultative home visits in addition to center based developmental intervention. If the clinician is unable to offer a home visit, they can make an appropriate referral to another agency that is able to provide home visits.

Follow up: Clinicians closely monitor child and family progress toward goals and frequency of visits should be modified accordingly and work collaboratively with the home based clinician to ensure continuity of care from the center to the home.

SUPPORTING INFORMATION

Background/Purpose of BEST Development:

Parents of children with ASD experience higher levels of stress than other parents which in turn impacts child outcomes (*Osborne 2008 [4a]*). Likewise, mothers of children with ASD report difficulty establishing order and routines in the home and community and find value in home based collaborative consultation services to focus on enhancing the child's participation in family life (*Larson 2008 [5a]*). Environmental factors can support or inhibit the performance of a child with ASD and therefore analysis of behavior should be performed in a variety of settings, including the home environment (*Tomchek 2009 [5a]*). Children with autism have difficulty generalizing skills across environments (*Brown 2012 [5a]*) and therefore it is important to consider the environment in which new skills are taught. Outpatient or center based services for children with ASD are often focused on skill development with little consideration for generalization of these skills into the natural environment. Parent involvement is a critical component in the treatment of ASD. It allows the child to receive treatment when the therapist is not present (*Burrell 2011 [5a]*). Parents spend time with their children in a variety of settings and have the opportunity to teach appropriate skills and improve generalizability. There are many ways in which parents can be involved, one of which includes in-home planning. This involvement can help parents manage difficult behaviors, feel a sense of control over their child and daily lives, and decrease stress levels (*Burrell 2011 [5a]*). Occupational therapists have a unique opportunity to impact the lives of children with ASD and their families. The Occupational Therapy Practice Framework 2008 includes the environment as 1 of 6 domains that occupational therapists are educated to address. Working under this framework, occupational therapists have an obligation to consider the environment or context in which a child with ASD is having difficulty and provide intervention to address these difficulties accordingly (*Roley 2008 [5a]*). The current model of center based occupational therapy does not include complementary home visits and requires therapists to rely on the ability of the parents to implement activities and strategies in the home setting.

Definitions:

Developmental intervention: occupational therapy, speech therapy, physical therapy, developmental interventionist, psychology

Center based developmental intervention: preschool services that include occupational therapy, speech therapy and/or physical therapy, outpatient or clinic based therapy services

Child outcomes include: Intelligence Quotient (IQ), behavior, communication, use of gestures, play skills, social skills.

Parent outcomes include: stress, depression, satisfaction with child outcomes.

Search Strategy:

Databases: Science Direct, Springer, Medline PICO, CINAHL, PubMed, PubMed Clinical Queries, Rehabilitation Reference Center

Search Terms: Autism, autism spectrum disorder, children, natural environment, home based, community based, home health, in home, intervention, treatment, parents, stress, depression

Limits, Filters, Search Dates: Human and English language; 1980 - February 16, 2012

Date Search Done: February 16, 2012

Relevant CCHMC Evidence-Based Documents:

BEST 031-Outcomes assessment tool for children with Autism Spectrum Disorder (ASD)

(<http://www.cincinnatichildrens.org/default/>)

Group/Team Members:

Group/Team Leader: Amy Johnson, OTR/L Team Leader/The Kelly O'Leary Center for Autism Spectrum Disorders Support/Consultant: Mary Ellen Meier, RN, MSN, CPN Center for Professional Excellence and Business Integration, Research and Evidence Based Practice, EBP Mentor

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Conflicts of Interest were declared for each team member:

- No financial or intellectual conflicts of interest were found
 No external funding was received for development of this BEST
 The following conflicts of interest were disclosed:

Note: Full tables of the [LEGEND evidence evaluation system](#) are available in separate documents:

- [Table of Evidence Levels of Individual Studies by Domain, Study Design, & Quality](#) (abbreviated table below)
- [Grading a Body of Evidence to Answer a Clinical Question](#)
- [Judging the Strength of a Recommendation](#) (dimensions table below)

Table of Evidence Levels (see note above):

| Quality level | Definition |
|---------------|-----------------------------------------------------------------------------|
| 1a† or 1b† | Systematic review, meta-analysis, or meta-synthesis of multiple studies |
| 2a or 2b | Best study design for domain |
| 3a or 3b | Fair study design for domain |
| 4a or 4b | Weak study design for domain |
| 5a or 5b | General review, expert opinion, case report, consensus report, or guideline |
| 5 | Local Consensus |

†a = good quality study; b = lesser quality study

Dimensions for Judging the Strength of the Recommendation: Number 1

Reflecting on your answers to the dimensions below and given that more answers to the left of the scales indicates support for a stronger recommendation, complete one of the sentences above to judge the strength of this recommendation.

(Note that for negative recommendations, the left/right logic may be reversed for one or more dimensions.)

| | | | |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------|----------------------------------------------------------------|---------------------------------------------|
| 1. Grade of the Body of Evidence | <input checked="" type="checkbox"/> High | <input type="checkbox"/> Moderate | <input type="checkbox"/> Low |
| <i>Comments:</i> | | | |
| 2. Safety/Harm (Side Effects and Risks) | <input checked="" type="checkbox"/> Minimal | <input type="checkbox"/> Moderate | <input type="checkbox"/> Serious |
| <i>Comments:</i> | | | |
| 3. Health benefit to patient | <input checked="" type="checkbox"/> Significant | <input type="checkbox"/> Moderate | <input type="checkbox"/> Minimal |
| <i>Comments:</i> For children with ASD, improvements in cognition-IQ (Rickards et al., 2007 [2a]) and communication-gestures, words said, words understood (Drew et al., 2002 [2a]; Oosterling et al., 2010 [2a]) have significant health benefits related to their ability to participate in activities of daily living and medical management of their condition. | | | |
| 4. Burden on patient to adhere to recommendation | <input type="checkbox"/> Low | <input checked="" type="checkbox"/> Unable to determine | <input type="checkbox"/> High |
| <i>Comments:</i> | | | |
| 5. Cost-effectiveness to healthcare system | <input type="checkbox"/> Cost-effective | <input checked="" type="checkbox"/> Inconclusive | <input type="checkbox"/> Not cost-effective |
| <i>Comments:</i> | | | |
| 6. Directness of the evidence for this target population | <input type="checkbox"/> Directly relates | <input checked="" type="checkbox"/> Some concern of directness | <input type="checkbox"/> Indirectly relates |
| <i>Comments:</i> | | | |
| 7. Impact on morbidity/mortality or quality of life | <input type="checkbox"/> High | <input checked="" type="checkbox"/> Medium | <input type="checkbox"/> Low |
| <i>Comments:</i> | | | |

Dimensions for Judging the Strength of the Recommendation: Number 2

Reflecting on your answers to the dimensions below and given that more answers to the left of the scales indicates support for a stronger recommendation, complete one of the sentences above to judge the strength of this recommendation.

(Note that for negative recommendations, the left/right logic may be reversed for one or more dimensions.)

| | | | |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------|---------------------------------------------------------|---------------------------------------------|
| 1. Grade of the Body of Evidence | <input type="checkbox"/> High | <input checked="" type="checkbox"/> Moderate | <input type="checkbox"/> Low |
| Comments: | | | |
| 2. Safety/Harm (Side Effects and Risks) | <input checked="" type="checkbox"/> Minimal | <input type="checkbox"/> Moderate | <input type="checkbox"/> Serious |
| Comments: | | | |
| 3. Health benefit to patient | <input checked="" type="checkbox"/> Significant | <input type="checkbox"/> Moderate | <input type="checkbox"/> Minimal |
| Comments: Increased parental stress in families of children with ASD impacts overall child outcomes (Osborne, McHugh, Saunders, & Reed, 2008 [4a]). Therefore, decreased parental stress and depression can lead to a significant improvement in overall health outcomes for the patient. | | | |
| 4. Burden on patient to adhere to recommendation | <input type="checkbox"/> Low | <input checked="" type="checkbox"/> Unable to determine | <input type="checkbox"/> High |
| Comments: | | | |
| 5. Cost-effectiveness to healthcare system | <input type="checkbox"/> Cost-effective | <input checked="" type="checkbox"/> Inconclusive | <input type="checkbox"/> Not cost-effective |
| Comments: | | | |
| 6. Directness of the evidence for this target population | <input checked="" type="checkbox"/> Directly relates | <input type="checkbox"/> Some concern of directness | <input type="checkbox"/> Indirectly relates |
| Comments: | | | |
| 7. Impact on morbidity/mortality or quality of life | <input type="checkbox"/> High | <input checked="" type="checkbox"/> Medium | <input type="checkbox"/> Low |
| Comments: | | | |

Copies of this Best Evidence Statement (BEST) and related tools (if applicable, e.g., screening tools, algorithms, etc.) are available online and may be distributed by any organization for the global purpose of improving child health outcomes.

Website address: <http://www.cincinnatichildrens.org/service/i/anderson-center/evidence-based-care/bests/>

Examples of approved uses of the BEST include the following:

- Copies may be provided to anyone involved in the organization's process for developing and implementing evidence based care;
- Hyperlinks to the CCHMC website may be placed on the organization's website;
- The BEST may be adopted or adapted for use within the organization, provided that CCHMC receives appropriate attribution on all written or electronic documents; and
- Copies may be provided to patients and the clinicians who manage their care.

Notification of CCHMC at EBDMinfo@cchmc.org for any BEST adopted, adapted, implemented, or hyperlinked by the organization is appreciated.

Please cite as: Johnson, A., Cincinnati Children's Hospital Medical Center, Best Evidence Statement: Adding home based services to complement center based intervention for children with autism, <http://www.cincinnatichildrens.org/svc/alpha/h/health-policy/best.htm>, BEST 131, pages 1-6, 2/6/13.

This Best Evidence Statement has been reviewed against quality criteria by two independent reviewers from the CCHMC Evidence Collaboration. Conflict of interest declaration forms are filed with the CCHMC EBDM group.

Once the BEST has been in place for five years, the development team reconvenes to explore the continued validity of the guideline. This phase can be initiated at any point that evidence indicates a critical change is needed. CCHMC EBDM staff perform a quarterly search for new evidence in an horizon scanning process. If new evidence arises related to this BEST, authors are contacted to evaluate and revise, if necessary.

For more information about CCHMC Best Evidence Statements and the development process, contact the Evidence Collaboration at EBDMinfo@cchmc.org.

Note

This Best Evidence Statement addresses only key points of care for the target population; it is not intended to be a comprehensive practice guideline. These recommendations result from review of literature and practices current at the time of their formulation. This Best Evidence Statement does not preclude using care modalities proven efficacious in studies published subsequent to the current revision of this document. This document is not intended to impose standards of care preventing selective variances from the recommendations to meet the specific and unique requirements of individual patients. Adherence to this Statement is voluntary. The clinician in light of the individual circumstances presented by the patient must make the ultimate judgment regarding the priority of any specific procedure.