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TRABAJO FIN DE GRADO EN PEDAGOGÍA

LA PARTICIPACIÓN DE LAS FAMILIAS EN LA ATENCIÓN TEMPRANA DE LOS NIÑOS CON TRASTORNO DEL ESPECTRO AUTISTA

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INTRODUCCIÓN: Justificación y Objetivos

El siguiente documento constituye el Trabajo Fin de Grado de Pedagogía de la Universidad de Salamanca, presentado según la normativa vigente recogida en la Resolución de 2 de mayo de 2011, de la Universidad de Salamanca, por la que se publica el plan de estudios de Graduado en Pedagogía (BOE de 19 de mayo de 2011), así como en la Normativa específica de TFG de Grado de Pedagogía (Normas complementarias de la Facultad de Educación al Reglamento de Trabajos de Fin de Grado de la USAL, aprobado por Junta de Facultad de 26 de julio de 2013). Dentro de las múltiples competencias del Grado descritas en la guía académica, se puede observar que el pedagogo es un profesional en sistemas, instituciones, contextos, recursos y procesos educativos y formativos, así como en los procesos de desarrollo personal, profesional, social y cultural que concurren de forma integrada en las personas y grupos a lo largo de toda la vida. De manera más concreta, la atención a la diversidad y la inclusión social es el área elegida para elaborar este trabajo, la cual incluye como competencias el diagnóstico de situaciones complejas y el desarrollo y aplicación de metodologías adaptadas a diferentes situaciones personales y sociales.

Cuando se habla de atención a la diversidad, la idea es dar respuestas educativas a un conjunto de personas que tienen unas necesidades específicas. Estas necesidades pueden ser dificultades de aprendizaje, personas en situación de desventaja social, o bien algún tipo de discapacidad física, cognitiva, sensorial o trastornos del desarrollo. Por lo tanto, se trata de un aspecto muy amplio que recoge diversas problemáticas, dentro de las cuales encontramos el Trastorno del Espectro Autista. Se trata de un trastorno generalizado del desarrollo que afecta sobre todo a la capacidad de comunicación e interacción social de la persona. Al ser un trastorno del desarrollo, cuyo origen aún no está claro, no se dispone de ninguna cura. Sin embargo, se puede intervenir de manera educativa con la finalidad de disminuir las características propias del trastorno y facilitar la inclusión de la persona con autismo en la sociedad y desarrollar su capacidad de autonomía. Para lograr una mejora significativa, el diagnóstico debe realizarse lo antes posible para comenzar con la intervención, que es lo que va a permitir al niño desarrollarse de la mejor manera posible. Aún así, en algunos casos se puede comenzar con la intervención a pesar de que no se haya clarificado el diagnóstico. Esto suele pasar cuando existen síntomas o anomalías en el desarrollo que deben ser tratadas, pero no se puede establecer

un diagnóstico dado que en niños muy pequeños resulta complicado. En ambos casos, y siempre y cuando el niño tenga hasta un máximo de seis años, se habla de Atención Temprana.

Las investigaciones más recientes en el ámbito del autismo, demuestran que la manera en que los niños interactúan con el entorno afecta directamente a las conexiones neuronales, con consecuencias a largo plazo tanto en el comportamiento del niño como en su desarrollo cerebral (Sullivan, Stone, & Dawson, 2014). De esta manera, dada la plasticidad neuronal que poseen los niños, la atención temprana es un elemento fundamental a la hora de prevenir o mitigar los síntomas característicos de los Trastornos del Espectro Autista (TEA). Hablamos de atención temprana para referirnos a aquellas intervenciones que están dirigidas a los niños de entre 0 y 6 años, a la familia y al entorno, y cuyo objetivo es responder lo antes posible a las necesidades transitorias o permanentes que presentan los niños con trastorno del desarrollo, como es el caso del autismo, y también a aquellos niños que están en riesgo de padecerlos (GAT, 2000).

Los programas de atención temprana están compuestos por una serie de elementos de igual importancia y que merecen un cuidadoso estudio y planificación para que el proceso se lleve a cabo de la mejor manera posible y que así los resultados sean óptimos. Algunos de estos elementos son: el contenido del programa de atención temprana, la previsibilidad y el establecimiento de rutinas y, entre otros, la participación de los padres en dicho proceso (Sullivan et al., 2014). Sin embargo, ¿es habitual que los padres o las familias participen o se impliquen de alguna manera en estos programas? A través de este Trabajo Final de Grado, elaborado a modo de revisión bibliográfica sistemática, se pretende averiguar si la participación de los padres es un componente habitual en los programas de atención temprana de los niños con autismo. En caso afirmativo, se plantea si existen distintas modalidades y también los posibles inconvenientes o factores adversos que puedan surgir.

Para dar respuesta a estas preguntas, primero se ha elaborado un marco teórico que contextualice y dé a conocer de manera básica el Trastorno del Espectro Autista y también, de manera más específica, se ha hecho hincapié en la intervención educativa y en la implicación de las familias.

A continuación, se especifica la metodología escogida para llevar a cabo la revisión sistemática y el proceso de recogida de documentos científicos. El siguiente

aspecto son los resultados y la discusión, para lo cual se han elaborado distintos criterios de comparación que permiten dar a conocer los resultados de una manera más completa y estructurada. Por último y para finalizar la revisión sistemática, se incorporan las conclusiones obtenidas.

Además, se incluyen en los anexos los artículos que han sido objeto del trabajo de revisión bibliográfica sistemática por si fueran de interés.

Objetivos:

El objetivo o finalidad principal de este trabajo es revisar sistemáticamente las últimas investigaciones sobre la participación de las familias como un componente habitual de la Atención Temprana en el Trastorno del Espectro Autista.

Se considera que con este trabajo se pueden demostrar las competencias desarrolladas a lo largo de la formación recibida en el título de Grado de Pedagogía en la USAL, tanto genéricas como específicas, en el ámbito de la atención a la diversidad. Desde el punto de vista genérico, con este estudio se muestra la competencia informacional, de gestión de información científica, de expresión escrita, capacidad para aportar ideas y soluciones, además de transmitir las a tanto a público especializado como no especializado. Desde un punto de vista más específico, a través de este estudio se desarrolla la habilidad en recogida e interpretación de datos para la emisión de juicios reflexivos sobre temas educativos y sociales, además de la evaluación de programas y proyectos educativos y formativos. También se pone en práctica la capacidad de aprendizaje autónomo y responsabilidad, y una actitud innovadora y creativa.

De manera más concreta, se pretende estudiar y conocer las distintas modalidades de participación de las familias en caso de que las hubiera, e indagar también acerca de los posibles inconvenientes de la implicación de las familias en la intervención temprana de los niños con autismo.

Otros objetivos que se podrían considerar secundarios son: aprender a realizar una revisión bibliográfica de carácter sistemática, empleando para ello metodologías propias de este tipo de investigaciones; aumentar el conocimiento sobre el Trastorno del Espectro Autista; y por último, dar a conocer el impacto del trastorno en las familias y en la sociedad, además de realzar la importancia de la educación en los distintos ámbitos del Trastorno.

MARCO TEÓRICO

Cap. 1. CONTEXTUALIZACIÓN DEL TRASTORNO DEL ESPECTRO AUTISTA

1.1 Aspectos generales del trastorno

El Trastorno del Espectro Autista, también conocido como TEA, es un trastorno generalizado del desarrollo cerebral. Debido a esta alteración de la función cerebral, se produce un comportamiento anómalo en el niño, que como explica Alonso Peña (2009), estos “se muestran indiferentes, ausentes, con dificultad para formar lazos emocionales con otras personas” (p. 21).

Existen tres características fundamentales propias del Trastorno del Espectro Autista, que cada niño puede mostrar con mayor o menor intensidad. Se trata de las siguientes:

- Dificultades en la interacción social. Se trata de niños que encuentran dificultad a la hora de entablar relaciones con otros. Según Alonso Peña (2009), estas dificultades aparecen no solo con otras personas, sino también con objetos y con situaciones cotidianas.
- Dificultades en la comunicación. Tanto de manera verbal como no verbal, los niños y adultos con autismo muestran problemas a la hora de comunicarse. Puede ser que su comunicación se base en algo meramente funcional, es decir, que se comuniquen para satisfacer necesidades que por sí mismos no pueden lograr, o como especifican diversos autores (Alonso Peña, 2009; Brock, Jimerson & Hansen, 2006; Chawarska & Volkmar, 2005; Loveland & Tunali-Kotoski, 2005; Ozonoff, Rogers & Hendren, 2003) algunos no muestran prácticamente ningún atisbo de comunicación, sin haber llegado a desarrollar un sistema de lenguaje.
- Repertorio limitado de comportamientos, actividades e intereses. Son frecuentes los casos de niños y adultos con estereotipias y que además siguen rutinas muy marcadas y restrictivas. Junto a esto, las personas con autismo tienen dificultades para interpretar las acciones de los demás y todo aquello que tiene que ver con el lenguaje corporal. Esto lo denomina Alonso Peña (2009) como “falta de flexibilidad mental” (p. 22), que va unido a la carencia de juego imaginativo.

El Trastorno del Espectro Autista afecta a entre 60 y 90 niños de cada 10.000, lo que equivale a 0.06-0.09%, siendo mayor la proporción en niños que en niñas (Alonso Peña, 2009). Destacar de nuevo que es una alteración de la función cerebral, por lo que tanto el entorno del niño como la educación que recibe nunca podrán ser las causas del trastorno. El origen es desconocido y, por lo tanto, no existe una cura. Sin embargo, sí existe la posibilidad de recibir una intervención que mitigue los síntomas o características y que facilite la adaptabilidad del niño al entorno y al mundo que le rodea. Es por este motivo que la educación es de vital importancia en el desarrollo de los niños con autismo, ya que actúa en su entorno, pudiendo modificarlo con el fin de lograr mejoras significativas en la vida del niño. Además, la creación de programas educativos dirigidos a este grupo de la población es algo necesario que demandan las familias, y que es por excelencia función del pedagogo.

Además de las tres características principales antes descritas, hay otras que también son comunes en el autismo, como la hipersensibilidad, la hiposensibilidad o una limitada capacidad de abstracción (Alonso Peña, 2009). En lo que a sensibilidad respecta, los niños con autismo tienen una alteración en ese aspecto y por lo tanto una respuesta anormal, que puede ir desde una sensibilidad extrema a los ruidos, por ejemplo, lo que llamaríamos hipersensibilidad, hasta el punto opuesto en el cual no sienten dolor (hiposensibilidad). Se trata de algo que es desconocido por muchos, pero que afecta por completo a la vida cotidiana de los niños con autismo y a la de sus familias. Ambas pueden darse en cualquiera de los cinco sentidos o incluso en varios, y aunque pueda tenerse la idea de que lo que más les molesta es el ruido, existen casos en los cuales el tacto o el gusto también están alterados. Basándome en la experiencia profesional que he podido adquirir gracias a la asignatura Practicum del Grado en Pedagogía, he observado el caso de un niño con autismo que padecía hipersensibilidad en el gusto, dificultando su ingesta de alimentos y viéndose reducida a la toma de alimentos líquidos únicamente. En cuanto a la limitada capacidad de abstracción que poseen, algunos autores como Alonso Peña consideran que es nula, y especifica que “pueden manejar un listado interminable y desestructurado de detalles, resultándoles difícil separar lo importante de lo accesorio” (p. 22).

1.2 Desde cuándo se conoce

La etimología de la palabra autismo proviene del griego, *autos* significa uno mismo, e *-ismos* es un sufijo que se emplea para formar sustantivos que expresan la tendencia a aislarse del mundo exterior. El término se utilizó por primera vez por un

psiquiatra suizo llamado Eugen Bleuler en el año 1911 para denominar a aquellos adultos diagnosticados con esquizofrenia pero que mostraban una inclinación a cerrarse en sí mismos (Rau, 2003 citado en Brock et al. 2006). Según Alonso Peña (2009), en 1926 Ssucharewa diagnosticó a seis personas con “trastorno esquizoide de la personalidad”, aportando una serie de características que coinciden con algunos de los síntomas de lo que hoy llamamos Trastorno del Espectro Autista. Más adelante, en 1943, Leo Kanner utilizó por primera vez el término “autismo infantil”, dado que él se dedicaba a la psiquiatría infantil en la Universidad Johns Hopkins en Estados Unidos. Se trataba de un grupo de once niños que habían sido diagnosticados como “síndrome sin describir”, y que todos compartían las mismas características: incapacidad para relacionarse con otros, dificultad en el uso del lenguaje y un deseo obsesivo por mantener todo igual rechazando los cambios. Sin embargo, Kanner descubrió que estos niños tenían una excelente memoria y capacidad visoespacial, además de un “fuerte interés en números y letras” (Ozonoff et al., 2003, p. 4).

El gran avance que realizó Kanner fue distinguir el autismo de la esquizofrenia, dado que durante muchos años, las personas con Trastorno del Espectro Autista se consideraba que tenían esquizofrenia y eran tratadas como tal. Ozonoff et al. (2003) explican que Kanner puntualizó que aunque parecía ser un síndrome poco frecuente, era probable que hubiera más casos sin identificar. Desde entonces se dedicó al estudio del autismo, relacionando síntomas entre los niños, como frecuentes infecciones de oído, alteraciones en el apetito, un tamaño de la circunferencia de la cabeza mayor y hasta incluso convulsiones (las cuales son poco frecuentes pero se dan en algunos casos). Kanner también estudió a las familias de los niños, observando que algunos eran obsesivos y detallistas, y otros incluso mostraban retrasos en el lenguaje y síntomas propios de lo que él definió como autismo. Por otro lado, algo en lo que Kanner se equivocó y que durante décadas dio falsas esperanzas a los familiares, es que al observar que los niños eran físicamente “normales”, supuso que su inteligencia también lo debía de ser y que en algún momento la acabarían por desarrollar (Alonso Peña, 2009).

A la par que Leo Kanner, Hans Asperger se dedicó también a estudiar sobre los desórdenes mentales en niños. De hecho, mantuvo que el autismo tenía una causa neurobiológica, pero los estudios de Asperger no se tuvieron en cuenta hasta décadas después. Esto es debido a que Asperger era austriaco, y escribió todos los avances sobre el trastorno en alemán en la época de la Segunda Guerra Mundial, mientras que

Kanner produjo sus estudios en Estados Unidos, por lo que ambos trabajos se compararon años después (Alonso Peña, 2009).

Desde entonces los avances han sido numerosos. Alonso Peña (2009) muestra la progresión en el conocimiento del autismo de manera cronológica. Por ejemplo, la Asociación Americana de Psiquiatría (APA) en su DSM-III (1980), reconoce el autismo como un trastorno mental, algo que hasta el momento era considerado como una variante de la esquizofrenia. En su cuarta versión publicada en 1994, gracias a la traducción al inglés sobre el síndrome de Asperger que realizó Uta Frith, se incluye por primera vez este síndrome catalogado como un trastorno mental. Desde entonces también se han creado centros específicos de investigación del autismo, como es Heliott House en Reino Unido y el Instituto MIND en Estados Unidos.

1.3 Tipología del Trastorno del Espectro Autista

Desde que en el año 2000 la Asociación Americana de Psiquiatría (APA) elaborara el DSM-IV-TR, existen cinco categorías diferentes dentro de lo que se denomina Trastorno del Espectro Autista:

- Autismo. En la literatura científica también se denomina “autismo clásico” y es el que describió Kanner como “autismo infantil”. Se caracteriza por un uso anormal del lenguaje no verbal para establecer contacto con otras personas, dificultad para mantener una conversación, retraso o nula capacidad de lenguaje verbal, déficits en el juego y en la imitación, estereotipias, etc. (Ozonoff et al., 2003). No todas las personas diagnosticadas con autismo muestran los mismos síntomas, por lo que se dice que es un trastorno muy heterogéneo. Además, pueden darse distintos niveles cognitivos, encontrando cocientes intelectuales por debajo de la media pero también igual o superior a esta (autismo de alto funcionamiento).
- Síndrome de Asperger. Las características son similares a las del autismo, sin embargo, tanto las habilidades del lenguaje como las cognitivas no están alteradas. Alonso Peña (2009) explica en su libro que “Hans Asperger identificó cuatro niños con características inusuales, lenguaje fluido pero con (...) aislamiento social, (...) un deseo de rutinas y comportamientos repetitivos”. Existen dos enfoques en torno al Síndrome de Asperger, uno es el que muestra la APA y es el aquí desarrollado, que lo considera como parte del Trastorno del Espectro Autista, y el otro enfoque que indica que a

pesar de presentar algunos síntomas en común, las diferencias son cualitativas, por lo que no consideran que el Síndrome de Asperger sea un tipo de TEA.

- Trastorno de Rett. Se trata de un trastorno que afecta únicamente a las niñas, las cuales parecen desarrollarse de forma normal. Entre los seis meses de vida y los dos años, comienzan a mostrar desinterés por otros y por la interacción social y una pérdida del lenguaje adquirido si lo hubiera. Las habilidades cognitivas y motoras también se pierden, y el uso funcional de las manos se ve corrompido por movimientos estereotipados constantes (Ozonoff et al., 2003). En los últimos años se ha relacionado este trastorno con un gen aislado del cromosoma X, pero en la actualidad no existe cura alguna.
- Trastorno desintegrativo infantil. Este trastorno puede ocurrir tanto en chicos como en chicas, pero es mucho más común en chicos. Consiste en un severo retroceso que puede ocurrir entre los dos y los diez años de vida, y que causa ansiedad e incluso pánico en el niño, ya que antes del retroceso su desarrollo es completamente normal. Además, se trata de algo bastante repentino, entre cuatro y ocho semanas el niño pierde sus habilidades cognitivas y motoras, perdiendo también el lenguaje por completo. Ozonoff et al. (2003) puntualiza que algunos investigadores sospechan que este trastorno posee una etiología muy diferente a la del autismo clásico, y que se trata de una alteración neurodegenerativa distinta a los TEA.
- Trastorno generalizado del desarrollo no especificado. Aquellos niños que muestran al menos dos tercios de los síntomas específicos del autismo son clasificados dentro de esta categoría (APA, 2000 en Brock et al. 2006). Muchos de ellos, con el avance de los años y en función de su desarrollo, son posteriormente diagnosticados en alguno de los trastornos anteriores o por el contrario se considera que tienen dificultades de aprendizaje o un retraso en el lenguaje pero no se considerarían TEA.

Tanto el autismo (clásico) como el Síndrome de Asperger son los más frecuentes dentro de los TEA. A lo largo de este trabajo, se utiliza de manera indistinta Trastorno del Espectro Autista como autismo, dado que esta última palabra, además de referirse a un tipo en concreto de TEA, también se emplea como sinónimo y se utiliza para referirse a todos los trastornos detallados anteriormente por igual.

1.4 Posibles causas y teorías

Actualmente, no se conoce la causa del autismo. Sin embargo, hay una tendencia que indica a creer que las causas son biológicas y que se trata de una alteración en el desarrollo de las estructuras cerebrales (Alonso Peña, 2009). Esto se basa en que se ha demostrado científicamente que existen factores genéticos que afectan al desarrollo cerebral, y que mediante una serie de factores externos (ambientales) se puede producir esta anomalía en la estructura cerebral, bien durante el embarazo o bien en etapas posteriores.

Desde Kanner y Asperger, se han elaborado distintas teorías acerca de las causas del autismo. Como indica Alonso Peña (2009) “la psicología freudiana postuló que el autismo surgía porque no se establecían lazos afectivos normales entre los padres y el hijo, lo que detenía el progreso psicológico del niño” (p.117). Durante mucho tiempo se ha creído que los niños autismo tenían padres que no les querían y que no les cuidaban, lo cual era la causa de su trastorno. El 1965 se publicaron las primeras evidencias sobre el origen biológico del trastorno, pero sin embargo a los niños con autismo se les separaba de sus familias creyendo que el problema era la falta de afecto. Años después, se descubrió que esta separación no resultaba en efectos positivos.

Otra teoría está en relación con la vacuna triple vírica que se le aplica a los niños, y se debe a que en muchos casos los síntomas del autismo se comienzan a percibir a la par que se administra la vacuna. Mediante múltiples estudios se ha demostrado que se trata de una coincidencia y que no existe relación alguna de causa-efecto entre las vacunas y la presencia de autismo.

Existen otras teorías de las cuales no hay una conclusión fiable por lo que no se ha demostrado que sean la causa del autismo. Algunas de estas teorías son la toxicidad, bien por contaminación ambiental o a través del mercurio en el pescado o en antibióticos y otros medicamentos, las infecciones por virus durante el embarazo, la aplicación de oxitocina para la inducción del parto, y otras relacionadas con enzimas como son las peptidasas y las sulfotransferasas (Alonso Peña, 2009). Ninguna de estas teorías ha resultado ser concluyente a día de hoy.

1.5 Principales características del niño con autismo

De manera resumida, se presentan a continuación las principales características que tiene un niño con TEA siguiendo el esquema de Alonso Peña (2009) y complementándolo con la información aportada por Chawarska & Volkmar (2005).

Remarcar que se trata de un trastorno heterogéneo, en el cual no todos los niños muestran los mismos síntomas ni lo hacen con la misma intensidad.

Discapacidad en el comportamiento y en la interacción social:

Los niños con autismo necesitan normas y rutinas estructuradas en su entorno, algo que ellos mismos intentan aplicar a todos los ámbitos de su vida. Algunos de estos niños poseen estereotipias, es decir, movimientos repetitivos de los cuales no son conscientes.

En términos generales, muestran poco interés por comunicarse, excepto para satisfacer sus necesidades, y algunos incluso pueden rechazar la atención y el afecto. Esto a veces se debe a su dificultad para interpretar lo que sienten y lo que piensan los demás, llevándoles a situaciones que ellos no son capaces de entender. Esto está también en relación con su escasa o nula habilidad de imitación, algo que algunos niños nunca llegan a desarrollar.

En la base de la interacción social, cuando los niños aún son muy pequeños, ocurre la denominada “atención conjunta”, que consiste en cuando padres e hijo se miran mutuamente a los ojos, compartiendo un momento de complicidad que viene dado por nuestra forma de ser social. En el caso de niños con TEA, la atención conjunta hay veces que no llega a darse, y en muchos casos cuando miran fijamente a los padres es para hacer saber una necesidad, algo que no se considera atención conjunta. Como explican Chawarska & Volkmar (2005), los niños con autismo “en el primer año de vida, orientan la vista menos frecuentemente a las personas” (p.234).

Discapacidad en la comunicación y en el lenguaje:

En algunos casos el lenguaje verbal no llega a desarrollarse, pero son capaces de comunicarse utilizando otros medios como el lenguaje de signos o los pictogramas. En los casos en los que sí existe el lenguaje verbal, este tarda en desarrollarse más de lo normal, surgiendo entre los 5 y los 8 años de manera irregular. Independientemente de si desarrollan lenguaje verbal o no, muestran dificultad para entender lo que otros les dicen o preguntan, por lo que las preguntas deben realizarse de manera clara y escueta.

No utilizan correctamente los nombres y los pronombres, por ejemplo, si tienen hambre puede ser que digan “tú tienes hambre” en vez de “(yo) tengo hambre”. También confunden los géneros dado que no entienden qué significan, de manera que

para referirse a un chico pueden decir “ella” y viceversa. Al hablar, muestran una entonación y un ritmo extraños.

Interpretan las palabras en sentido literal, no entienden la ironía ni el sarcasmo, ni tampoco las preguntas implícitas en las frases. Alonso Peña (2009) emplea el siguiente ejemplo: “puede que si le preguntas ¿sabes cuál es la capital de Italia?, conteste «sí» sin seguir adelante y revelar la respuesta” (p. 54). De la misma manera, ocurre que no comprenden algunas situaciones sociales, por lo que no adaptan el lenguaje y no prestan atención a las diferencias de edad o de estatus, pudiendo ofender a otros.

Discapacidad en la información sensorial:

Es frecuente que los niños con autismo muestren hipersensibilidad (sensibles en extremo) o hiposensibilidad (poco sensibles), dos características que con el tiempo suelen disminuir. En algunos casos se da la sinestesia, es decir, mezclar los sentidos. Por ejemplo, al escuchar un sonido determinado, lo experimentan como un color. Hay figuras artísticas en la historia que muestran a través de sus obras una posible sinestesia, como el caso del poeta Arthur Rimbaud o el músico Rimsky-Korsakov.

En caso de que estén enfermos o les duela algo, les resulta difícil localizar la zona del cuerpo que les duele y hacerlo saber a los demás. En general, tienen cierta dificultad para obtener una visión de conjunto mientras que por el contrario se fijan en los detalles de manera exhaustiva, de manera que si, por ejemplo, se cambiaran de lugar pequeños elementos de su clase en el colegio, se percatarían nada más entrar en esta.

Discapacidad en la imaginación y el juego:

Existen cuatro fases en el desarrollo del juego de cualquier niño, que en orden cronológico son las siguientes (Flippin & Crais, 2011):

- Fase exploratoria, de tanteo, en la cual el niño comienza a investigar las propiedades de un juguete a través de manipulaciones simples, como morder una pelota.
- Fase de juego relacional, durante el cual el niño combina dos o más juguetes como por ejemplo apilar cubos.

1.6 Screening e instrumentos de diagnóstico

El proceso de diagnóstico suele comenzar cuando los padres se dan cuenta de algunas anomalías en el comportamiento y/o desarrollo de su bebé. Algunos ejemplos que aporta Alonso Peña (2009) son: “se muestra indiferente o no le gusta que le abracen (...), no establece con claridad contacto visual (...), no imita (...), no responde a sonidos o voces, pero en otras ocasiones se ve que oye bien” (p. 37). Posteriormente también hay otros indicadores, como resistencia al cambio en las rutinas o indiferencia hacia otras personas.

En este caso, los padres se pondrían en contacto con el pediatra del niño, el cual debe realizar unas pruebas de cribado (*screening*). La más frecuente es CHAT, un cuestionario que requiere en torno a 20 minutos y que se emplea cuando el niño tiene unos 18 meses, aproximadamente. No es una prueba de diagnóstico, sino que establece si el niño está en el grupo de riesgo de TEA o no. En caso afirmativo, el niño es derivado a otros servicios más especializados, como un neurólogo infantil. Es en este momento cuando comienza el proceso de diagnóstico como tal, descartando otros posibles trastornos o enfermedades.

Para el diagnóstico del autismo existen dos escalas mayoritarias: el DSM y el CIE-10. Este último está elaborado por la Organización Mundial de la Salud (OMS), y es el que se emplea en el Sistema Público de Salud en España (Alonso Peña, 2009). El DSM está desarrollado por la Asociación Americana de Psiquiatría (APA) y tiene un alcance mundial, de manera que los documentos científicos de esta revisión bibliográfica es la escala de diagnóstico que utilizan. La versión más reciente es el DSM-V, publicada en el año 2013.

Son muchas las escalas estandarizadas las que se emplean para el diagnóstico del autismo, sin embargo muestro aquellas más representativas y que aparecerán más adelante en este trabajo en relación con los documentos científicos recogidos:

- Escala de Conducta Adaptativa de Vineland (*Vineland Adaptive Behavior Scales*), que evalúa el funcionamiento adaptativo de niño a su entorno mediante cuatro sub-escalas centradas en la comunicación, la vida diaria, la socialización y las habilidades motoras.
- Escalas Mullen de Aprendizaje Temprano (*Mullen Scales of Early Learning*), la cual evalúa el funcionamiento cognitivo y adaptativo a través de los siguientes

aspectos: percepción visual (emparejamiento, clasificación, etc.), habilidades motoras finas, recepción del lenguaje y lenguaje expresivo.

- Escalas Bayley de Desarrollo Infantil (*Bayley Scales of Infant Development*), que mide el desarrollo cognitivo, psicomotor y comportamental de los niños de un mes hasta los tres años y medio.
- Escala de Evaluación del Autismo Infantil (*Childhood Autism Rating Scale, CARS*), la cual permite la codificación del comportamiento del niño y permite su clasificación en grados de severidad.

Una vez se haya establecido un diagnóstico, se puede elaborar un plan de intervención. En el caso del autismo, la intervención recoge también la ayuda psicológica que puedan necesitar las familias, la intervención psicoeducativa del niño, y un plan de atención global con perspectivas de futuro y con posibilidad de someterlo a cambios, ya que el niño se encuentra en edad de desarrollo y sus características es posible que varíen con frecuencia, por lo que el plan de intervención deberá variar también.

Cap. 2. INTERVENCIÓN EDUCATIVA: LA IMPORTANCIA DE LAS FAMILIAS

2.1 La relevancia de la intervención educativa y el papel del pedagogo

A pesar de que el autismo no tenga cura ni un tratamiento médico válido demostrado, es posible intervenir de manera tanto psicológica como educativa con la finalidad de mejorar el desarrollo de las capacidades del niño y, consecuentemente, incrementar su calidad de vida y la de su familia (Alonso Peña, 2009). La educación juega un papel primordial en la intervención, pues no solo se centra en la educación formal, bien sea en un colegio ordinario o específico, sino también la educación que recibe en casa, por parte de su familia o cuidadores, y en actividades extraescolares. Se trata de niños con unas características concretas, que necesitan de personas expertas que sepan guiarles para lograr un buen desarrollo y conseguir una adecuada adaptabilidad al entorno y a la sociedad. Como es obvio, la educación informal, es decir, aquellas cosas que aprenden mediante la observación y la imitación, se ve alterada y requiere también de un entorno estructurado sobre el cual intervenir. De esta manera, el pedagogo como experto en educación, es el profesional más indicado para actuar sobre la educación formal, no formal e informal.

El campo de la Pedagogía es muy amplio dado que la educación forma parte del sistema cultural de cada sociedad, siendo algo único de los seres humanos. De la misma forma que existen culturas distintas, la educación también varía en función de esta, pero las bases del aprendizaje son siempre las mismas. Con el autismo ocurre exactamente lo mismo, las bases del trastorno y la sintomatología son las mismas, pero en función de la cultura el tratamiento se realiza de una manera o de otra. Ozonoff et al. (2003) dedican un apartado de su libro a explicar la relación existente entre la cultura y el autismo. Sin embargo, algo que se echa en falta en el ámbito del Trastorno del Espectro Autista, es la actuación y la implicación del pedagogo, profesional de la educación que tiene mucho que aportar en el diagnóstico pero sobre todo en la intervención del trastorno. También puede investigar sobre la historia del autismo, se sabe que hace menos de un siglo se consideraba a las personas con autismo como esquizofrénicas, pero poco conocemos de épocas anteriores y de la educación que recibían. El curriculum de las intervenciones, la metodología, la comparación sobre cómo se llevan a cabo estos aspectos en los distintos países del mundo, la formación y orientación de profesores, educadores y padres en relación al

autismo, la creación de contenidos planificados y estructurados para las distintas etapas en la vida de una persona con autismo, la transición a la vida adulta o la evaluación de programas y curriculum, entre otros muchos aspectos, son todos propios de la labor del pedagogo. Dada la formación que he recibido a lo largo de estos años, me siento capacitada para especializarme e incluso realizar dichas acciones que son imprescindibles para el Trastorno del Espectro Autista y que sin duda conllevarían un avance sobre el estudio y la investigación del trastorno, algo que se hace cada día más necesario.

2.2 Enfoques y técnicas de la intervención educativa específicas del Trastorno del Espectro Autista

La intervención educativa varía en función de dos bloques o enfoques, lo que en la literatura científica americana llaman *preschool* y *school age* (Brock et al., 2006; Loveland & Tunali-Kotoski, 2005; Ozonoff et al., 2003). El primero de ellos lo traduciríamos como preescolar, y se refiere a los niños de entre 0 y 6 años, y el segundo son los niños en edad escolar de entre 6 y 12 años. El primer caso, aunque la traducción literal al español sea “preescolar”, la literatura científica española habla de Atención Temprana y de intervención educativa en la Atención Temprana, que también abarca de 0 a 6 años.

Dentro de las técnicas empleadas para la intervención educativa en la Atención Temprana del autismo, existen dos puntos de vista. Uno de ellos consiste en establecer un número amplio de objetivos dirigidos a múltiples áreas de desarrollo del niño como el lenguaje, la comunicación, la interacción social, habilidades motoras, cognitivas, etc. (Brock et al., 2006). El otro punto de vista consiste en planificar un número muy limitado de objetivos, incluso únicamente un objetivo, encaminados a la mejora en el desarrollo de alguno de los aspectos más deficientes en el niño o alguno de los síntomas principales del autismo. La intención es que al mejorar uno o dos de estos aspectos, repercuta en las demás áreas y se produzca también una mejora, algo que Wallace & Rogers (2010) denominan “efectos colaterales”. A día de hoy se trata de una discusión abierta que va a ser uno de los puntos de la posterior revisión sistemática.

En cuanto a los niños de entre 6 y 12 años, primero se evalúa su nivel de desarrollo y habilidades, y luego se establecen los objetivos en torno a los resultados de dicha evaluación. De esta manera, los objetivos se pueden elaborar de manera más amplia o más limitada, siempre adecuando las técnicas educativas al nivel y

realizando un seguimiento del proceso por si fuera necesario realizar cambios (Brock et al., 2006). Ozonoff et al. (2003) aportan algunas estrategias más específicas como la elaboración de horarios visuales, la redacción de normas por escrito o el acceso a las TICs en el aula.

Una de las metodologías educativas más aplicada para el autismo es el Análisis Conductual Aplicado (ACA), basado en el condicionamiento operante y en las teorías de Skinner. La idea principal de este enfoque es la modificación de la conducta del niño, para lo cual se observa su comportamiento en un determinado entorno, se analiza, se establecen objetivos medibles, y se interviene. Se ha demostrado ser eficaz para tratar el Trastorno del Espectro Autista, pero Ozonoff et al. (2003) especifican que debe llevarse a cabo por “profesionales bien formados y supervisados y unas 27 horas o más a la semana” (p.150). Brock et al. (2006) indican que el mínimo de horas por semana debe ser 25, y al año se debe llevar a cabo durante 52 semanas, por lo que emplear el análisis conductual aplicado debe hacerse de manera intensiva. Sin embargo, Alonso Peña (2009) indica que hay detractores de este método que argumentan que se trata de técnicas excluyentes ya que solo sirven para niños con autismo de alto funcionamiento, los aprendizajes no son contextualizados por lo que resulta difícil su generalización y el coste es elevado. Otro enfoque también conductual y que debe ser aplicado de manera intensiva es *Pivotal Response Training (PRT)* que en español se podría traducir como “entrenamiento de respuesta esencial”. La principal diferencia entre un método y otro, es que este último establece objetivos dirigidos a la consecución de mejoras en un área, y no se centra tanto en comportamientos determinados. Según Brock et al. (2006), el *PRT* además de permitir la posibilidad de cambiar algunos comportamientos del niño (ya que la base del método también es conductual), permite enseñar nuevas habilidades de manera eficaz. En esta misma línea, otra metodología conductual que también se emplea en el ámbito del autismo es el *Discrete Trial Training (DTT)* mediante la cual se establece un rango amplio de objetivos y la diferencia es que se lleva a cabo en sesiones grupales, mientras que las otras son intervenciones individuales (Ozonoff et al., 2003).

Existe otra metodología que se emplea en el desarrollo de la comunicación de los niños con TEA, y que no es de base conductual, sino que se basa en observar la iniciación y la espontaneidad en la comunicación del niño y aprovechar los elementos de motivación para conseguir desarrollarla. Se trata del Enfoque del Desarrollo (EDD) cuyas bases según Alonso Peña (2009) son “imitar las conductas del niño (...), repetir

sus acciones haciendo turnos alternativos (...) y tener paciencia y constancia hasta que el niño nos incluya en su actividad” (p.166). Este mismo autor sintetiza las principales diferencias entre el Análisis Conductual Aplicado y el Enfoque del Desarrollo en el siguiente párrafo:

“El ACA enseña estructuras (conductas). El EDD enseña funciones (a usar conductas). El ACA impide las distracciones imponiendo otras actividades, en tanto que el EDD, participa activamente en las “distracciones”, para luego atraer la atención y motivación hacia actividades más funcionales.”
(p. 168).

En último lugar, existe un enfoque ambiental basado en la idea de que el entorno se puede modificar y diseñar para adaptarse a las necesidades y características del niño, reduciendo de esta manera los comportamientos disruptivos. Así es como surge el programa TEACCH, que parte de la comprensión de las necesidades y limitaciones del niño y adecúa el entorno y la educación que recibe. Existe una colaboración entre los profesionales y los padres, para que puedan adaptar la educación que dan a su hijo y generalizarla a diversos entornos. Se trata de un programa individualizado, elaborado para cada niño en concreto pero que comprende al niño en su conjunto, en vez de tratar áreas o síntomas por separado (Alonso Peña, 2009; Brock et al., 2006; Ozonoff et al., 2003).

Además de estos enfoques o metodologías, existen técnicas específicas como son las ayudas visuales, que son muy útiles en el Trastorno del Espectro Autista. El compañero-modelo, que requiere la supervisión de un experto que asegure que la técnica se está realizando de manera positiva, y que es algo que se realiza en muchos colegios. Hay casos en los que el lenguaje verbal no se ha desarrollado, por lo que la comunicación a través del lenguaje de signos, mediante imágenes e incluso a través de un ordenador, son técnicas que ayudan a facilitar la comunicación y también a conseguir los objetivos propuestos (Alonso Peña, 2009). Además, hay autores como Canal Bedia et al. (2015) que sugieren que combinar distintas técnicas específicas puede ser la mejor opción para lograr los objetivos propuestos.

2.3 La Atención Temprana en el Trastorno del Espectro Autista

Cuando hablamos de Atención Temprana nos referimos a intervenciones dirigidas a niños de entre 0 y 6 años, a su familia y entorno, y que pretenden dar respuesta a sus necesidades transitorias o permanentes, ya que no es necesario que los niños tengan un diagnóstico en algún trastorno del desarrollo para recibir Atención

Temprana, aquellos que están en riesgo también forman parte de estos programas (GAT, 2000; Ozonoff et al., 2003). El principal objetivo es “potenciar su capacidad de desarrollo y bienestar, posibilitando de la forma más completa su integración en el medio familiar, escolar y social, así como su autonomía personal” (GAT, 2000, p. 14). Mediante la Atención Temprana se pretende reducir los efectos del trastorno e introducir los mecanismos necesarios para la eliminación de barreras y para la adaptación del niño según sus necesidades específicas. A lo largo de este proceso, los profesores y educadores juegan un papel importante, ya que en la escuela se da una interacción entre los niños que no ocurre en el entorno familiar, lo cual permite observar comportamientos que pueden ser clave tanto para el diagnóstico como para la adaptación de la intervención a las necesidades del niño.

Investigaciones realizadas sobre el desarrollo cerebral de los niños con autismo, han demostrado que una intervención temprana es eficaz debido a la plasticidad neuronal que poseemos y que permite al niño una apertura al mundo social, con consecuencias como la prevención o la mitigación de los síntomas propios del Trastorno del Espectro Autista (Sullivan et al., 2014). La idea que aportan estos autores es que el entorno con el que interactúa el niño afecta a las conexiones neuronales, y esto tiene consecuencias a largo plazo en su comportamiento y desarrollo cerebral. Dada la importancia que muestran estas investigaciones, se establecen una serie de elementos que todo programa de atención temprana debe incluir: currículum enfocado a los déficits del autismo, entornos educativos que permitan la generalización de estrategias, una planificación que permita establecer rutinas, enfoques dirigidos a los problemas de comportamiento, plan de transición a la edad escolar para aquellos niños próximos a los seis años y, por último pero no menos importante, la participación de las familias.

En relación a estos componentes, hay otros aspectos que también son importantes a la hora de intervenir. El acceso lo antes posible a estos programas, una participación activa e intensiva, una ratio baja alumnos-profesor, un plan individualizado y adaptado a las necesidades de cada niño, y una evaluación continuada del programa de intervención que permita su modificación cuando fuera necesario, son elementos que hay que tener en cuenta a la hora de crear un plan de atención temprana. En cuanto al acceso a estos programas, Sullivan et al. (2014) destacan que para que el tratamiento sea efectivo, este debe comenzar antes de los dos años y medio de edad.

2.4 La participación de las familias en el tratamiento de sus hijos y sus consecuencias

Como puntualizaba en el apartado anterior, la participación de las familias ha demostrado ser un componente imprescindible en los programas de atención temprana para niños con autismo (Sullivan et al., 2014). Si pensamos en que se trata de un trastorno generalizado del desarrollo, y que obviamente se da en todos los ámbitos de la vida del niño con TEA, carece de sentido creer que con un cierto número de horas aisladas que se trabaje sobre sus síntomas o dificultades bastará para lograr mejoras. Esto lo ponen de relieve múltiples autores indicando que los programas deben ser intensivos e individualizados, pero en los últimos años ha aumentado una tendencia que pretende incluir a los padres en dichos programas.

Brock et al. (2006) explican que todo programa de intervención debe involucrar a los padres de manera activa, y Matson, Mahan, & Matson (2009) aportan que cuando los padres forman parte de la atención temprana, llevando a cabo técnicas propias de profesionales (como ACA o EDD), el tratamiento será más efectivo. Según ellos, “mejora la generalización, es más barato y requiere menos recursos además de ser un tratamiento intensivo, y (...) se mantienen los beneficios del tratamiento” (p. 872). Brooke & Gergans (2006) y Coolican, Smith & Bryson (2010) aportan las mismas ideas, aunque estos últimos añaden que el concepto de los padres de auto-eficacia aumenta, lo cual repercute de manera beneficiosa tanto en la educación que le dan a sus hijos como en la convivencia en el entorno familiar. Destacar que dado que el autismo afecta de manera distinta a cada persona, por lo que se considera un trastorno heterogéneo, y que en cada caso existen unas “singularidades personales y familiares que llevan a que (...) precisen atenciones únicas, ajustadas a cada caso particular” (Canal Bedía et al., 2015, p.27), cuando involucramos a los padres en este proceso la intervención debe ser más que nunca algo individualizado, creado en función de las características y necesidades de cada familia.

En definitiva, la literatura científica muestra varios puntos en común en cuanto a intervención en atención temprana se refiere:

- Debe comenzar lo antes posible, incluso cuando no se tiene un diagnóstico claro pero hay indicios.
- Lo ideal es que sea intensiva y con una ratio estudiante-profesor baja.
- El plan se debe elaborar de manera individualizada, atendiendo a las necesidades de cada niño.

- Las familias son parte del programa y deben formar parte del proceso, además de recibir ayuda y apoyo.
- Es conveniente evaluar el proceso de la intervención de forma regular y reajustar o rediseñar aquello que fuera necesario.

Los estudios científicos elaborados al respecto, muestran que la participación de las familias es indispensable ya que suma beneficios a la intervención, sin embargo, surgen las siguientes dudas al respecto: ¿es frecuente encontrar programas de atención temprana que incluyen la participación de los padres? En caso afirmativo y dado que la implicación de los padres se puede llevar a cabo de múltiples formas, ¿existen modelos para ello? Los resultados beneficiosos están demostrados pero, ¿son éstos significativos?, ¿existen también aspectos negativos o inconvenientes?

REVISIÓN BIBLIOGRÁFICA SISTEMÁTICA

Cap. 3. METODOLOGÍA

1.1. Objetivos

Antes de comenzar con el proceso de revisión bibliográfica sistemática, resulta conveniente recordar de forma breve los objetivos planteados para este Trabajo Final de Grado.

- Revisar sistemáticamente las últimas investigaciones sobre la participación de las familias como un componente habitual de la Atención Temprana en el Trastorno del Espectro Autista.
- Estudiar y conocer las distintas modalidades de participación de las familias en caso de que las hubiera, e indagar también acerca de los posibles inconvenientes de la implicación de las familias en la intervención temprana de los niños con autismo.
- Desarrollar las competencias, tanto genéricas como específicas, adquiridas a lo largo de la formación recibida en el título de Grado de Pedagogía en la USAL. Algunas de ellas son: competencia informacional, gestión de información científica, de expresión escrita, capacidad para aportar ideas y soluciones, y transmitirlos a tanto a público especializado como no especializado, recogida e interpretación de datos para la emisión de juicios reflexivos sobre temas educativos y sociales, evaluación de programas y proyectos educativos y formativos, capacidad de aprendizaje autónomo y responsabilidad, además de una actitud innovadora y creativa.
- Aprender a realizar una revisión bibliográfica de carácter sistemática, empleando para ello metodologías propias de este tipo de investigaciones.
- Incrementar el conocimiento sobre el Trastorno del Espectro Autista.
- Dar a conocer el impacto del trastorno en las familias y en la sociedad, además de realzar la importancia de la educación en los distintos ámbitos del Trastorno.

1.2. Selección de la metodología PRISMA: antecedentes metodológicos

Para la elaboración de esta revisión bibliográfica se ha empleado la declaración PRISMA, herramienta mediante la cual se consigue que una revisión bibliográfica sea sistemática. Antes de entrar de lleno en el proceso metodológico que se ha llevado a cabo, es conveniente aclarar primero en qué consiste la declaración PRISMA.

En 1999 surgió de declaración QUORUM con el objetivo de establecer unas normas para mejorar la calidad de los metaanálisis y cuyas siglas hacen referencia en inglés a *Quality of Reporting of Meta-Analysis*, es decir, calidad de los informes de los metaanálisis. Como Urrútia & Bonfill (2010) explican en su artículo, QUORUM consiste en una lista de comprobación estructurada que los autores de los metaanálisis y que los editores de las revistas médicas debían considerar a la hora de publicar estos trabajos. A lo largo de los diez años siguientes, QUORUM fue revisada periódicamente hasta que finalmente en el año 2009 salió a la luz la declaración PRISMA, una versión mejorada de QUORUM que aporta un mayor número de normas para la mejora de la calidad de los metaanálisis pero que sobre todo incorpora una importante novedad, y es la extensión de estas normas también para las revisiones sistemáticas. De esta manera, la declaración PRISMA se emplea en la elaboración de revisiones sistemáticas y metaanálisis con la finalidad de obtener publicaciones científicas objetivas y de calidad. PRISMA son las siglas de *Preferred Reporting Items for Systematic reviews and Meta-Analysis*, que en español lo traduciríamos como lista de ítems apropiados para las revisiones sistemáticas y metaanálisis. Dispone de una página web propia donde se incorporan todas estas normas o ítems y se explican detalladamente una a una con la ayuda de ejemplos aclarativos. El proceso de una revisión sistemática está dividido en varias fases que se especifican de manera visual en un diagrama de flujo que forma parte también de la declaración PRISMA y que está al alcance de todo el mundo a través de su página web. A día de hoy se emplea fundamentalmente en el campo de la biomedicina y dado que el ámbito de los trastornos del desarrollo y, en concreto los Trastornos del Espectro Autista, es un campo multidisciplinar y multiprofesional, actualmente se está haciendo hincapié en el uso de la declaración PRISMA para las revisiones sistemáticas y metaanálisis en busca de una mayor calidad y objetividad por parte de los distintos profesionales implicados en dicho campo de investigación.

1.3. Selección de la estrategia PICO

Además de la declaración PRISMA, existe una estrategia denominada PICO que se emplea en la elaboración de la pregunta de investigación, lo cual es la base de la revisión sistemática. Da Costa Santos, de Mattos Pimenta, & Nobre (2007) explican que el objetivo de la estrategia PICO es establecer una pregunta estructurada en torno a cuatro componentes de una manera objetiva y rigurosa de forma que sea útil para establecer los criterios de inclusión y de exclusión para la búsqueda de documentos científicos empleados en la revisión sistemática. Esta estrategia aparece dentro de la declaración PRISMA como sugerencia en algunos de los ítems que la componen dado que sus características la hacen propicia para conseguir una revisión sistemática (o metaanálisis) de calidad. Los cuatro elementos de la estrategia PICO corresponden a sus cuatro siglas, que son las siguientes:

- P (paciente): definición del problema o paciente.
- I (intervención): intervención que se desea realizar.
- C (comparación): no siempre procede por lo que no tiene por qué emplearse esta variable, en la cual se especifica si se comparan intervenciones o no.
- O (outcomes, resultados): el resultado que se espera obtener.

Siguiendo esta estructura, aplicada al tema que nos atañe en esta revisión sistemática, los resultados se muestran en la figura que aparece en la siguiente página.

1.4. Criterios de selección de documentación científica

Para la selección de los documentos científicos empleados en esta revisión bibliográfica, se han establecido unos criterios de inclusión y de exclusión con la finalidad de adaptar la búsqueda a la pregunta objeto de este trabajo. La especificación que supone formar la pregunta mediante la estrategia PICO ha sido clave para la elaboración de los criterios.

CRITERIOS DE INCLUSIÓN:

- Documentos que sean artículos, libros y capítulos de libros.
- Estudios cuantitativos y cualitativos.
- Estudios prospectivos y retrospectivos.
- Revisiones sistemáticas y estudios comparativos.

- Programas de atención temprana para niños con autismo que incluyen la participación de los padres.
- Rango de tiempo: 2000-2016.
- Idiomas: inglés y español.

CRITERIOS DE EXCLUSIÓN:

- Cualquier otro trastorno, síndrome o dificultad de aprendizaje tratado mediante atención temprana.
- Otros trastornos del desarrollo que no sean Trastornos del Espectro Autista.
- Tesis y disertaciones.
- Artículos que no hayan sido publicados en ninguna revista de investigación.

Cuadro 1. Estrategia PICO Nota: tomada de Da Costa Santo et al, (2007)

P	Paciente Características del paciente u objeto de la investigación.	Niños de 0 a 6 años de edad diagnosticados con Trastorno del Espectro Autista y que forman parte de un programa de atención temprana.
I	Intervención Tipo de intervención y factores a tener en cuenta.	Participación e implicación de los padres en los programas de atención temprana específicos para Trastorno del Espectro Autista.
C	Comparación Alternativas para comparar los distintos tipos de intervención.	Comparación de distintos programas de atención temprana en niños con autismo en los cuales existe una participación por parte de los padres.
O	Resultados (Outcomes) Resultados que se esperan obtener al finalizar el estudio	Eficacia de los programas de intervención con resultados en la mitigación de algunos síntomas y mejoras en el desarrollo del niño con Trastorno del Espectro Autista.

1.5. Fuentes de Información científica

Entre las fuentes de información científica actuales, las más utilizadas en el campo de la Educación y de la Psicología, son ERIC (Education Resources Information Center) y PsycINFO. ERIC posee más de un millón y medio de

documentos científicos en su base de datos publicados desde el año 1966. Estos documentos científicos incluyen artículos de revistas, libros, informes de conferencias y tesis, entre otros. Por otro lado, PsycINFO es una base de datos creada por la Asociación Americana de Psiquiatría (APA) que contiene más de cuatro millones de registros bibliográficos desde el siglo XIX hasta hoy en día. Acoge artículos de revistas, libros, capítulos de libros y disertaciones pertenecientes al ámbito de las Ciencias Sociales y de la Psicología, por lo que dispone también de documentos relacionados con la Pedagogía y con aquello relacionado con la educación especial, educación terapéutica, intervención educativa y, por supuesto, es una gran base de dato para el Trastorno del Espectro Autista en todas sus vertientes.

Las fuentes empleadas han sido recopiladas mediante una búsqueda electrónica en las bases de datos PsycINFO y ERIC, también mediante artículos aportados por profesionales en el campo y por último, a través de las fuentes bibliográficas de algunos de los artículos. Se han aplicado límites en el rango de tiempo, seleccionando aquellos publicados a partir del año 2000 y hasta el año 2016. En cuanto al idioma, la búsqueda se ha limitado a inglés y a español, estando escritos todos los documentos encontrados en inglés.

1.6. Términos de búsqueda en campos específicos

Los términos empleados en la búsqueda de referencias bibliográficas tanto en PsycINFO como en ERIC están basados en conjuntos de letras que hacen referencia a una palabra. En este caso, se han empleado los términos KW (keyword o palabra clave), TX (texto) y AU (autor). Ocurre que en muchos artículos se aporta información relevante sobre la participación de los padres en los casos de atención temprana para niños con autismo pero no se incluyen en la sección de palabras clave, por lo que estos términos se han incluido directamente para la búsqueda en texto en vez de en las palabras clave. En el caso del autor, se ha hecho una búsqueda específica para Brooke Ingersoll, dado que es investigadora especialista en la implicación de los padres en casos de autismo. Destacar que esta búsqueda se ha realizado también en español, sin resultados concluyentes.

1. KW autism
2. KW ASD
3. KW Autism Spectrum Disorders
4. KW early intervention
5. TX parent training

6. TX parents participation
7. AU Ingersoll, Brooke

1.7. Fases en la selección de documentos

Para seleccionar los documentos empleados en la revisión sistemática, se ha dividido en proceso en tres fases:

1. Inclusión en la revisión sistemática: se han recopilado un total de 91 referencias bibliográficas basadas en los criterios de inclusión anteriormente especificados. La mayor parte de las referencias son artículos de revistas, habiendo un reducido número de libros y manuales. De entre todos los artículos, hay revisiones sistemáticas, meta-análisis, ensayos y estudios cualitativos. Además, los 91 documentos están escritos en inglés, a pesar de que en los criterios de búsqueda se establecieron dos idiomas: inglés y español. Antes de comenzar el primer proceso de cribado de documentos, se eliminaron 3 referencias por repetición, pasando así a la siguiente fase 88 referencias.
2. Primer proceso de cribado: se ha realizado en función del título y resumen de cada una de las referencias, siendo lo más específico posible para reducir al máximo el número de documentos y conseguir una mayor validez y fiabilidad de los restantes. Uno de los criterios decisivos a la hora de realizar este proceso, ha sido la posibilidad de acceso al texto completo del documento, lo cual ha conllevado la expulsión de una gran cantidad de referencias. De las 88 referencias recogidas, tras este proceso han pasado a la siguiente fase 18.
3. Segundo proceso de cribado: se ha tenido en cuenta el contenido de cada uno de los 18 documentos y ese ha sido el criterio clave para escoger los más fiables y válidos a fin de realizar una revisión bibliográfica sistemática de calidad. Con la misma finalidad, también se ha tenido en cuenta el esquema que han llevado a cabo los autores para estructurar el artículo. Para las revisiones bibliográficas se ha tenido en cuenta que siguieran una metodología como puede ser PRISMA y para los demás ha sido de especial relevancia que siguieran un esquema similar al siguiente:
 - a. Introducción o antecedentes
 - b. Método: criterios de búsqueda, selección de artículos y metodología de la investigación
 - c. Resultados

d. Discusión y/o conclusiones

Al finalizar este proceso, el número de referencias empleadas en la revisión sistemática es 9, de las cuales 6 son artículos de programas de intervención que se han llevado a cabo y 3 son revisiones sistemáticas.

Este proceso queda reflejado en el diagrama de flujo propuesto por la declaración PRISMA que aparece al final del capítulo 3.

1.8. Categorías de análisis de contenido de estudios seleccionados

ÍTEMS PARA LA EXTRACCIÓN DE DATOS

Los datos se han extraído en base a las características de los estudios en función de si se trata de un programa de intervención o de una revisión bibliográfica. Para los programas de intervención, los ítems o elementos han sido los siguientes:

- Edad de los destinatarios de los programas.
- Estructuración y organización.
- Enfoque de la intervención, que puede ser o conductual o evolutivo.
- Aspecto en concreto de la sintomatología del autismo en torno al cual se ha desarrollado el programa. Por ejemplo, algunos programas se centran en las habilidades espontáneas de imitación, mientras que otros están enfocados a la consecución de habilidades comunicativas o al juego simbólico.
- Empleo de medios estadísticos para la obtención de los resultados.
- Nivel de detalle y especificación, como por ejemplo el número de horas del programa y cómo se han repartido en el tiempo.

En cuanto a las revisiones bibliográficas, recogen datos de distintos programas integrándolos en un único estudio. Los ítems que se han tenido en cuenta son los siguientes:

- La fecha de publicación de los programas que aparecen en la revisión bibliográfica.
- Puede existir un punto en común referido a la sintomatología entre los programas de una misma revisión. Por ejemplo, si se ha realizado un estudio de distintos programas enfocados en la intervención en el lenguaje y comunicación del niño con autismo en intervención temprana.

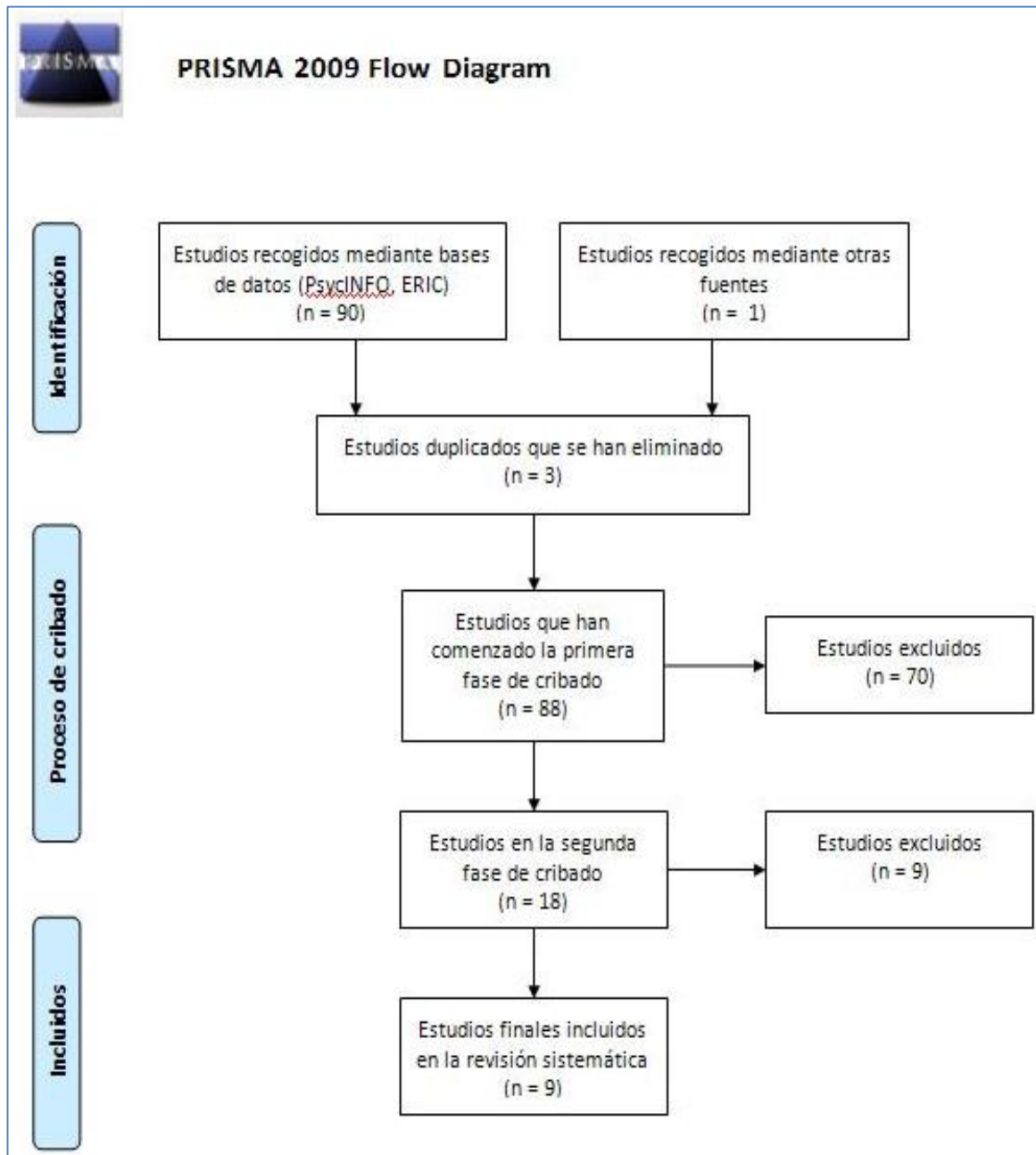
- La estructuración de la revisión bibliográfica, es decir, si se trata de una revisión bibliográfica sistemática o no.
- Si se realiza una comparación entre distintos estudios o programas.

1.9. Control de calidad de validez de los estudios

Para esta revisión sistemática no se ha creado un proceso claramente definido para evaluar el riesgo de parcialidad de los estudios. Sin embargo, en el segundo proceso de cribado que consistía en la lectura completa de los 18 artículos obtenidos tras el primer cribado, se han tenido en cuenta una serie de elementos propuestos por la declaración PRISMA. Estos elementos están basados a su vez en un sistema propuesto por el centro Iberoamericano Cochrane en su manual de revisiones sistemáticas (Higgins et al., 2011). Se trata de un manual muy extenso del cual se ha tenido en cuenta el sesgo de informe de resultado, que consiste en el informe selectivo de algunos resultados pero no de otros. Existen otros tipos de sesgo, como es el sesgo de ubicación, que tiene que ver con la revista en la cual se publica el artículo, pues se demostró que cuanto más bajo impacto tenga la revista, se obtienen más resultados significativos. Algo similar ocurre con el idioma, pues aquellos artículos que se publican en inglés tienen un mayor alcance y por tanto un mayor impacto, aunque los hallazgos del estudio no sean tan significativos, esto se conoce como sesgo de idioma (Gisbert, J.P. & Bonfill, X., 2004; Meca, 2010).

Se trata de una serie de sesgos muy específicos y que requieren un equipo de investigación o al menos una gran cantidad de tiempo. Es por esto que para conseguir una cierta calidad en los estudios de esta revisión sistemática, se han empleado algunos de estos sesgos pero no todos ellos, y no se ha realizado siguiendo un proceso minucioso y exhaustivo.

Figura 2: Diagrama de flujo de la declaración PRISMA. Nota: adaptado de <http://www.prisma-statement.org/> (2 de junio de 2016).



Cap. 4. RESULTADOS Y DISCUSIÓN

Una vez llevadas a cabo las fases explicadas en la metodología, son nueve los artículos resultantes. Tres de ellos son revisiones sistemáticas y los otros seis son programas de atención temprana que se han llevado a cabo en niños con autismo y que conllevan la participación de los padres de alguna manera. Cada uno de los programas se centra en elementos distintos que refieren a la sintomatología del Trastorno del Espectro Autista y que tratan de abordarlos con el objetivo de que esos síntomas se mitiguen y así la calidad de vida del niño y de su familia mejore.

Existe una serie de elementos en común entre todos los artículos, como es la importancia de un diagnóstico lo antes posible y la atención temprana como medio de intervención con efectos muy positivos a largo plazo. Todos ellos están de acuerdo en que incluir a los padres en la intervención educativa del niño es beneficioso no solo a la hora de reducir o mitigar los síntomas del niño sino que también la relación entre padres e hijo mejora, y la seguridad de los padres en sí mismos y en su capacidad de ejercer como padres ante un niño con autismo también.

Cada programa está orientado a la consecución de unos objetivos específicos, y para conseguirlos cada uno ha empleado distintas técnicas, divididas en distintas fases, con una duración determinada y una serie de profesionales con distintos roles, a veces liderando la situación y otras veces aportando críticas constructivas a las actuaciones de los padres. Para llevar a cabo la comparación de los programas, se han establecido unos criterios de comparación.

4.1. En función de los objetivos del estudio

Los objetivos de los distintos programas se fundamentan en la mejora de alguno de los síntomas propios del autismo. Algunos enfoques plantean establecer una amplia gama de objetivos dado que la sintomatología del autismo lo permite, de manera que la intervención se convierte en algo más holístico. Sin embargo, Wallace & Rogers (2010) explican que proponer como objetivo un solo déficit o al menos los más básicos, parece prevenir dificultades en otras áreas como si de efectos colaterales se tratara. Como resultado de su revisión bibliográfica, aseguran que establecer un campo limitado de objetivos en vez de amplio, resulta en efectos positivos.

Las habilidades sociales y de comunicación es uno de los aspectos en los cuales estos niños tienen más dificultades, por lo que es un objetivo frecuente en los programas de atención temprana, como es el caso de Ingersoll & Dvortcsak (2006) y Anan, Warner, McGillivray, Chong & Hines (2008). Se debe tener en cuenta que son programas de atención temprana, por lo que la edad de los niños es de 0 a 6 años, y el desarrollo de la comunicación es clave en esta etapa, pero hay que diferenciar entre comunicación y lenguaje verbal. Comunicación se refiere a la manera en que los niños expresan sus necesidades, lo cual se denomina comunicación funcional, y también se refiere a la manera de relacionarse con las personas desde un carácter más social y no tan funcional. Esto lo pueden hacer con gestos o produciendo sonidos, pero no necesariamente hablando y empleando el lenguaje verbal. De esta manera, únicamente Coolican, Smith & Bryson (2010) se proponen como objetivo, además de conseguir mejoras en la comunicación, aumentar el uso del lenguaje.

En el caso de Ingersoll & Gergans (2006), su programa está enfocado a una habilidad de comunicación social no verbal, la capacidad de imitación. Esta capacidad surge a edades muy tempranas pero sin embargo, en el caso del autismo existe una clara deficiencia. La imitación juega un papel fundamental a la hora de desarrollar habilidades sociales y cognitivas más complejas, por lo que tratarla cuanto antes es de primordial importancia. El juego, el lenguaje y la atención conjunta están relacionados con la imitación, por lo que las autoras del programa proponen una intervención enfocada en la imitación a través del juego y de la atención conjunta. Esto último es el objetivo principal de Schertz & Odom (2007), quienes explican que cuando el niño es capaz de coordinar la mirada con sus padres o cualquier persona que esté cerca, está empleando la atención conjunta. Se trata de un aspecto social, es compartir un momento y centrar la atención en la persona que le está mirando, por lo que aquellas situaciones en las cuales el niño coordina la mirada para pedir algo o hacer saber una necesidad, no se pueden considerar como atención conjunta. Además, se puede dar de dos maneras, la primera consiste en corresponder a la mirada de la otra persona, y la segunda es la iniciación de la atención conjunta por parte del niño. Este aspecto se considera el inicio del desarrollo social del niño, por lo que el programa lo establece como único objetivo a conseguir. Es un claro ejemplo de la teoría de Wallace y Rogers (2010), dado que se espera que intervenir para incrementar la habilidad de atención conjunta del niño resulte en una mejora en el desarrollo social del niño en un futuro.

Tanto la imitación como la atención conjunta son objetivos de los programas propuestos por Kasari, Gulsrud, Paparella, Helleman & Berry (2015), quienes llevaron a cabo dos programas a la vez en el mismo estudio, pero además también proponen conseguir mejoras en el juego simbólico ya que, según Flippin & Crais (2011), el juego simbólico ha demostrado ser un indicador de un posterior desarrollo en el lenguaje. Estos dos últimos autores explican las cuatro fases del juego, que por orden cronológico de aparición son las siguientes: fase exploratoria, fase de juego relacional, juego funcional y, por último, juego simbólico. En el caso de los niños con Trastorno del Espectro Autista, esta trayectoria se ve modificada. Según los autores que explican dichas etapas, "su juego es menos elaborado y más repetitivo [...] y pasan un mayor período de tiempo en la fase de juego exploratorio" (Flippin & Crais, 2011, p.32). El programa denominado JASPER elaborado por Kasari et al. (2015) se centra en las dos últimas fases del juego (funcional y simbólico) y tiene como finalidad desarrollar ambas fases.

Otro objetivo muy frecuente propuesto en algunos de los programas, es reducir los comportamientos disruptivos. Estos comportamientos son habituales en niños con autismo, y muchas veces se deben a su hipersensibilidad. Por ejemplo, si son muy sensibles a los ruidos y a los sonidos en un volumen alto, es probable que lloren, chillen o incluso que pretendan salir corriendo del lugar donde se encuentren. Se trata de un aspecto muy relevante para las familias y que cuanto antes se comience a intervenir, mejores serán los resultados, por lo que Ingersoll & Dvortcsak (2006) y Coolican et al. (2010) lo proponen como objetivo. La diferencia es que este último especifica y divide el comportamiento disruptivo en: vocal (gritar, llorar), físico (golpear, empujar, dar patadas) y oral (morder, escupir), con intención de elaborar unos objetivos medibles para un posterior análisis estadístico.

Además de estos objetivos enfocados en la mitigación de algunos de los síntomas clave del autismo, los programas pretenden enseñar a los padres una serie de técnicas para lograrlo. De esta manera, se plantea un nuevo objetivo que es la formación de los padres. En el caso de Anan et al. (2008), se propone que los padres sean los principales terapeutas de sus hijos, mientras que Ingersoll & Dvortcsak (2006) plantean el inconveniente de es necesario que haya más profesionales en el ámbito del Trastorno del Espectro Autista que además tengan formación en educación de adultos.

Un aspecto muy relevante es el estrés de los padres, del cual se habla durante los resultados y la conclusión en función de cada programa, con la excepción del programa PEI. Se trata de uno de los dos programas elaborados por Kasari et al. (2015) cuyo objetivo es reducir el estrés de los padres mediante un modelo psicoeducativo.

Por último, un objetivo que plantean todos los programas excepto los de Ingersoll & Dvortcsak (2006) y Schertz & Odom (2007), es la generalización de lo aprendido por los padres a otros ámbitos y contextos, y la duración en el tiempo de los logros obtenidos.

En el siguiente cuadro aparecen de manera esquemática y visual los objetivos correspondientes a los distintos programas:

Cuadro 2: *Objetivos de los programas.*

Referencia bibliográfica	Objetivos
Anan et al. (2008)	Habilidades de comunicación, sociales y de juego y disminución de comportamientos disruptivos
Coolican et al. (2010)	Habilidades de comunicación, disminución de comportamientos disruptivos
Ingersoll & Dvortcsak (2006)	Habilidades de comunicación
Ingersoll & Gergans (2006)	Habilidades de imitación
Kasari et al. (2015)	Habilidades de juego y atención conjunta
Schertz & Odom (2007)	Atención conjunta

4.2 En función del enfoque o terapia

Todos los programas de intervención siguen al menos un enfoque o terapia para conseguir los objetivos propuestos.

El enfoque más empleado no solo para la atención temprana en autismo sino para la intervención en general en dicho trastorno es el conductual. Consiste en establecer una serie de objetivos que se deseen obtener, que deben ser medibles, y además se deben especificar lo máximo posible. El modelaje es clave en este enfoque, de manera que el experto realiza una estrategia determinada para la consecución del objetivo propuesto mientras la persona que desea aprender dicha estrategia observa (pueden ser padres o bien otros profesionales que deseen aprender). En el siguiente paso, es la persona que desea aprender la estrategia quien

la realiza, mientras que el experto es el que observa para corregir lo que crea conveniente. El enfoque o terapia conductual, dado que tiene un carácter muy estructurado y medible, y sus estrategias se pueden enseñar a otras personas, tiene la ventaja de que “se puede emplear y generalizar a cualquier contexto”, como Anan et al. (2008) especifican en su artículo (p. 166). Coolican et al. (2010) hablan de “intervención conductual temprana e intensiva” (p. 1321) mientras que Ingersoll & Dvortcsak (2006) denominan este enfoque como “técnicas directas” (p. 81), el cual explican que es compatible con otros enfoques pero que es el idóneo para tratar el lenguaje, la imitación y las habilidades de juego.

Skinner se dedicó al estudio de las conductas observables, de manera que estableció una serie de categorías que son la base del enfoque conductual que se emplea hoy en día. Las categorías que estableció Skinner son: contigüidad, condicionamiento clásico, condicionamiento operante y aprendizaje observacional. El condicionamiento operante en concreto está basado en el control de las consecuencias, dando que dependiendo de estas, una persona repetirá la acción o no en el futuro. De él surge el modelo de comportamiento organizacional, en el cual se tiene en cuenta la motivación de la persona y se basa en la medición y en la aplicación de incentivos. Este modelo está en relación con el enfoque naturalista en lo que a motivación se refiere, por lo que Kasari et al. (2015) lo emplean junto con el enfoque conductual para desarrollar la intervención en su programa JASPER.

En el enfoque naturalista, basado en la Teoría del Naturalismo de Rousseau, el educador debe identificar los intereses del niño y conseguir que este desarrolle sus capacidades innatas. Esto lo llevará a cabo no mediante actividades en contra de su voluntad sino mediante actividades basadas en sus intereses. En este caso el contexto es de primordial importancia, pues es donde se desarrolla el niño, y dada la edad de los niños en los programas de atención temprana, Ingersoll & Gergans (2006) consideran que es el mejor enfoque para llevar a cabo su programa.

Por último encontramos el enfoque evolutivo o de desarrollo, denominado por Ingersoll & Dvortcsak como “estrategias indirectas” (2006), basado en la interacción entre padres e hijo y que se emplea sobre todo para conseguir mejoras en la comunicación social del niño. El programa que utiliza este enfoque es el de Schertz & Odom (2007), los cuales establecen una serie de objetivos a conseguir pero no de una manera tan exhaustiva y precisa como en la terapia conductual, y en este caso no se

trata de objetivos medibles. Cuando ciertos comportamientos o habilidades ocurren, se aportan refuerzos estructurados.

Destacar que el programa PEI (Kasari et al., 2015) no sigue ninguno de estos enfoques dado que su principal objetivo es reducir el estrés de los padres, y lo clasifican como un programa psicoeducativo.

A continuación se muestra un cuadro que permite la comparación de los enfoques o terapias de cada uno de los programas de intervención temprana:

Cuadro 3: *Enfoque o terapia de los programas.*

Referencia bibliográfica	Enfoque o terapia
Anan et al. (2008)	Enfoque conductual
Coolican et al. (2010)	Enfoque conductual
Ingersoll & Dvortcsak (2006)	Enfoque conductual
Ingersoll & Gergans (2006)	Enfoque naturalista
Kasari et al. (2015)	JASPER: enfoques naturalista y conductual PEI: programa psicoeducativo
Schertz & Odom (2007)	Enfoque evolutivo

4.3 En función de diferentes elementos metodológicos del estudio

Los criterios de comparación en relación a la metodología de cada estudio, se han dividido en los siguientes elementos: duración del programa, número de familias involucradas, edad de los niños y requisitos de acceso al programa, instrumentos de evaluación, profesionales implicados, fases, características de las sesiones y estudio de los resultados cuantitativos y cualitativos.

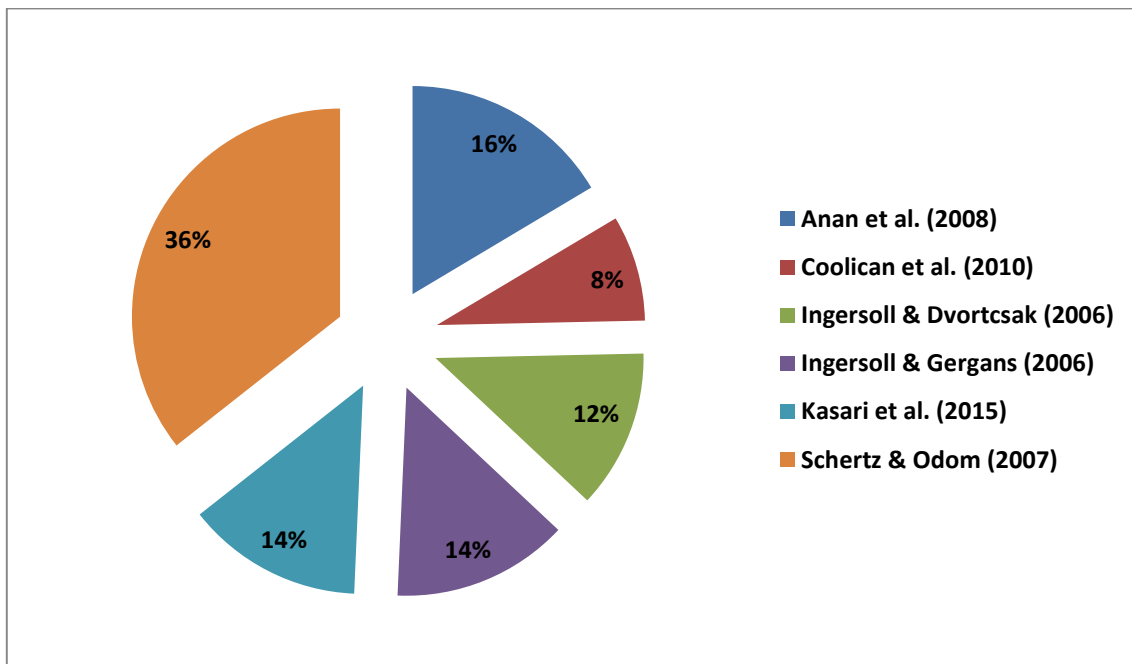
4.3.1. Duración del programa

Como normal general los programas duran en torno a 10 semanas, siendo el máximo 12 semanas. Sin embargo, hay dos excepciones que llaman la atención. La primera de ellas es el programa de Schertz & Odom (2007), puesto que se adapta a las demandas y necesidades de las familias. En este caso la duración varía, y en los datos registrados el mínimo de semanas que ha durado el programa ha sido de 9 mientras que el máximo han sido 26 semanas. La otra excepción corresponde al programa de Coolican et al. (2010), cuyo programa tiene una duración de tan solo 6

horas. Es la principal característica del programa, ya que tratan de aportar una solución a las largas listas de espera para los programas de atención temprana que hay en su país, Canadá, formando a los padres mediante un programa intensivo. En contra de este programa, Wallace & Rogers sugieren que “la intensidad del tratamiento, comenzando lo antes posible, con una larga duración, son elementos que contribuyen a una intervención más eficaz” (2010).

En el siguiente gráfico circular fraccionado se puede observar la proporción de tiempo que duran los distintos programas. Para aquellos programas que se adaptan a las características de las familias y por lo tanto varía su duración, se ha escogido para la realización del gráfico el máximo tiempo que especifican los autores.

Figura 3: Duración de los programas.



4.3.2. Número de familias involucradas y requisitos

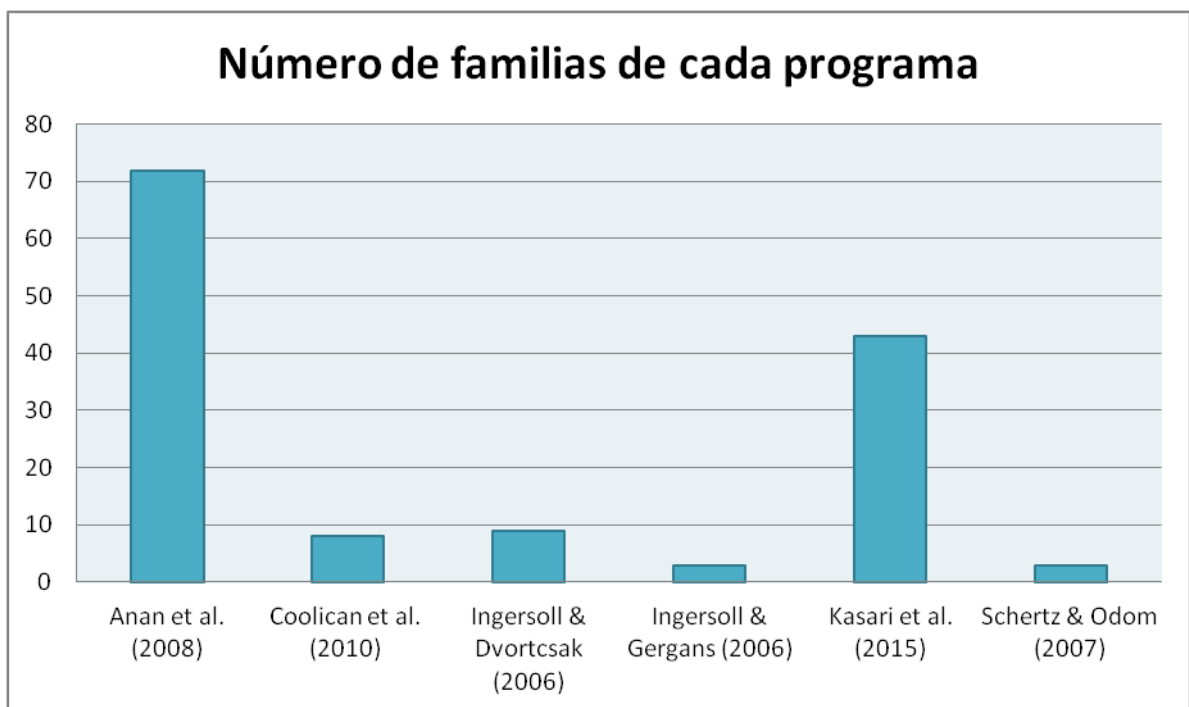
Existen programas que acogen un máximo de tres padres con sus respectivos hijos como el de Ingersoll & Gergans (2006) o el de Schertz & Odom (2007). Por el contrario, hay programas que acogen un número bastante mayor de familias, como el programa de Anan et al. (2008) que acoge hasta 72 familias o bien ambos programas de Kasari et al. JASPER y PEI (2015), que incluyen 43 familias cada uno de ellos. Los dos programas restantes están dirigidos a 9 familias (Ingersoll & Dvortcsak, 2006) y a 8 familias (Coolican et al., 2010).

El número de familias de cada programa ha dependido del alcance del mismo y de sus características, por lo que muchos de ellos comenzaron con un mayor número de familias involucradas que se fueron dando de baja.

En el caso de Coolican et al. (2010), se establecieron dos requisitos: que los padres debían tener un mínimo de estudios cursados y que no vivieran 30km o más lejos de la clínica. En ningún otro programa se han encontrado requisitos, incluso en aquellos en los que el número de familias es menor. Destaca el programa de Schertz & Odom (2007), con tan solo tres familias, en las cuales una madre había informado de que sufría depresión, otra de las madres tenía diagnosticada epilepsia, y la tercera de ellas había tenido una adicción a los narcóticos y en el momento de participar en el programa sufría de trastorno bipolar.

Se ha elaborado el siguiente gráfico de columnas apiladas para mostrar de manera visual el número de familias que han formado parte de los diferentes programas:

Figura 4: *Número de familias de cada programa.*



4.3.3. Edad de los niños y requisitos

Al tratarse de programas de Atención Temprana, la edad de los niños debe estar comprendida al menos entre el nacimiento del niño y los seis años como máximo. Encontramos programas en los que los niños que participan tienen entre un año y tres años, como es el caso de Schertz & Odom (2007) y de Kasari et al. (2015), mientras que otros programas amplían el rango de edad de los dos a los cinco años, como ocurre en los programas de Anan et al. (2008) y Coolican et al. (2010). Por último, con un menor rango de edad, encontramos el programa de Ingersoll & Dvortcsak (2006) que acepta niños que tengan entre tres y cuatro años.

El requisito más ampliamente aprobado por casi todos los programas es que los niños debían tener autismo previamente diagnosticado, pero en el programa de Schertz & Odom (2007) los niños habían mostrado indicios que durante el programa se confirmaron en un diagnóstico. Otro de los requisitos está en relación con la posible comorbilidad del Trastorno del Espectro Autista, en cuyo caso hay programas como el de Anan et al. (2008) que no ponían impedimento a aquellos niños con algún síndrome o trastorno asociado. Por el contrario, en ambos programas de Kasari et al. (2015), el requisito es que los niños no tuvieran ningún tipo de discapacidad física. Coolican et al. (2010) especifican que:

“las familias serían excluidas del programa en caso de que el niño estuviera recibiendo algún tipo de tratamiento conductual; y también en caso de que el niño tuviera alguna dificultad o trastorno sensorial, motor o neurológico (por ejemplo, problemas de vista sin corregir o pérdida de audición, o daño cerebral)” (p.1322).

4.3.4. Instrumentos de evaluación

Se han empleado instrumentos de evaluación para saber el grado de gravedad de autismo de cada niño. En algunos casos se han empleado escalas de diagnóstico como son el DSM-IV y el DSM-IV-TR (Anan et al., 2008; Coolican et al., 2010; Ingersoll & Gergans, 2006). Otras dos escalas que aparecen con frecuencia en estos programas son *Autism Diagnostic Observation Schedule (ADOS)* y *Autism Diagnostic Interview Revised (ADI-R)*. (Coolican et al., 2010; Kasari et al. 2015). De nuevo, una escala común entre algunos de los programas es la denominada *Childhood Autism Rating Scale (CARS)* cuya peculiaridad es que se emplea en niños de dos años o más, pero que permite conocer el grado de severidad de autismo.

Dos escalas que se utilizan para saber el grado de adaptabilidad y de desarrollo cognitivo de los niños, son *Vineland Adaptive Behavior Scales* y *Mullen Scales of Early Learning*. Ambas escalas han sido clave en los programas de Anan et al. (2008) y de Kasari et al. (2015), mientras que Ingersoll & Gergans (2006) han utilizado la escala *Bayley Scales of Development*, que mide el nivel de desarrollo cognitivo, psicomotor y comportamental del niño.

De manera más concreta, existe una escala que evalúa el grado de imitación de niños que ya tienen un diagnóstico en autismo, se llama *Motor Imitation Scale (MIS)*. Otra escala también más específica, en este caso del lenguaje, es *MacArthur-Bates Communicative Development Inventory (CDI)*, que junto con la escala anterior, han sido la base del programa de Ingersoll & Gergans (2006).

El programa que se centra en la atención conjunta (Schertz & Odom, 2007), como se especificaba en el apartado anterior, no exigían como requisito que los niños tuvieran un diagnóstico previo, por lo que se emplearon cuestionarios de cribado mediante los cuales se identifican algunos de los síntomas. Estas pruebas se denominan *Modified Checklist for Autism in Toddlers (M-CHAT)* y deben ser realizadas por pediatras. Otras pruebas de esta índole también empleadas en el mismo programa son *Infant Social-Communication Questionnaire (ISCQ)* y *Pervasive developmental disorders screening test-II (PDD-ST-II)*.

La importancia de ejecutar estas pruebas reside en conocer la situación de los niños en el momento inicial del programa, para luego al finalizarlo volverlas a realizar y comprobar si se han producido mejoras o no y, en caso afirmativo, saber en qué aspectos. El único programa que no ha empleado ningún instrumento de evaluación ha sido el de Ingersoll & Dvortcsak (2006).

Para que estas pruebas sean eficaces, lo ideal es que se encargue de realizarlas un experto que sea ajeno a los niños y a sus familias, y que no conozca previamente los síntomas. De esta manera se evitan expectativas o ideas preconcebidas que puedan afectar al resultado final de las pruebas. Esto requiere la presencia de un mayor número de profesionales, por lo que no puede llevarse a cabo en todos los programas. En el artículo de Anan et al., se explica que un “factor que limita el programa es que los examinadores no eran ajenos al estado de los niños antes y después de la intervención” (2008).

En el siguiente cuadro aparecen las escalas que se han empleado junto con los programas de intervención en atención temprana:

Cuadro 4: Escalas de evaluación empleadas

	Anan et al. (2008)	Coolican et al. (2010)	Ingersoll & Dvortcsak (2006)	Ingersoll & Gergans (2006)	Kasari et al. (2015)	Schertz & Odom (2007)
DSM-IV y DSM-IV-TR		X	X	X		
ADOS			X			X
ADI-R			X			X
CARS				X	X	
Vineland Adaptive Behavior Scales		X				
Mullen Scales of Early Learning		X				X
Bayley Scales of Development				X		
MIS				X		
CDI				X		
M-CHAT					X	
ISCQ					X	
PDD-ST-II					X	

Los instrumentos de evaluación no solo se han empleado para los niños, también se han realizado test y cuestionarios a los padres e incluso a algunos de los profesionales que han formado parte del programa de intervención. Ingersoll & Dvortcsak (2006) además de realizar una encuesta de satisfacción a los padres, realizaron otra a los profesionales implicados. Coolican et al. (2010) quisieron evaluar también el grado de eficacia que sentían los padres sobre ellos mismos mediante la escala *Parental Self-Efficacy Scale*, y Kasari et al. (2015) se han centrado en el nivel de estrés de los padres, empleando la escala *Parenting Stress Index*. Dos de los seis

programas no han empleado ningún tipo de instrumento de evaluación a los padres (Anan et al., 2008; Schertz & Odom, 2006).

Por último, un instrumento de evaluación empleado para ambos, niños y padres, son las grabaciones de vídeo. Su uso es muy frecuente en las situaciones en las que los padres, sin la presencia del experto, deben poner en práctica con sus hijos y en su casa las estrategias que han aprendido. Esto permite a los profesionales evaluar si los padres han aprendido las estrategias, si las llevan a cabo correctamente, y si el niño responde de manera efectiva. Además, también son beneficiosas para que en reuniones o sesiones posteriores, los profesionales puedan aportar críticas constructivas a los padres.

4.3.5. Profesionales implicados en el programa

En general los profesionales implicados en los distintos programas son bastante dispares. En todos ellos hay expertos en autismo, pero cada uno trabaja con distintos profesionales. En el programa de Anan et al. (2008) encontramos que hay cuatro pediatras especializados en desarrollo conductual que se encargan de llevar a cabo el programa, y en el programa de Schertz & Odom (2007) son los pediatras los que se encargan de realizar las pruebas *M-CHAT*, pero el grueso del programa lo llevan investigadores en autismo. En los programas de Kasari et al. (2015), un psicólogo y ocho terapeutas especializados en psicología del desarrollo son los encargados de la intervención y de la recolección y análisis de datos, mientras que en el programa de Ingersoll & Gergans (2006), además de la investigadora experta en autismo, trabajan dos profesionales especializados en recolección y análisis de datos estadísticos.

Uno de los instrumentos de evaluación, como se especificaba anteriormente, son las grabaciones de vídeo, las cuales hay que codificar para poderlas analizar. Para ello hay profesionales tanto en el programa de Coolican et al. (2010) como en el de Schertz & Odom (2007) que se encargan tanto de la codificación como de la grabación de vídeo, y su posterior análisis.

Destaca el programa de Ingersoll & Dvortcsak (2006), en el que trabajan en conjunto dos profesores de educación especial en atención temprana, un logopeda, un terapeuta ocupacional y, por último, un especialista en autismo.

En el siguiente gráfico aparece la distribución de profesionales según cada programa:

Figura 5: *Distribución de expertos en función de los programas.*

4.3.6. Fases del programa

Existen al menos cuatro fases generales a todos los programas:

- a) Selección de los participantes, durante la cual se realizan las pruebas pertinentes.
- b) Intervención, que puede estar enfocada a la formación teórica de los padres, o a la puesta en práctica con sus hijos.
- c) Periodo de seguimiento, dado que la finalidad es que las mejoras obtenidas durante la intervención se prolonguen en el tiempo, suele haber un periodo de seguimiento durante el cual se resuelven dudas.
- d) Resultados, una vez finalizado el periodo de seguimiento, se procede a analizar los datos que se han ido recogiendo y se vuelven a realizar las pruebas pertinentes para comprobar si ha habido alguna mejora en el niño.

Durante la segunda fase, la intervención, hay programas que han elaborado una estructura en función de las características y objetivo principal del mismo. Schertz & Odom (2007) establecen cuatro fases para lograr su objetivo de la atención conjunta: fijarse en las caras, capacidad de seguir los turnos, responder a la atención conjunta e

iniciar la atención conjunta. Por otro lado, Ingersoll & Gergans (2006) dividen la intervención en tres fases: incremento en la reciprocidad, incremento en la imitación con objetos e incremento en la imitación de gestos, de manera que al pasar de una fase a otra se continúe trabajando con las técnicas de la anterior, para finalmente conseguir una mejora general en la imitación.

En el programa de Anan et al. (2008), la intervención se ha dividido por meses. Durante el primer mes, los expertos realizaban las técnicas mientras que los padres observaban para luego hacerlo a la inversa, y así los expertos podían aportar críticas constructivas. Durante el segundo mes, los padres llevaban a cabo las técnicas aprendidas con distintos niños del programa. El tercer y último mes, los padres debían llevar a algún familiar para enseñarle las distintas técnicas y cómo aplicarlas.

Ingersoll & Dvortcsak (2006) elaboraron una programación a lo largo de 9 semanas, que es lo que dura la intervención, especificando por cada sesión lo que se iba a trabajar en cada una de ellas. La peculiaridad de este programa es que los profesores de educación especial no tenían formación en educación de adultos, por lo que los expertos en autismo primero se enfocan en enseñarles las estrategias básicas que se van a llevar a cabo en el programa, y así puedan generalizarlas a otras situaciones y programas en un futuro.

En cuanto al periodo de seguimiento, cada programa lo establece de una manera distinta. Wallace & Rogers (2010), como resultado de su revisión bibliográfica, establecen que tanto la intensidad del tratamiento como su duración, son factores relevantes a la hora de comprobar la eficacia del mismo, por lo que alargar la intervención mediante un periodo de seguimiento es una alternativa que utilizan algunos programas. Hay dos de ellos que no llevan a cabo periodo de seguimiento, que son el de Ingersoll & Dvortcsak (2006) y el de Schertz & Odom (2007). El periodo de seguimiento de Kasari et al. (2015) consiste en la observación en la clase de los niños, mientras que el de Anan et al. (2008) consiste en una serie de grabaciones realizadas en la casa de los niños, recogiendo las estrategias llevadas a cabo por los padres en situaciones cotidianas. Ingersoll & Gergans (2006) optaron por un periodo de seguimiento de un mes durante el cual se establecieron reuniones entre los expertos y los padres para responder dudas, y Coolican et al. (2010) siguen la misma estructura pero la alargan de 2 a 4 meses, en función de las necesidades de cada familia.

4.3.7. Características de las sesiones

La duración de las sesiones es como máximo de una hora, exceptuando el programa de Coolican et al. (2010), en el cual las sesiones tienen una duración de dos horas. En general, la duración depende en mayor medida de si en las sesiones están presentes los niños, en cuyo caso duran menos tiempo, o de si están solo los padres. Por ejemplo, en los programas de Kasari et al. (2015), JASPER tiene sesiones de media hora en las que los padres ponen en práctica las estrategias aprendidas con sus hijos, mientras que PEI está enfocado únicamente a los padres y las sesiones duran una hora.

La duración también depende de si las sesiones son individuales o grupales. Hay programas que optan por sesiones individuales únicamente, como es el caso de Ingersoll & Gergans (2006), mientras que hay programas que mezclan ambas modalidades. Ingersoll & Dvortcsak (2006) han estructurado su programa en nueve sesiones, de las cuales seis son grupales y duran una hora, y las tres restantes son individuales con una duración de 45 minutos. En el caso del programa de Coolican et al. (2010), cuya principal característica es su breve duración, seis horas, se trata de sesiones individuales intensivas de dos horas cada una.

Otra característica relevante de las sesiones, es el lugar donde éstas se realizan. Hay autores como Wallace & Rogers que indican que el lugar apropiado es “en casa del de niño, con su familia, centrándose en sus necesidades de desarrollo, de manera sensible, siendo receptivo del estilo de interacción padres-hijo y ofreciendo apoyo a las familias” (2010). Sin embargo no todos los programas sitúan su intervención en las casas sino que lo hacen en sus instalaciones (laboratorios, clínicas, etc.) o a veces combinan ambas modalidades. Coolican et al. (2010) realizan dos de las tres sesiones en su laboratorio durante las cuales enseñan a los padres las estrategias y las realizan con sus hijos, los cuales también acuden, y la última sesión se realiza en la casa de las familias con la intención de aprender a generalizar lo aprendido en el laboratorio a otros contextos. El programa de Anan et al. (2008) se desarrolla en el hospital al que pertenecen los pediatras que dirigen la intervención, pero en el último mes se realizan grabaciones de los padres empleando las técnicas en sus casas que luego los expertos analizan para aportar críticas constructivas y seguir trabajando con las familias. En el caso de Ingersoll & Gergans (2006), se disponía de una sala con un cristal especial a través del cual las sesiones eran grabadas en vídeo. Por el contrario, programas como el de Schertz & Odom (2007) se desarrollan por completo en las

casas de las familias, adaptándose a sus necesidades, por lo que la duración de las sesiones es variable, al igual que ocurre con la duración del programa, que con algunas familias se ha desarrollado a lo largo de 9 semanas mientras que con otras familias ha durado hasta 26 semanas.

Estas características están relacionadas con el enfoque de cada programa y su metodología. En algunos casos se prefiere impartir unas sesiones teóricas, explicando las técnicas, los principios básicos del enfoque e incluso ciertos aspectos sobre el Trastorno del Espectro Autista. Para ello, algunos programas optan por facilitar a las familias un manual como hicieron Schertz & Odom (2007) con el manual *Joint Attention Mediated Learning (JAML) Parent Manual* elaborado por ellos mismos en el año 2005 y que no está publicado. Coolican et al. (2010) también optan por emplear un manual, escrito por R. L. Koegel en 1989 cuyo título es *How to teach pivotal behaviors to children with autism: A training manual*.

Otros autores prefieren comenzar directamente con la práctica, lo que en inglés denominan *hands-on*, como ocurre en el programa de Ingersoll & Gergans (2006), dividido en tres fases enfocadas en mejorar las habilidades de imitación, durante las cuales se enseñan las técnicas a seguir de una manera completamente práctica. Las investigadoras realizan la técnica o estrategia mientras los padres observan, y luego cambian los roles.

Para concluir con las características de las sesiones, se adjuntan dos gráficos a continuación. El primero de ellos muestra la relación entre la cantidad de sesiones grupales e individuales, y el segundo muestra la relación entre los programas que realizan las sesiones en las casas de las familias o bien en su clínica o laboratorio.

Figura 6: Sesiones individuales y grupales.

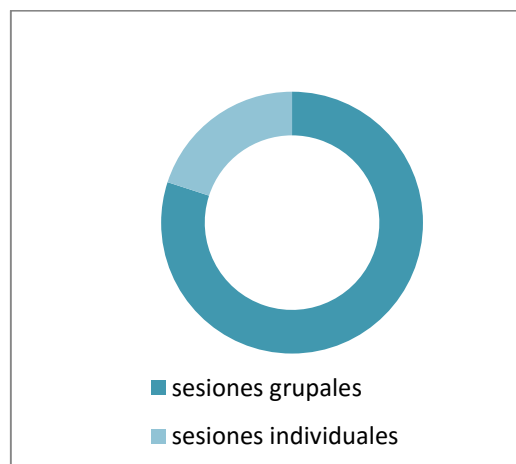
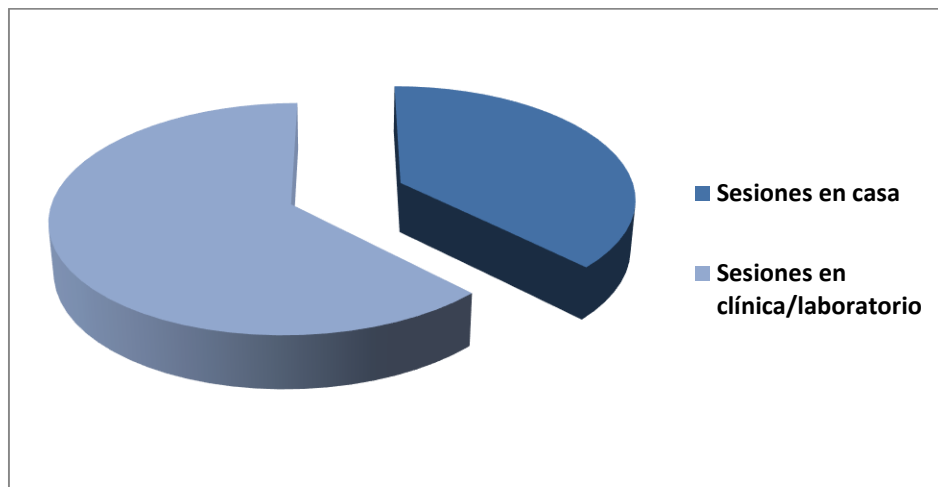


Figura 7: Sesiones en casa y en la clínica/laboratorio.

4.3.8 Resultados cuantitativos y cualitativos

Dado que la mitad de los programas han escogido una terapia conductual, con objetivos medibles, los resultados se han obtenido de manera cuantitativa empleando técnicas estadísticas. Para ello, la codificación de las grabaciones de vídeo ha sido primordial, por lo que algunos estudios, como se indica en el punto 4.3.5, disponen de uno o más profesionales encargados de la codificación y el análisis posterior. Tanto en el programa de Ingersoll & Gergans (2006) como en el de Schertz & Odom (2007), los datos cuantitativos se han basado por completo en la codificación de los vídeos. En el primero de ellos, los resultados se muestran de manera más exhaustiva, por fases y con el apoyo visual de gráficos, además de explicar el uso de la r de Pearson y la k de Cohen's Kappa en el proceso de obtención de los resultados. En el caso de JASPER (Kasari et al., 2015), cuyo enfoque es tanto naturalista como conductual, el análisis de los resultados se ha obtenido en base a la recogida de datos desde el punto de vista conductual, midiendo la frecuencia y duración de los efectos de las técnicas empleadas durante la fase de la intervención y el periodo de seguimiento. De esta manera, los resultados han sido clasificados en primarios y secundarios. Coolican et al. (2010) también han hecho un uso exhaustivo de la estadística, empleando entre otros métodos la correlación de Spearman para evaluar la relación entre los cambios en la confianza de los padres en ellos mismos y los cambios en la comunicación del niño.

Por otro lado Anan et al. (2008), han medido los resultados de la intervención realizando dos de las tres pruebas que emplearon al comienzo del programa. Éstas

son: *Mullen Scales of Early Learning* y *Vineland Adaptive Behavior Scales*. La finalidad es comprobar si los resultados de las pruebas han cambiado al realizar la intervención y el uso de estas escalas es muy útil para conseguirlo. La primera de ellas es eficaz en la percepción de los cambios en el lenguaje y en la inteligencia, además ambas poseen una consistencia interna que aporta fiabilidad a los investigadores y se dividen en subescalas permitiendo así un análisis más profundo.

Ingersoll & Dvortcsak (2006) proponen un programa más enfocado a la formación de los padres en técnicas y estrategias y no tanto a la mejora del niño como tal, aunque el objetivo final de toda intervención sea eso, por lo que la elaboración de los resultados va encaminada a tal aspecto. Se elaboraron unos cuestionarios que miden el conocimiento de los padres sobre las técnicas que realizaron antes y después de la intervención, de manera que se pudieran comparar los resultados y llegar así a unas conclusiones.

El análisis cualitativo también se ha realizado en programas que han empleado estadísticas, como por ejemplo Coolican et al. (2010), que se han basado en las notas de los padres sobre el proceso y las mejoras de sus hijos que han visto a lo largo del tratamiento en su casa. Schertz & Odon (2007) planificaron una serie de reuniones entre los padres y un investigador durante las cuales los padres aportaban su opinión y comentaban los cambios de su hijo. Estos comentarios se emplearon para elaborar resultados de forma cualitativa sobre la calidad de la intervención.

Con la finalidad de comparar entre los estudios que siguen una elaboración de los resultados de manera cuantitativa o bien de forma cualitativa, se adjunta el siguiente cuadro:

Cuadro 5: *Resultados cuantitativos y cualitativos.*

RESULTADOS	Anan et al. (2008)	Coolican et al. (2010)	Ingersoll & Dvortcsak (2006)	Ingersoll & Gergans (2006)	Kasari et al. (2015)	Schertz & Odom (2007)
Cuantitativos/estadísticos		X	X	X	X	X
Cualitativos/análisis de contenido	X		X		X	

Un elemento al que todos los programas le han dado especial importancia es la satisfacción de los padres, por lo que se han elaborado cuestionarios que se han realizado al finalizar la intervención o incluso después del periodo de seguimiento, en función de cada programa. Ingersoll & Dvortcsak (2006), elaboraron también un

cuestionario de satisfacción para los profesores, ya que además de formar a los padres, también formaron a dos profesores de educación especial en técnicas conductuales dirigidas a niños con autismo.

En términos generales, los resultados de todos los programas han sido positivos. Continuando con el ejemplo del programa anterior, el conocimiento de los padres aumentó de un 29% a un 75%, y la satisfacción tanto de los padres como de los profesores resultó ser positiva. En el caso de Anan et al. (2008) se comprobó la equivalencia en edad de desarrollo del niño (no cronológica), aumentando de los 43.3 meses obtenidos al principio del programa hasta los 47.5 meses obtenidos después de la intervención.

Puntualizar que, sin embargo, Coolican et al. (2010) en su estudio estadístico no encontraron una correlación significativa entre la confianza de los padres en sí mismos y los cambios en la comunicación de su hijo. En ninguno de los programas se han encontrado datos negativos ni ningún tipo de retroceso en el comportamiento y habilidades de los niños, pero sí que hay ciertos aspectos en los cuales no se han obtenido mejoras. Por ejemplo, en el programa de Schertz & Odom (2007), uno de los niños mejoró únicamente en una de las cuatro fases propuestas, mientras que los otros dos niños mejoraron con distinta intensidad dependiendo de cada fase.

4.4 Discusión de resultados y avances en el conocimiento de la implicación de las familias en la intervención de atención temprana

Uno de los puntos más frecuentes en la discusión de los programas, son los niveles de estrés que sufren los padres y también los niños. Recibir un diagnóstico en autismo es algo que causa estrés en las familias, por ejemplo, Schertz & Odom puntualizan que “a lo largo del curso de la intervención, dos maridos dejaron sus familias, algo que ambas mujeres atribuyeron al estrés de tener un hijo con autismo” (2007). En el caso concreto de ese programa, los niños comenzaron la intervención sin un diagnóstico firme de autismo, algo que luego recibieron durante el proceso, por lo que los autores pudieron recoger ese tipo de datos. A esto hay que sumarle que el hecho de que los padres se conviertan en terapeutas de sus hijos es algo que puede aumentar más aún esos niveles de estrés, por lo que Kasari et al. (2015), mediante su programa psicoeducativo PEI consiguieron reducir los niveles de estrés. Además, según Flippin & Crais, “unos niveles altos de estrés han demostrado reducir la efectividad de la intervención temprana para niños con autismo” (2011). El estrés no

es algo que afecte únicamente a los padres, Matson et al. (2009) en su revisión bibliográfica indican que los niños con autismo también sufren altos niveles de estrés. Explican que las deficiencias en las habilidades sociales están particularmente ligadas al estrés, por lo que sugieren que tratar las habilidades sociales desde los programas de atención temprana es algo positivo. Dado que los padres son el factor clave de estos programas, buscar los medios para regular los niveles de estrés o para que al menos los mismos programas no lo incrementen es un aspecto fundamental. Schertz & Odom indican que “la atención a las preocupaciones de las familias puede jugar un papel importante en una intervención basada en la implicación de los padres” (p. 1572, 2007).

La formación de los padres es otro de los aspectos frecuentes tratados en los distintos programas. Puesto que la intención es que aprendan las técnicas correctamente para poderlas emplear con sus hijos en cualquier contexto y situación, la manera en que se enseñan las técnicas es de vital importancia. Ingersoll & Dvortcsak afirman que “unos modelos óptimos de educación de padres significa un incremento en el conocimiento de los padres” (p. 86, 2006). Schertz & Odom (2007) abordan el tema desde el punto de vista del experto o investigador, ya que recae en él la responsabilidad de elaborar situaciones de aprendizaje durante las cuales transmitir sus conocimientos de una manera adecuada y accesible para los padres. También indican que el experto debe apoyar a los padres y debe reconocer y afirmar su competencia. Wallace & Rogers (2010) diferencian dos modelos de educación para padres. El primero de ellos consiste en un modelo más teórico, que puede darse en sesiones grupales e individuales, y durante el cual no tiene por qué estar el niño presente. El segundo modelo está basado en el *coaching* y pretende ser completamente práctico e individualizado a cada caso. Siguiendo ambos modelos, Kasari et al. (2015) crearon PEI, un programa basado en el primer modelo propuesto, y JASPER, desde un punto de vista más cercano al *coaching*. Los autores de ambos modelos indican que se consiguieron mejoras significativas en la comunicación y habilidades sociales en los niños que, aleatoriamente, formaron parte de JASPER.

El contexto en el cual se lleva a cabo la intervención se convierte en un elemento que puede jugar a favor o en contra cuando el tratamiento es para niños con Trastorno del Espectro Autista. Es por esto que a la hora de plantear y estructurar el programa hay que tener en cuenta el lugar donde se van a realizar las sesiones, y va a depender en gran medida del tipo de formación que se vaya a impartir. También depende del

material que se necesite, dado que a veces se emplea material fotográfico y de grabación, o juguetes que pretenden estimular ciertas habilidades. En algunos casos se preparan salas con juguetes u objetos estratégicamente situados en determinados lugares con la finalidad de medir las reacciones del niño. Sin embargo, como se trata de programas en los cuales son los padres los que deben llevar a cabo las estrategias, y además interesa generalizar las estrategias en distintas situaciones y contextos (Schertz & Odom, 2007), enseñarlas en las propias casas de los padres tiende a ser lo más empleado. La idea es introducir las técnicas y estrategias en las rutinas diarias de los niños para conseguir unos mayores resultados, por lo que sacarlos de su contexto habitual no parece lo más apropiado. Wallace y Rogers hablan del éxito de los modelos de “visitas a casa” donde el apoyo por parte del experto es fundamental (2010). Matson et al.(2009) sugieren además que establecer unas reuniones posteriores a la intervención de manera periódica es de utilidad a la hora de mantener las habilidades adquiridas por los padres.

Otro objeto de discusión es la definición de los objetivos. Esto se puede realizar a través de dos puntos de vista, uno más amplio que recoge múltiples objetivos y otro enfocado a la consecución de uno o dos objetivos como máximo. Este es un aspecto al que Wallace y Rogers (2010) otorgan mucha importancia dado que aseguran que centrarse en uno o dos objetivos resulta en una consecuente mejora en otras áreas de desarrollo del niño. Siguiendo esta idea, los programas de Ingersoll & Dvortcsak (2006), Ingersoll & Gergans (2006) y Schertz & Odom (2007) establecen un único objetivo a conseguir y además hacen hincapié en que la consecución de ese objetivo será beneficioso a la hora de desarrollar otros aspectos o deficiencias del niño con autismo. Por el contrario, el programa de Anan et al. (2008) propone hasta cuatro objetivos a conseguir mediante un único programa, siendo los resultados a corto plazo positivos. Se trata de un aspecto para el que hoy en día no se tiene una respuesta clara, pero parece ser que los programas tienden a establecer sus objetivos desde un punto de vista más reducido, eligiendo uno o dos síntomas o deficiencias para la intervención.

Por último, todos los programas se han encontrado con distintos inconvenientes. El más frecuente, es la participación de los padres, y es que muchos comienzan el programa pero lo van dejando. Esto puede deberse a distintas causas, pero una de ellas es la cantidad de tiempo que emplean los padres en el programa, de manera que Coolican et al. (2010) proponen un programa intensivo de seis horas, aunque la mayor

parte de los programas tienen una duración de cerca de 10 semanas. Otro motivo es que los padres han recibido recientemente el diagnóstico de su hijo ya que se trata de programas de atención temprana y los niños son aún muy pequeños. Para solventar esto, la idea que proponen algunos autores como Kasari et al. (2015) mediante su programa PEI, es que los padres dispongan de la ayuda y el apoyo de profesionales en el campo del autismo, capaces de resolver sus dudas e inquietudes sobre el trastorno. Otro inconveniente que hay en común entre los programas son los costes que deben afrontar las familias. Hay que situar los programas en su contexto, y cinco de ellos se han llevado a cabo en Estados Unidos y tienen un carácter privado. Anan et al. (2008) aportan datos sobre los costes del programa, que asciende a 6500\$ en total, por lo que no todas las familias pueden permitírselo. El último de los inconvenientes encontrados en los programas, es propio de aquellos en los que los padres se tienen que desplazar hasta la clínica o laboratorio para llevar a cabo la intervención. Esto, explican los distintos autores, no está al alcance de todas las familias e incluso en algunos casos como en Coolican et al. (2010) se ha considerado como criterio de exclusión que aquellas familias que vivieran a 30km de distancia o más de de la clínica no podían acceder al estudio, dado el riesgo de dejar el programa sin finalizar.

En conclusión, la revisión de los nueve documentos permite observar los avances que se están consiguiendo en los últimos diez años y la línea que se está siguiendo. Cada vez con más frecuencia, los programas que incluyen la implicación de los padres y que están dirigidos a niños con autismo, se llevan a cabo en sus propios hogares, algo que ha demostrado científicamente ser beneficioso no solo para el niño sino también para la familia. Además, la existencia de programas dirigidos a apoyar y ayudar a las familias se trata de un gran avance, pues se sabe que un diagnóstico en Trastorno del Espectro Autista es difícil de afrontar y supone muchos retos. Sin embargo, aún queda mucho en lo que avanzar, como los inconvenientes comentados anteriormente o la formación de adultos. La formación, tanto de adultos como de niños, adolescentes y jóvenes, es una función que pertenece al campo de la Pedagogía y que por tanto, es un punto de partida de la figura del pedagogo dentro del ámbito del Trastorno del Espectro Autista.

4.5 Grado de Innovación en los estudios analizados

En lo que a innovación se refiere, destaca el programa de Coolican et al. (2010) que ha intentado dar respuesta a un problema de su sociedad, las largas listas de

espera a las que se ven sometidos los niños con autismo y sus familias para poder recibir un tratamiento de atención temprana. Para ello, elaboraron un programa intensivo de tan solo seis horas de duración que obtuvo unos resultados positivos a corto plazo, como mejoras en la comunicación y en el lenguaje de los niños. Sin embargo, no hubo disminución de los comportamientos disruptivos, a pesar de lo cual los padres valoraron positivamente el programa con nueve puntos sobre diez.

Otro programa que llevó a cabo un aspecto novedoso aunque arriesgado, es el de Schertz & Odom (2007), ya que se adaptaron por completo a las necesidades de cada familia. Para poder llevar a cabo esto, solo acogieron a tres familias en el programa, según las cuales adaptaron la duración de la intervención, además de realizarla en sus casas. De hecho, con la finalidad de generalizar las técnicas aprendidas por los padres, durante el periodo de seguimiento los profesionales apoyaron a los padres para realizar las técnicas en otros entornos como por ejemplo en restaurantes. En términos generales, los resultados del estudio han sido positivos.

Un elemento que se echa en falta en los programas, como destacan Wallace y Rogers (2010), es la inclusión de las nuevas tecnologías como recurso de apoyo a conseguir los objetivos propuestos pero también como apoyo a las familias. Las TICs tienen múltiples usos y pueden ser una ventaja y servir de ayuda a la hora de desarrollar cualquier programa, además de que vivimos en una sociedad que está inmersa en las nuevas tecnologías. Sin embargo, incluir las TICs en los programas de intervención requiere de profesionales especializados, por lo que investigar a cerca de este tema sería beneficioso para el Trastorno del Espectro Autista.

Finalmente, destacar que los programas de atención temprana que incluyen la participación de los padres son algo relativamente común en algunos países como Estados Unidos y Canadá. Sin embargo, en España no es algo que esté tan extendido, por lo que es de esperar que la investigación en este campo lleve a su inclusión en este país, dados los resultados positivos de los programas en esta revisión analizados y la importancia que se ha demostrado que tiene el incluir a los padres en la intervención.

Cap. 5. CONCLUSIONES

Nos encontramos ante un trastorno generalizado del desarrollo, que afecta a muchos aspectos evolutivos del niño, pero más concretamente al ámbito de la comunicación y la interacción social. En términos generales se trata de un gran desconocido, pues aunque muchos hayan oído hablar de él, no saben en qué consiste y cuáles son sus principales características. Indagando en esto último, se puede descubrir que realmente es un trastorno muy heterogéneo, dentro del cual es muy difícil establecer unos criterios de intervención válidos para todos los niños y que, además, no afecta solo al niño sino también a su familia. El modo de vida que conocían los padres cambia cuando llega el diagnóstico, y no se trata de algo transitorio sino que es un trastorno crónico que no tiene cura. A pesar de las características propias de cada niño y de su familia, existen una serie de criterios para la intervención. Muchos expertos en autismo hacen especial hincapié en la implicación de las familias en el tratamiento de los niños con autismo, y de hecho especifican que debe ser un componente de todo programa de atención temprana. Algunos plantean incluso que sean los propios padres los principales terapeutas de su hijo. Esto me llevó a preguntarme si realmente se trata de algo que ocurre con frecuencia, lo cual es la pregunta con la que surgió esta revisión sistemática.

Mediante los resultados obtenidos en la revisión sistemática, efectivamente existen programas de atención temprana que cuentan con una amplia participación de las familias pero sin embargo, todos esos programas han sido encontrados en Estados Unidos y en Canadá. En el proceso de búsqueda de documentos científicos, se realizó una búsqueda exhaustiva de documentos en español, no únicamente de programas llevados a cabo, sino también revisiones sistemáticas y otros artículos que hablaran de la evidencia de la participación de los padres. Como resultado, no se encontró ningún documento relevante al respecto, lo que me lleva a pensar que es algo que en España no es algo que esté muy extendido, y que si en algún momento se han llevado a cabo este tipo de intervenciones, no se han divulgado mediante revistas científicas o libros.

En cuanto a si es algo frecuente o no, los programas de intervención encontrados en Norteamérica se muestran como algo innovador sobre lo que todavía hay que investigar y seguir mejorando, por lo que no parece estar implantado por completo pero sí que existen numerosos programas y revisiones sistemáticas, por lo que tampoco es algo que sea extraordinario o fuera de lo común. Esto lleva a la

segunda pregunta planteada, que son los tipos o modalidades de implicación de las familias en la intervención. No se ha encontrado evidencia de que existan modelos claramente elaborados y descritos, sino que cada programa se ha ajustado a las necesidades y características del entorno en el cual se ha llevado a cabo. Hay programas cuya finalidad es la formación de los padres, ya que como explicaba anteriormente, su idea es que los padres se conviertan en terapeutas. Sin embargo hay otros programas que se basan en dar un apoyo a los padres y resolver sus dudas en torno al autismo, a la par que les enseñan aspectos clave sobre modificación de conducta. De hecho, no existen evidencias científicas del enfoque o teoría que sería más conveniente a la hora de involucrar a los padres en estos programas (conductual, de desarrollo, naturalista o basado en el entorno), ni de las características de las sesiones (individuales o grupales, volumen). Existe una tendencia que indica que es mejor llevar a cabo este tipo de programas en las casas de los niños, pero no siempre puede llevarse a cabo. Un elemento de discusión es el establecimiento de los objetivos del programa, pues aún a día de hoy no está claro si es mejor proponer unos objetivos amplios o si, por el contrario, lo indicado es centrarse en los mínimos objetivos posibles, esperando que al mejorar estos, repercuta en otros aspectos.

En definitiva, no parece haber unos modelos establecidos para la participación de las familias en la intervención temprana, sin embargo hay una serie de elementos en los que todos están de acuerdo. Por ejemplo, la importancia de individualizar el programa, la intensidad de este, el comenzar lo antes posible y la imprescindible evaluación del mismo. De la misma manera, todos se proponen la implicación de las familias como algo primordial, y aportan argumentos como que el tratamiento es más efectivo cuando los padres forman parte de este de manera activa. Sin embargo, y dado que propuso analizar distintos programas, surgió la duda de si realmente los resultados son significativos o no. Se trata de una pregunta que se debe responder mediante el meta-análisis, lo cual no es el objetivo de este trabajo, por lo que al menos se ha querido analizar detalladamente los resultados de cada programa y compararlos. Así es como se descubre que aunque todos ellos muestran resultados positivos, para algunos de los objetivos propuestos los resultados obtenidos no son concluyentes dado que no se ha encontrado mejora alguna.

La última pregunta planteada es si, además de los resultados beneficiosos de la intervención temprana con la implicación de las familias, existen también inconvenientes o factores negativos. Un aspecto común a todos los documentos aquí

revisados, es el estrés que sufren los padres bien sea por el diagnóstico o por los cambios en la forma de vida que conlleva el autismo. Pero también han demostrado algunos resultados que es la propia implicación de los padres en el programa la que aumenta el nivel de estrés, ya que se trata de programas intensivos y que para muchos padres suponen un desafío. Por lo tanto, uno de los factores negativos de la inclusión de las familias en el tratamiento es el aumento de su nivel de estrés. De esta manera, uno de los programas cuyo objetivo principal es disminuir el estrés que sufren las familias, obtuvo resultados positivos, por lo que podemos hablar de un inconveniente para el que existe una posible solución.

A modo de conclusión, se podría decir que los programas de Atención Temprana que incluyen la participación de las familias son relativamente frecuentes en algunos países como Estados Unidos y Canadá, pero que sin embargo es algo que en España no parece estar implantado al mismo nivel. En cualquier caso, aún es necesario desarrollar más programas de este tipo y aumentar la investigación acerca de los componentes de los programas para poder crear en un futuro lo que podríamos llamar «modalidades» dentro de la implicación de los padres, y también para encontrar la forma de disminuir ese aspecto negativo que es el estrés.

De lo que no cabe duda alguna, es que las familias son un componente de la intervención temprana que debe participar de alguna manera, ya que ha demostrado tener efectos positivos, además de que les ayuda a elevar su percepción de auto-eficacia y, por tanto, serán más capaces de lidiar con las adversidades que puede provocar el tener un hijo con Trastorno del Espectro Autista.

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ANEXOS

Anexo I: Anan, R. M., Warner, L. J., McGillivray, J. E., Chong, I. M., & Hines, S. J. (2008). Group Intensive Family Training (GIFT) for preschoolers with autism spectrum disorders. *Behavioral Interventions*, 23(3), 165–180. Índice de impacto: JCR (Journal Citation Reports) 2014: 1.409.

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Anexo I

Anan, R. M., Warner, L. J., McGillivray, J. E., Chong, I. M., & Hines, S. J. (2008). Group Intensive Family Training (GIFT) for preschoolers with autism spectrum disorders. *Behavioral Interventions*, 23(3), 165–180. Índice de impacto: JCR (Journal Citation Reports) 2014: 1.409

GROUP INTENSIVE FAMILY TRAINING (GIFT) FOR PRESCHOOLERS WITH AUTISM SPECTRUM DISORDERS

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Early, intensive behavioral intervention is effective in treating children with autism spectrum disorders (ASDs), but can be cost prohibitive. Expenses may be defrayed if children can benefit from parents acting as therapists. This quantitative case series examines the efficacy of the Group Intensive Family Training (GIFT) program, a 12-week (180 h, delivered 3 h each weekday) parent-training for preschoolers with ASDs. Parents were individually mentored in the hands-on application of behavior analytic techniques, implementing these skills *in vivo* within a group of six parent-child dyads. Seventy-two parents and children (ages 25–68 months) with ASDs participated in this study. Children's cognitive and adaptive functioning was assessed before and after the intervention program. Analyses revealed average gains of eight standard score points on the Mullen Early Learning Composite and five standard score points on the Vineland Adaptive Behavior Composite after 12 weeks of treatment. Additionally, 14% and 11% of the children moved from the 'impaired' to 'non-impaired' range on Mullen and Vineland composite scores, respectively. This preliminary investigation suggests that GIFT's behavioral, group parent-training can lead to significant, yet cost- and time-efficient gains for children with ASDs. Results must be interpreted with caution because of the absence of a control group. Copyright © 2008 John Wiley & Sons, Ltd.

INTRODUCTION

Parents and professionals alike are increasingly concerned with the rising rates of individuals diagnosed with autism spectrum disorders (ASDs), an often disabling continuum of neuro-developmental conditions (Fombonne, 2003). Autism's core symptoms include a reduced capacity for reciprocal social interaction, qualitative impairments in verbal and nonverbal communication, and the presence of restricted or repetitive patterns of behavior (Volkmar & Cohen, 2005). Especially in the absence of effective treatment, young children with autism often develop increasingly

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problematic behavior, including disruptive actions, aggression, and self-injury (Durand, 1990).

Fortunately, more clinicians now routinely screen for ASDs in younger patients, allowing diagnosis in children as young as 18–24 months (Johnson, Myers, & American Academy of Pediatrics, Council on Children with Disabilities, 2007a; Matson, Wilkins, & Gonzalez, 2008). The primary goal of early diagnosis is early intervention, which is particularly important in light of negative correlations between age at onset of intervention and treatment gains (Fenske, Zalinski, Krantz, & McClannahan, 1985). The National Research Council, Committee on Educational Interventions for Children with Autism (2001) reports that children who receive individualized, intensive intervention starting at an early age show the most dramatic treatment response. Their guidelines recommend preschoolers receive a minimum of 25 h of treatment a week, year-round.

Treatment programs applying behavioral principles have received strong empirical support (Cohen, Amerine-Dickens & Smith, 2006; Eikeseth, 2008; Eikeseth, Smith, Jahr, & Eldevik, 2002; Eikeseth, Smith, Jahr, & Eldevik, 2007; Howard, Sparkman, Cohen, Green, & Stanislaw, 2005; Lovaas, 1987; Matson & Smith, 2008; Sallows & Graupner, 2005). Children receiving early, intensive behavioral intervention demonstrate substantial improvement in measures of both cognition and adaptive behavior (Smith, 1999). Behavioral approaches are rooted in learning theory and focus on direct observations and measurement of behavior to identify motivational factors, antecedent stimuli, and various consequences that facilitate skill development and reduce problem behavior. Progress is measured using systematic methods, and the resulting data are used to guide intervention (Cooper, Heron, & Heward, 2007). The overall goal of behavior therapy is to generalize behavior change from the therapeutic setting to the natural environment in order to maximize an individual's ability to function independently (Stokes & Baer, 1977).

To be effective, early behavioral intervention must be sufficiently intensive (Fenske et al., 1985; Lovaas, 1987) and of adequate quality (Eikeseth et al., 2002; Perry, Prichard, & Penn, 2006). Thousands of skills must be systematically taught via hundreds of teaching trials each day, across dozens of hours each week, for several years. Because such treatment is time- and labor-intensive, for many it is prohibitively costly, with estimates ranging upwards of \$60 000 per child per year (Butter, Wynne, & Mulick, 2003). Cost-analyses (Chasson, Harris, & Neely, 2007; Jacobson, Mulick, & Green, 1998) demonstrate that 'front-loading' expenses (i.e., providing the highest intensity of intervention during the preschool years) actually saves public dollars in the long-run, but few public agencies allocate such large amounts on preschoolers who have not yet posed serious behavioral problems. Additionally, intensive behavioral intervention is seldom covered by insurance, and most families cannot afford to pay for private treatment.

One viable option has been for parents to be trained to serve as their child's therapist. A growing body of literature demonstrates the efficacy of teaching parents to implement behavioral intervention techniques (Ingersoll & Gergans, 2007; Sheinkopf & Siegel, 1998; Smith, Buch, & Gamby, 2000). In a study by Koegel, Schreibman, Johnson, O'Neill, and Dunlap (1984), parent training proved to be a more powerful adjunct than lengthening the hours of behavioral treatment in a clinic setting. However, other researchers have found the effectiveness of parent-managed behavioral treatment to be substantially lower than professionally delivered services (Bibby, Eikeseth, Martin, Mudford, & Reeves, 2001), perhaps in part because of difficulty in maintaining the quality of such intervention (Mudford, Martin, Eikeseth, & Bibby, 2001; Symes, Remington, Brown, & Hastings, 2006).

Authors of recently published work in this area (Johnson et al., 2007b; RUPP Autism Network, 2007) urge the development of comprehensive, structured parent-training programs. For such programs to be effective, they must provide intensive, 'hands-on' teaching and include follow-up to maintain the quality of parent-implemented intervention. Finally, Tonge, Brereton, Kiomall, Mackinnon, King, and Rinehart (2006) found parent-training conducted in group settings provides the added advantage of promoting parent mental health and adjustment.

With the above considerations in mind, the Division of Developmental-Behavioral Pediatrics at a large, suburban hospital developed the Hands-On Parent Education (HOPE) Center. Within the HOPE Center, the Group Intensive Family Training (GIFT) program was designed to provide an efficient and effective parent-training model. In this 12-week program, six parent-child dyads attend a preschool-like facility 5 days a week for 3 h a day, for a total of 180 h of training. Enrollment is staggered (i.e., two families exit and two families enter the program every 4 weeks), allowing experienced parents and children to serve as models for incoming families. Parents are taught to function as their child's primary therapist via didactic instruction, modeling, coaching, and constructive feedback provided from videotaped homework. The end objective of the program is to help parents move the intervention from the clinic to their home, with their child's treatment monitored via periodic (and less costly) follow-up consultation from a behavioral psychologist, approximately twice a month.

At the time of this study, the total cost for the 180 h GIFT program was \$6500. Follow-up consultation with a behavioral consultant twice monthly at the conclusion of the program averaged \$200 per month. Thus, total expense for a full year of services was about \$8000, with subsequent years costing only \$2400. These costs are substantially lower than the annual cost of \$60 000 for professionally implemented intensive behavioral intervention reported in 2003 by Butter et al.

The GIFT program bears similarity to Schreibman and Koegel's (2005) behavioral parent training that targets three 'pivotal' areas shown to affect generalized treatment

gains in children. As detailed by Schreibman and Koegel, parents first learn to increase children's motivation by giving clear instructions, interspersing maintenance tasks, providing choices, using natural reinforcers when possible, and reinforcing successive approximations to learning targets. Second, to remediate children's stimulus overselectivity, parents learn to teach their children a series of successive conditional discriminations. The third pivotal behavior taught to parents by Schreibman and Koegel is child self-management skills, such as self-monitoring. The GIFT program likewise incorporates these pivotal skills in the teaching curriculum. Differences include a shorter duration of treatment (Schreibman and Koegel report an average of 25 h per family) and the lack of a group-treatment model.

Tonge et al. (2006) describe a behavioral parent-training model that alternates between ten 60-min, individual family sessions and ten 90-min, small group sessions consisting of four to five families. The goals of increasing communication, socialization, and play skills and decreasing behavior problems are consistent with the GIFT program. Unique to the program described by Tonge et al. is a focus on parental stress, grief, and associated mental health problems.

The Research Units on Pediatric Psychopharmacology (RUPP) Autism Network recently developed a 16-week, behavior analytic parent-training model to examine the efficacy of combined pharmacological and behavioral treatment (Johnson et al., 2007b; RUPP Autism Network, 2007). Like the GIFT program, the RUPP protocol focuses on teaching functional communication, reducing problem behaviors, developing new skills, and promoting generalization. Another similarity is the use of videotaping to facilitate parental acquisition of therapeutic techniques. However, the RUPP program provides fewer and shorter parent-training sessions (11–14 sessions lasting 75–90 min versus GIFT's 60, 3 h sessions) and does not utilize a group training format. The RUPP program includes several 'booster' sessions designed to troubleshoot implementation of previously learned strategies, similar to the goal addressed via follow-up behavioral consultation available to families after they complete the GIFT program.

METHOD

As a preliminary examination of the efficacy of this intensive, short-term, multiple-family group treatment model, a quantitative case series was conducted.

Participants

Participants were child-caregiver dyads completing the HOPE Center's GIFT program during the first two years of its operation. Ninety-two families initially

expressed interest, qualified, and were offered enrollment. Eleven families subsequently declined to participate, primarily due to concerns regarding the financial and time commitment. Of the 81 participants, one parent discontinued treatment prior to the conclusion of the intervention program, citing conflict with her employment. Charts of eight families who completed the program during the time parameters of this study were unavailable to the archivist collecting data. The remaining 72 parent–child dyads served as participants in this study.

All children were diagnosed with an ASD (either Autistic Disorder or Pervasive Developmental Disorder, Not Otherwise Specified) using DSM-IV criteria by experienced physicians and/or clinical psychologists in the community. At the time children began the intervention, their ages ranged from 25 to 68 months, with a mean age of 44 months ($SD = 12.6$). As expected with ASDs, the majority of children were male (84.7%). To qualify for this intervention, children needed to demonstrate significant impairment(s) relative to their chronological age (i.e., their score on measures of cognitive and/or adaptive functioning fell more than two standard deviations below the mean). Many exhibited co-morbid behavior problems (e.g., noncompliance, aggression, self-injury).

Most caregivers participating in the training program were mothers (96%); others included a father, a grandmother, and an in-home caregiver. For convenience, all will be referred to as 'parents'. Parents' ages ranged from 21 to 46 (excluding the grandmother), with an average age of 35 years ($SD = 4.96$). Parents had completed an average of 3 years of post-high school education, and most were married (96%).

Setting and Staff

Treatment occurred in the HOPE Center, part of an outpatient developmental-behavioral pediatric setting in a suburban hospital. A Board Certified Behavior Analyst designed each child's individualized behavioral intervention and supervised the treatment program. Four staff members with experience implementing behavior analytic treatment provided hands-on training to each cohort of six families. Each parent–child dyad worked individually with staff members (1:1 ratio) for the first month of treatment; the ratio changed to one staff member for two parent–child dyads (1:2 ratio) thereafter.

Description of Treatment Program

All parents attended a 12 h didactic weekend workshop addressing basic behavioral principles. This provided parents with introductory information about behavior analysis and allowed them to make an informed decision regarding participation in the GIFT program.

Prior to starting treatment, each child's skill strengths and deficits were evaluated (the criterion-referenced measure used to assist in this process can be found in Partington & Sundberg, 1998a; Partington & Sundberg, 1998b; and the revised version in Partington, 2006a, 2006b). When necessary, the function of any interfering problem behaviors was assessed (Glasberg, 2006). Informal preference assessments were conducted to identify effective reinforcers for each child's acquisition of new skills (Barbera & Rasmussen, 2007). Taken together with any priorities identified by parents, this information was used to design an individualized treatment protocol. Each child's program consisted of hierarchically arranged component skills selected for training, and any problem behaviors targeted for reduction/elimination.

For children with minimal skills, initial goals included pivotal prerequisite behaviors such as attending and cooperating with simple requests. Goals necessary for establishing more complex learning were arranged hierarchically within skill areas such as imitation, matching, receptive and expressive language (Sundberg & Partington, 1998). The design of language goals was guided by Skinner's (1957) functional analysis of verbal behavior (see Carr and Firth's 2005 paper for description of differences between this approach and the structural account of language used by Lovaas in his 1987 study).

Developing spontaneous functional communication skills was an essential treatment goal for all children, as this establishes the basic rules of social interaction, and allows children to initiate social exchanges (Greer & Ross, 2008). Children who were unable to imitate vocal sounds initially learned to use either signs (Carr, 1979) or pictures (Frost & Bondy, 2002) to communicate their requests. The selected mode depended on the relative strength of children's motor imitation versus visual discrimination abilities. Customized play, social, and motor goals were also included as part of each child's curriculum.

In keeping with developmental expectations of preschoolers, children's treatment programs were implemented in the context of short, playful activity sessions. During some sessions, parents learned to teach their children in both adult-directed and child-directed activities. Other sessions paired two children together, teaching parents to use carefully crafted behavioral interventions to teach reciprocal interactive peer play. Still other sessions brought all six children together for small-group activities showing parents how to help their children master targeted prerequisite skills essential for success in a preschool environment (Taubman et al., 2001).

In order to implement their child's individualized therapy, parents were taught numerous intervention procedures. Although a full description is beyond the scope of this paper, techniques included differential reinforcement, response-cost, reinforcement thinning, shaping, chaining, prompting, programmatic generalization, errorless teaching, establishing and transferring stimulus control (Cooper et al., 2007), behavioral momentum (Mace et al., 1988), mand training, and application of

motivational operations (Michael, 1988; Sweeney-Kerwin, Carbone, O'Brien, Zecchin, & Janecky, 2007). Perhaps most important, parents were taught to incorporate many of these behavioral principles during various day-to-day activities with their children.

Initially, staff modeled the intervention techniques for parents. Subsequently, parents implemented the treatment with staff providing coaching and feedback. Once basic intervention skills were mastered, parents learned data collection techniques essential in determining when their child's mastery (or alternatively, an inadequate acquisition rate) warranted curricular changes.

In the second month, each parent briefly worked with another child in the program. In addition to helping parents think conceptually about behavioral principles, learning from other adults fosters generalization of children's skills. In the third month, parents were encouraged to bring their spouse and/or other adult(s) to the program. With staff assistance, parents taught others how to implement their child's therapy, which further solidified parents' learning and decreased stress by sharing the work of providing therapy (Harris, Peterson, Filliben, Glassberg, & Favell, 1998).

To facilitate the eventual transition of the treatment to the home setting, parents were encouraged to practice their intervention skills with their child at home for approximately 5 h a week. This homework also ensured that children received a high level of treatment intensity. Staff reviewed a weekly videotaped sample of this homework and provided constructive feedback to ensure treatment integrity (Lerman, Swiezy, Perkins-Parks, & Roane, 2000).

Assessment Measures

Children's cognitive and adaptive functioning was assessed using the Mullen Scales of Early Learning (Mullen, 1995) and the Vineland Adaptive Behavior Scales (Sparrow, Balla, & Cicchetti, 1984). Both measures are widely used for this population and provide two independent sources of information about children's functioning. Standard scores for both measures have a mean of 100 and standard deviation of 15 in the normative sample.

The Mullen's Early Learning Composite score estimates young children's global cognitive functioning by averaging four scales measuring subdomains of development: visual reception (includes matching, sorting, and non-verbal problem-solving), fine motor skills, receptive language, and expressive language. The Mullen was standardized on a nationally representative sample of children ranging in age from 2 days to 69 months. This wide range was ideal for participants in this study, as the majority functioned below basal levels on other measures of cognition such as the Wechsler Preschool and Primary Scales of Intelligence. Mullen scores have been found to be sensitive to changes in language and intelligence over

time (Bradley-Johnson, 1997) and to demonstrate good internal consistency (median reliability of the composite is .91) and inter-rater reliability (ranging from .91 to .99; Mullen, 1995). The Mullen was administered by experienced psychologists using standard procedures. However, these psychologists were not blind to children's intervention status.

Children's adaptive functioning was assessed via parent interview using the Vineland Adaptive Behavior Scales. This measure provides an overall Adaptive Behavior Composite score by averaging four scales assessing separate adaptive domains: communication, socialization, daily living (includes self-help ability), and motor skills. The Vineland is a well-validated tool with strong internal consistency (split-half reliability coefficients range from .91 to .97) and reliability (inter-rater reliability for composite score = .74; Sparrow et al., 1984). It is widely used for individuals with various developmental disabilities, including autism (Sparrow & Cicchetti, 1987).

Children were initially assessed using the Mullen and Vineland at an intake appointment, before families enrolled in the GIFT intervention program. As mentioned previously, to qualify for the program, children needed to demonstrate significant impairment(s) relative to their chronological age (i.e., their score on at least one domain on each measure fell more than two standard deviations below the mean). Intake assessment occurred, on average, 5 weeks prior to the 12-week intervention. Children were evaluated again using the Mullen and Vineland in the final week of the treatment program. Time two assessment was implemented by the psychologist who developed and supervised the individualized intervention, but who had not provided direct treatment (i.e., children were not familiar with the testers).

To address social validity of the GIFT program, a subset of 37 parents (51%) completed a parent satisfaction measure (this measure was not designed until midway through this study). This questionnaire asked parents to rate their level of approval of the program and staff using a 4-point Likert scale (1 = highly satisfied, 2 = satisfied, 3 = mildly satisfied, 4 = dissatisfied).

RESULTS

Preliminary analyses revealed children's standard scores on the Mullen and Vineland did not differ as a function of gender. Due to significant positive skewing of the distribution of Mullen composite and domain scores (this measure does not permit composite standard scores below 49 or domain *T*-scores below 20), nonparametric statistical testing (Wilcoxon signed ranks test) was used.

As shown in Table 1, the mean post-treatment Mullen composite score was significantly higher than at intake and, on average, children performed significantly

Table 1. Mean cognitive and adaptive standard scores at intake and following intervention

<i>Variable</i>	<i>Intake Mean (SD)</i>	<i>Post-intervention Mean (SD)</i>	<i>Significance test</i>
Mullen composite	51.69 (6.27)	59.65 (16.58)	-5.38 ^{a**}
Visual reception	60.10 (11.84)	70.99 (23.00)	-4.90 ^{a**}
Fine motor	57.35 (7.59)	65.29 (18.97)	-4.42 ^{a**}
Receptive language	56.58 (5.62)	63.94 (20.86)	-3.57 ^{a**}
Expressive language	56.31 (5.24)	63.81 (19.40)	-4.14 ^{a**}
Vineland composite	53.11 (7.39)	58.27 (9.59)	6.91 ^{b**}
Communication	54.61 (8.35)	60.09 (12.19)	6.48 ^{b**}
Socialization	56.17 (5.29)	61.54 (8.39)	7.84 ^{b**}
Daily living skills	57.59 (7.96)	59.70 (8.65)	3.18 ^{b*}
Motor skills	62.74 (13.50)	70.06 (16.20)	5.08 ^{b**}

SD = Standard deviation.

^aWilcoxon signed ranks test (*z*-score).

^bPaired *t*-test.

p* < .01. *p* < .001.

better after treatment on all Mullen domains (domain scores were converted from *T*-scores to standard scores for ease of comparison). Children made the largest gains in their Mullen visual reception scores, and evidenced similar, more modest improvements in the other domains.

The distribution of Vineland composite and domain scores did not violate assumptions of homogeneity, permitting parametric statistical analysis (paired *t*-tests). Children's mean post-treatment composite and all domain scores on the Vineland were also significantly higher than at intake (Table 1). Vineland motor skills increased most, and daily living skills improved least. Communication and socialization skills fell between these extremes, with relatively similar levels of improvement.

In addition to these tests of statistical significance, clinical significance of the change in Mullen and Vineland composite scores pre- and post-intervention was examined. At intake, the majority of composite scores fell in the impaired range (i.e., standard scores of less than 70) on the Mullen (97%) and the Vineland (96%). This finding was not surprising, given the aforementioned program entry criteria. After the intervention, a total of 10 children's Mullen composite scores (14%) moved from the impaired to the non-impaired range (i.e., score ≥ 70) and eight children's Vineland composite scores (11%) moved from the impaired to the non-impaired range.

Another way to look at the change in children's pre- and post-intervention functioning on the Mullen and Vineland is to examine developmental age-equivalencies (Table 2). Although such scores are less reliable than standard scores, they provide an estimate of the size of children's developmental gains during the course of the treatment program. Because intake assessment often took place several

Table 2. Mean cognitive and adaptive age-equivalencies at intake and following intervention

	<i>Intake</i> (mean age = 43.3 months) Mean AE (SD)	<i>Post-intervention</i> (mean age = 47.5 months) Mean AE (SD)
Mullen composite	16.99 (5.64)	25.20 (7.93)
Visual reception	20.90 (6.52)	29.51 (7.61)
Fine motor	21.44 (5.30)	28.46 (8.81)
Receptive language	13.39 (7.17)	21.85 (10.22)
Expressive language	12.21 (7.12)	21.00 (10.36)
Vineland composite	15.91 (3.60)	21.65 (5.71)
Communication	11.90 (4.71)	17.87 (6.37)
Socialization	10.30 (2.56)	15.75 (4.83)
Daily living skills	17.86 (3.96)	21.68 (5.67)
Motor skills	23.57 (6.20)	30.99 (9.41)

AE = age-equivalency; SD = standard deviation.

weeks before families began the program, the average time interval between pre- and post-intervention assessment was 4.1 months ($SD = 1.2$), slightly longer than the length of the intervention. During this time period, children made an average of 8.2 and 5.7 months of overall developmental gains on the Mullen and Vineland, respectively. This rate of developmental progress is particularly impressive, as these children had not made month-for-month developmental gains prior to treatment. For the sake of completeness, pre- and post-intervention age-equivalencies on the Mullen and Vineland domains are also provided in Table 2, although domain age-equivalencies are even less reliable than composite age-equivalencies.

Finally, satisfaction with the GIFT program, as rated by the subset of 37 parents completing the parent satisfaction survey, was quite high. The mean overall satisfaction rating was 1.5 (i.e., falling midway between 'satisfied' and 'highly satisfied') indicating that, on average, families were pleased with the program and judged it to be worthwhile.

DISCUSSION

Examination of this quantitative case series provides preliminary evidence that participation in an intensive, but short-term, group parent-training program is associated with statistically and clinically significant improvement in children's short-term cognitive and adaptive functioning. At the intervention's conclusion, mean composite standard scores on the Mullen and Vineland improved by 8.0 and 5.1 points, respectively. Bearing in mind that this intervention was only 12 weeks in length, these findings are generally in keeping with data from Eikeseth and his

colleagues (2002) who found mean increases in cognitive and adaptive functioning of 17 and 11 standard score points, respectively, following a full year of intensive behavioral treatment from professional therapists. A review by Smith (1999) cites IQ gains ranging from 7 to 28 points, and recent studies by Sallows and Graupner (2005) and by Howard et al. (2005) document IQ gains of 18 and 29 points, respectively, for children receiving intensive behavioral intervention for more than a year.

One could argue that the dramatic Mullen score gains observed at the conclusion of the GIFT program could be due, in part, to the development of pivotal skills such as 'testing compliance'. That is, perhaps some abilities were present at the time of intake testing, but were not demonstrated due to poor instructional control (Matson, 2007). Developing the ability to respond consistently to a typical testing (or learning) environment—sitting at a table, attending to relevant stimuli, engaging with the examiner (or teacher), and following instructions—is a worthwhile goal in and of itself. However, the parallel gains noted on the Vineland argue against the hypothesis that participants' cognitive gains were due solely to their developing pivotal learning skills. Of course, adaptive behavior gains could be due, in part, to parent-expectancy effects. But potential artifacts such as improved compliance and/or parental expectations would not be expected to produce the magnitude of developmental changes observed.

The findings of this quantitative case series have significant limitations. Dependent variables consist solely of clinical data routinely collected as part of families' participation in the GIFT program. Several factors that may influence children's developmental gains, such as the severity of autistic symptoms, were unable to be examined. Although children with interfering behavior received treatment targeting these problems, aberrant behavior could not be quantitatively measured. Systematic assessment of parental treatment fidelity and its relation to children's gains was also beyond the scope of the current study. This limits the ability to definitively determine that parental intervention was responsible for children's gains.

As is often the case in clinical field research, children could not be randomly assigned to alternative modalities of treatment. Many children discontinued other types of therapy during the 12 weeks of this intervention, while others continued to receive a myriad of treatments (e.g., speech therapy, special education services, dietary restrictions, nutritional supplements, etc.). The lack of random subject assignment to treatment and a control group reduces confidence that children's improvements observed in this study are a direct result of the GIFT intervention program and leaves open the possibility that gains may have occurred without this treatment (i.e., could be explained by other factors occurring during this time period).

Another limiting factor is that examiners were not blind to children's pre- or post-intervention status. The psychologists administering assessment measures at the conclusion of treatment did not work directly with the children and thus Mullen

scores should not have been inflated due to children's familiarity with the examiners. However, these psychologists were involved in developing the children's intervention. As such, they may have been less objective than blind examiners, potentially biased in favor of treatment results.

There are other questions that cannot yet be answered by this preliminary study. Despite the robust effects observed during the 3-month GIFT program, assessment of participants' long-term progress is needed. After completion of parent training, families varied with respect to continued treatment intensity. Although parents learned to effectively implement behavioral intervention, they were not taught to design new treatment programs as their children's skills advanced. For this reason, most utilized a behavioral psychologist an average of twice monthly for follow-up services to oversee in-home intervention. In an effort to maintain at least 20 weekly intervention hours, some parents hired tutors to assist in their child's home treatment. Other parents were unable to maintain this level of intensity, but continued to provide behavioral teaching techniques during day-to-day activities such as dressing, eating, bathing, etc. Long-term follow-up is essential to determine the conditions under which children continue their improvement in cognitive and adaptive functioning after participating in the GIFT program. Finally, because this intervention is not based on a written, standardized manual or protocol, the extent to which it can be replicated is limited.

This treatment model may not be an optimal fit for some families, as it places a significant burden on parents as primary providers of intervention and requires their daily attendance. However, the 3-month training was designed to correspond with the time allotment of the Family Medical Leave Act. Out-of-town families were assisted with local housing and parents from remote areas report that the GIFT program is particularly suited to their needs, citing the lack of service providers near their home as their primary motivation for wanting to learn to serve as their child's therapist. Additionally the program appears to have good social validity based on high parent satisfaction rating.

For many families, the GIFT program shows strong promise as an effective and efficient way for children to obtain early affordable behavioral intervention. This parent-training model is 'hands-on' and builds from a simple to complex level of proficiency. Parents in the GIFT program report a growing sense of empowerment, as a result of observing their efforts produce concrete gains in their children's abilities (Feldman & Werner, 2002). Parents also report receiving social support from one another as they learn together, another benefit of a group intervention model (Hastings & Symes, 2002).

In summary, this study provides preliminary support for the hypothesis that children benefit when their parents receive hands-on training in behavioral interventions during the 3-month, group format described in this study. At the

conclusion of this parent-training program, children's cognitive and adaptive functioning significantly improved: mean composite standard scores on the Mullen and Vineland increased by 8.0 and 5.1 points, respectively. Additionally, after this relatively short treatment, some children's scores moved out of the impaired range on both cognitive and adaptive measures. On average, children gained 2 months of overall cognitive skills and 1.5 months of overall adaptive skills for each month of intervention.

In conclusion, while factors such as high cost and lack of adequately trained clinicians prevent many children from receiving early, intensive behavioral intervention, this study gives hope that there may be another equally effective way to meet the needs of young children with ASDs. The HOPE Center's GIFT program shows promise in offering a cost- and time-effective behavioral parent-training model in which children can make significant short-term gains. The program merits more rigorous evaluation in controlled studies. Follow-up research should randomly assign participants to wait-list or other control groups, use evaluators blind to intervention status, assess other factors potentially related to treatment response (e.g., treatment adherence), and include longer-term outcome measures.

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Anexo II

Coolican, J., Smith, I. M., & Bryson, S. E. (2010). Brief parent training in pivotal response treatment for preschoolers with Autism. *Journal of Child Psychology and Psychiatry*, 51(12), 1321–1330. Índice de impacto: ISI Journal Citation 2014: 6.459.

Brief parent training in pivotal response treatment for preschoolers with autism

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Background: Evidence of improved outcomes with early behavioural intervention has placed the early treatment of autism as a health priority. However, long waiting lists for treatment often preclude timely access, raising the question of whether parents could be trained in the interim. Parent training in pivotal response treatment (PRT) has been shown to enhance the communication skills of children with autism. This is typically provided within a 25-hour programme, although less intensive parent training may also be effective. The main objective of the present study was to evaluate the efficacy of brief training in PRT for parents of preschoolers with autism, who were awaiting, or unable to access, more comprehensive treatment. **Method:** Eight preschoolers with autism and their parents participated in the study. A non-concurrent multiple (across-participants) baseline design was used, in which parents were seen individually for three 2-hour training sessions on PRT. Child and parent outcomes were assessed before, immediately after, and 2 to 4 months following training using standardised tests, questionnaires and behaviour coded directly from video recordings. **Results:** Overall, children's communication skills, namely functional utterances, increased following training. Parents' fidelity in implementing PRT techniques also improved after training, and generally these changes were maintained at follow-up. A moderate to strong relationship was found between parents' increased ability to implement PRT techniques and improvement in the children's communication skills. **Conclusion:** Our findings suggest that brief parent training in PRT promises to provide an immediate, cost-effective intervention that could be adopted widely. **Keywords:** Autism, pivotal response treatment, parent training, communication.

Evidence has demonstrated that outcomes for children with autism spectrum disorder (hereafter referred to as autism) are substantially improved with early intensive behavioural intervention (EIBI; e.g., National Autism Center, 2009; National Research Council, 2001; Rogers & Vismara, 2008). However, currently for many children access to EIBI is either precluded or delayed beyond the recommended age (e.g., Majnemer, Shevell, Rosenbaum, & Abrahamowicz, 2002) due to long waiting lists. Training parents in evidence-based intervention techniques is generally considered an efficient method of expanding the availability of intervention services to children with autism. Additional advantages of parent training are the potential for increased maintenance and generalisation of child skills, and increased parental self-efficacy (e.g., Bryson et al., 2007).

There is some evidence for the effectiveness of training programmes for parents of children with autism (e.g., Aldred, Green, & Adams, 2004; Drew et al., 2002; McConachie, Randle, Hammal, & Le Couteur, 2005), although the results of a recent RCT show minimal effects on symptoms of autism and moderate effects on child communication (Green et al., 2010). These programmes vary in orientation, although most focus on enhancing the children's ability to communicate. Currently, parent training programmes for children with autism are relatively intensive (25 to 180 hours of training), which is

problematic when confronted with long waiting lists for service. It is therefore critical to determine whether briefer parent training has a positive impact on child and parent outcomes. To date, only three studies have addressed this question (Baker-Ericzen, Stahmer, & Burns, 2007; Stahmer & Gist, 2001; Vismara, Colombi, & Rogers, 2009).

One non-random assignment group design study ($N = 22$) demonstrated that some parents are able to learn the techniques of pivotal response treatment (PRT) after 12 weekly one-hour individual sessions (Stahmer & Gist, 2001). PRT focuses on increasing the child's motivation to communicate, using the principles of applied behaviour analysis in play and other natural daily-life settings (R.L. Koegel et al., 1989; R.L. Koegel & L.K. Koegel, 2006). Parents who participated in both the parent training sessions and a parent support group ($n = 11$) were more likely to master the strategies than parents who completed the training sessions alone (8/11 versus 4/11 parents met the fidelity criterion, respectively). Parents who mastered the PRT techniques reported significantly larger increases in their children's vocabularies. Also, the number of words children used (coded from video) increased from pre- to post-intervention, regardless of parental skill level. While these results are promising, no follow-up data were collected and child outcomes were based largely on parent-report measures.

Additional support for 12 weekly, one-hour individual parent training sessions in PRT comes from a large-scale ($N = 158$) community-based study in

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which significant improvements were found in parent-reported adaptive skills immediately following training (Baker-Ericzen et al., 2007). Unfortunately, the researchers did not evaluate other child outcomes or parents' fidelity of implementation, and there was no follow-up evaluation.

More recently, Vismara and colleagues (2009) used a multiple baseline design ($N = 8$) to evaluate 12 one-hour weekly sessions of parent training in the Early Start Denver Model. This model of intervention incorporates PRT and other techniques from the Denver Model, which focuses on teaching imitation, non-verbal communication and pragmatics. Parent fidelity increased with training, with most parents (87.5%) meeting the fidelity criterion after 6 hours of training. In addition, children's spontaneous functional utterances, imitation skills, and engagement improved following 12 hours of training and were maintained at the 3-month follow-up. Furthermore, the largest gains in children's spontaneous functional utterances occurred once parents demonstrated the ability to implement the strategies with fidelity. This study's results raise the question of whether parents are able to acquire the intervention skills with 6 hours of training and have a positive impact on their children's outcomes.

The present study was designed to examine the efficacy of brief (6-hour) training in PRT for parents of young children with autism. Eight families of preschoolers with autism, who were waiting to access a more intensive intervention programme, participated in 6 hours of training in PRT. The main question was whether child gains would occur in multiple domains of behaviour, notably in communication and disruptive behaviour, post-training and at follow-up. Secondly, the study examined whether brief training in PRT would be sufficient for parents to learn how to implement the strategies with fidelity, and whether parent training would be associated with improvements in their perceived self-efficacy. Finally, we examined whether gains in parent fidelity were associated with gains in child communication.

Method

Participants

Participants were eight families of children newly diagnosed with autism, recruited through an eligibility list for a publicly funded EIBI Programme. One parent of each child participated in the study (5 mothers and 3 fathers). Inclusion criteria were that families had a child aged 2–5 years diagnosed with autism, lived within 30 km of the IWK Health Centre, and that parents had a minimum Grade 8 education. Families were excluded from the study if the child was already receiving some form of applied behavioural analysis treatment; and if the child had a major sensory, motor or neurological impairment/disorder (e.g., uncorrected visual or hearing loss, or physically incapacitating brain damage). Only one family was excluded, specifically because they lived too far from the study site.

All children were diagnosed with autism by an independent developmental pediatrician and psychologist with expertise in autism using DSM-IV-TR (APA, 2000). Seven of the eight children met criteria for autism on the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 1999) and the Autism Diagnostic Interview – Revised (ADI-R; Lord et al., 1994). Child 2's ADI-R scores fell below the cut-off (4 and 3 points below the cut-off for reciprocal social interaction and communication, respectively); however, his ADOS scores were above the autism cut-off, and he was given a clinical diagnosis of autism. Table 1 summarises the children's characteristics at baseline. Prior to training, children's word use ranged from one-word approximations (e.g., 'mmm' for 'more') to short phrases. All families spoke English as their primary language and were of middle to upper-middle socioeconomic status (Hollingshead Index; Miller, 1983). Parent education ranged from partial high school to graduate degree. All but two families (Child 1 and 2) had completed the Hanen 'More than Words' programme (Sussman, 1999) within 1 to 2 months prior to beginning the study. This is a training programme designed to help parents promote communication and social skills in their children, consisting of eight 2.5-hour group sessions and three home visits. The programme is publicly funded in this province, and was facilitated by two speech-language pathologists.

Table 1 Child characteristics at baseline

Child	Age (yrs; mo)	Sex	Cognitive ability (percentile, test)	PLS AC ^a Age-equivalent	PLS EC ^b Age-equivalent
1	4;8	M	1st, DAS ^c	3;10	2;11
2	3;3	M	2nd, WPPSI-III ^d	2;7	2;9
3	3;8	M	<1st, Bayley-III ^e	1;3	1;5
4	3;9	M	9th, Bayley-III	2;7	2;3
5	4;3	M	16th, Bayley-III	2;5	1;10
6	2;4	F	<1st, Bayley-III	0;7	1;3
7	4;4	M	<1st, Bayley-III	1;6	2;0
8	4;1	M	<1st, Bayley-III	2;1	1;11

^aPreschool Language Scale 4th Edition (Zimmerman et al., 2002), Auditory Comprehension; ^bPreschool Language Scale 4th Edition, Expressive Communication; ^cDifferential Ability Scales (Elliot, 1990); ^dWechsler Preschool and Primary Scale of Intelligence, 3rd Edition (Wechsler, 2002); ^eBayley Scales of Infant and Toddler Development 3rd Edition (Bayley-III; Bayley, 2005).

Study design

A non-concurrent multiple (across-participants) baseline design was used. Participants remained in the baseline (pre-training) phase for 3 to 7 weeks. The effects of the intervention were evaluated at both the end of the 2-week training period (post-training) and 2 to 4 months following training (follow-up).

Parent education procedures, settings and materials

Parent training sessions. Parents received three separate 2-hour training sessions over 2 consecutive weeks, for a total of 6 hours of individual training in PRT techniques. Prior to the first session, parents were provided with 'How to teach pivotal behaviours to children with autism: A training manual' (R.L. Koegel et al., 1989). The first two parent training sessions were conducted at our clinical lab and the third session was conducted in family homes in order to promote generalisation of parents' PRT skills. During the first session, parents were introduced to basic PRT principles, and the trainer modelled the techniques with the child. For the remainder of the session, parents implemented PRT techniques with their child, while receiving feedback from the trainer. PRT was taught in the context of play with the child. The second and third sessions consisted mainly of in vivo feedback for the parents, as well as problem solving on issues that had arisen since the previous session.

Cameras. Two Sony Handycam DVD camcorders with surround sound microphones were used to collect the video probes.

Child outcome measures

Communication. Two methods, functional verbal utterances and type of utterance, were used to measure changes in child communication. Following R.L. Koegel, Symon, and L.K. Koegel (2002), the presence or absence of functional verbal utterances (FVUs; for details, see Supplementary Appendix A) was coded from each 15-second interval of a 10-minute video recording, and the percentage of intervals with FVUs served as the dependent variable.

As the second communicative outcome measure, 5-minute video segments were coded for whether child utterances were appropriate (i.e., functional and directed) or inappropriate (e.g., stereotypic, echolalic or incomprehensible) and the degree to which they were prompted (i.e., model prompted, indirectly prompted, or child initiated) using an incidence scoring form (see Supplementary Appendix B for definitions). Overall responsivity was calculated as the percentage of times the child responded appropriately, following either a model prompt or an indirect prompt.

Language. Two standardised measures were used to determine whether expressive and receptive language improved at follow-up. The Preschool Language Scale, 4th Edition (PLS-4; Zimmerman, Steiner, & Pond, 2002) and the Peabody Picture Vocabulary Test, 3rd Edition (PPVT-III; Dunn & Dunn, 1997) are individually administered tests of language.

Disruptive behaviour. Disruptive behaviour was assessed by coding its occurrence or non-occurrence during each 15-second interval of a 10-minute video segment. Disruptive behaviour was operationally defined as (a) vocal (e.g., screaming, whining or crying); (b) physical (e.g., hitting, kicking, throwing, pushing); or (c) oral (e.g., biting, spitting).

Parent outcome measures

Fidelity of PRT implementation. A continuous 1-minute interval coding system was used (ten 1-minute intervals) to code fidelity of PRT implementation. Each interval was coded as either correct or incorrect for each of the following 5 techniques: Clear Opportunities, Child Choice, Contingent, Natural Rewards, and Rewards Attempts (for definitions, adapted from R.L. Koegel et al., 2002, see Supplementary Appendix C). The fidelity of implementation score was the average percentage of intervals, across all five strategies, during which parents demonstrated appropriate use of the techniques. Following Stahmer and Gist (2001), the criterion for fidelity of implementation was 75%.

Self-efficacy. Parental self-efficacy was measured using the Parental Self-Efficacy Scale, which is a domain-specific measure of parents' perceived self-efficacy related to their child's challenging behaviour (Hastings & Brown, 2002). This parent-report questionnaire consists of five items, each rated on a 7-point scale; the total score was used.

Satisfaction. Parents completed a questionnaire assessing their satisfaction with the training, created for the purpose of the current study.

Data collection procedures

Fifteen-minute video-recorded probes were collected during pre-training, post-training and at follow-up. In each phase, a research assistant video-recorded the parent interacting with his/her child during typical play with toys at the family's home. Four to five video probes were collected on separate days during the pre-training phase (ranged from 3 to 7 weeks), and 3–5 probes were collected on separate days during each of the post-training and follow-up phases. The first 10 minutes of each probe were coded for the outcome measures, and data were averaged across the video probes in each phase.

Parents completed the parental self-efficacy questionnaire at all three time points (pre- and post-training and at follow-up) and the Parent Satisfaction Questionnaire after completing the training. Before training and at follow-up, the children completed a standardised language assessment (PPVT-III and/or PLS-4).

Inter-observer reliability

The primary coder for each outcome measure was blind to treatment phase. In order to establish inter-observer agreement on each of the measures coded from video recordings, an independent coder coded 30% of the videos, including an equal number of randomly selected

pre-training, post-training, and follow-up videos from different children. For videos coded for the occurrence versus non-occurrence of behaviours, inter-observer reliability was calculated using both inter-observer agreement per interval and kappa coefficients (Cohen, 1960). Intra-class correlations were calculated for interval/ratio measures.

Overall, inter-observer reliability was good for all measures coded from videos. The mean inter-observer agreement was 86%, with kappa of .85 for FVUs; 97%, with kappa of .97 for disruptive behaviour; and 80%, with kappa of .79 for fidelity of implementation. With regard to utterance type, intra-class correlations were excellent (model prompted: .79; indirectly prompted: .96; initiations: .91; inappropriate responses: .88; no response: .98).

Analyses

Both visual inspection and statistical analyses were used to evaluate the data. For child FVUs and parent fidelity of implementation, individual data were displayed graphically and inspected for changes in level upon introduction of the training (as recommended by Kazdin, 1982). The Wilcoxon matched-pairs signed-ranks test (Sheskin, 2007; Wilcoxon, 1945) was used to determine whether, overall, a statistically significant change occurred after training (i.e., pre-training to post-training), and whether gains were maintained at follow-up (i.e., post-training to follow-up). In order to determine the magnitude of the changes, effect sizes were also calculated (Cohen, 1992). Spearman's correlations were used to assess the relationship between changes in parent fidelity and changes in child communication (i.e., FVUs and responsivity) from pre-training to post-training and follow-up.

Results

Child outcomes

Functional verbal utterances. Figure 1 provides data on the percentage of intervals with FVUs during parent-child interactions. As shown there, all eight children demonstrated an increase in FVUs after training, although gains were minimal for Child 1 and Child 6 (mean increase of 9.0% and 4.5%, respectively). Between post-training and follow-up, Children 1, 5, and 6 made gains in FVUs (mean increase of 8.3%, 11.2%, and 25.7%, respectively). Three children (3, 4, and 7) demonstrated a slight decrease in FVUs between post-training and follow-up (mean decrease of 4.5%, 5.7%, and 9.0%, respectively), while Children 2 and 8 displayed a larger decrease in FVUs from post-training to follow-up (mean decrease of 29.4% and 20.0%, respectively). No general patterns, based on initial language level, were observed across the three treatment phases.

Overall, the children's FVUs increased following training (Wilcoxon ($Z = -2.52$, $p < .05$, $d = 1.00$; mean change = 25.84%, range = 4.5–58%). More-

over, the group gains in FVUs observed post-training were maintained at follow-up ($Z = -.92$, $p > .05$, $d = .14$).

Nature of child utterances. The percentage of times the children responded appropriately (Responsivity) increased significantly following training ($Z = -2.52$, $p > .05$, $d = .85$; see Table 2), and was maintained at follow-up ($Z = -.56$, $p > .05$, $d = .25$). The percentage of responses that were preceded by a model prompt did not differ from pre- to post-training, or from post-training to follow-up ($Z = -1.12$, $d = -.42$ and $Z = -.14$, $d = .14$, $p > .05$, respectively). However, there was a significant increase in the percentage of responses that were indirectly prompted ($Z = -2.24$, $p < .05$, $d = .91$), which was maintained at follow-up ($Z = -.14$, $p > .05$, $d = -.18$). The percentage of initiations did not change significantly following training ($Z = .0$, $p > .05$, $d = .04$) or from post-training to follow-up ($Z = -.28$, $p > .05$, $d = -.11$). Similarly, the percentages of inappropriate responses did not change across the three phases ($Z = -.56$, $d = .11$ and $Z = -.84$, $d = .30$, $p > .05$, for pre- to post-training and post-training to follow-up, respectively). There was a significant decrease in the percentage of no responses following training ($Z = -2.24$, $p < .05$, $d = .73$), which was maintained at follow-up ($Z = -.14$, $p > .05$, $d = .16$).

Standardised language measures. Overall, there was no significant difference in age-equivalent scores between pre-training and follow-up (4 to 6 months) on the Auditory Comprehension (AC) scale of the PLS-4 ($Z = -.34$, $p > .05$, $d = .05$, $n = 8$). However, there was a trend towards higher age-equivalent scores at follow-up compared to pre-training on the Expressive Communication (EC) scale of the PLS-4 ($Z = -1.83$, $p = .07$, $d = .34$, $n = 8$). In two children, large age equivalence gains were made on the PLS-4: 13 and 12 months (Child 2), and 3 and 7 months (Child 6), for AC and EC respectively.

Overall, there was no significant difference in age-equivalent scores between pre-training and follow-up on the PPVT-III ($Z = -1.60$, $p = .11$, $d = 1.16$, $n = 5$). Individual PPVT-III scores indicated that single-word receptive vocabulary increased at a rate greater than expected following training for 3 of the 5 children who were able to complete the test: over the 4- to 6-month period of the study, age equivalence increased by 7 months (Child 1), 23 months (Child 2), and 12 months (Child 4).

Disruptive behaviour. With two exceptions (Children 1 and 6), there was minimal disruptive behaviour during the video-recording sessions (i.e., average of less than 10% of intervals), regardless of treatment phase. Child 1 displayed disruptive behaviour during the pre-training phase, which decreased immediately following training (mean decrease of 10%) and was maintained at the

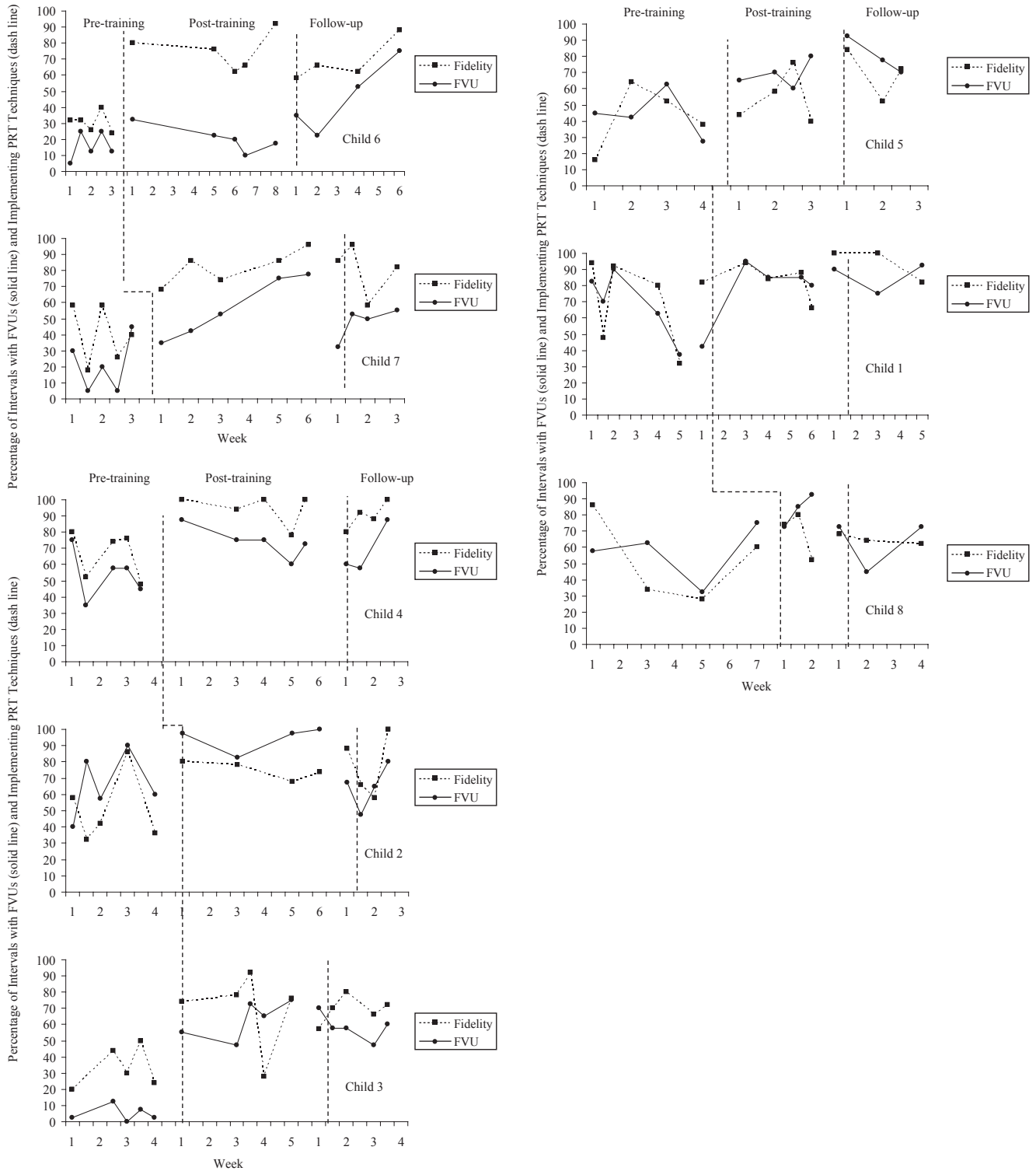


Figure 1 Percentages of intervals during which children produced functional verbal utterances (FVUs) and parents implemented PRT techniques during each video probe, by week of participation in the study. Three to five video probes were taken during each phase (i.e., pre-training, post-training, and follow-up). The order of presentation is based on the length (i.e., 3 to 7 weeks) of the pre-training phase

3.5-month follow-up (mean increase of 2%). Child 6 also displayed some disruptive behaviour, which decreased slightly by the follow-up phase (mean decrease of 5.5% from pre-training to follow-up). Overall, no change was seen in disruptive behaviour between pre- and post-training phases ($Z = -.73$,

$p > .05$, $d = .17$) or between post-training and follow-up phases ($Z = -1.18$, $p > .05$, $d = .08$).

Qualitative notes. Parents universally reported positive changes in child communication. The parents of Child 3 noted that he ‘seems to be initiating

Table 2 Mean responsivity (number of appropriate responses by number of language opportunities) across the three treatment phases

Child	Pre- training	Post- training	Follow-up
1	130/224 58.04%	181/239 75.76%	135/148 91.22%
2	107/134 79.85%	182/206 88.35%	81/91 89.01%
3	8/66 12.12%	133/169 78.70%	90/112 80.36%
4	130/193 67.36%	163/213 76.53%	106/174 60.92%
5	65/135 48.15%	88/144 61.11%	137/165 83.03%
6	18/73 24.66%	26/101 25.74%	65/99 65.66%
7	25/108 23.15%	90/129 69.77%	39/65 60.00%
8	128/184 69.57%	91/101 90.10%	74/106 69.81%
Mean	49.98% (27.75)	70.75% (20.44)	75.00% (12.48)

more ... saying words first without any prompting'. Child 6's parent noted that 'she started using a lot of words without prompting. She's saying new words every day'. Child 7's parent reported that 'he understands more'.

Parent outcome measures

Fidelity of PRT implementation. Figure 1 shows that during the pre-training phase, none of the parents met the criterion for fidelity (i.e., implementation of the PRT techniques during a minimum of 75% of the intervals). However, 5 of 8 parents (62.5%; 4 mothers) met the criterion for fidelity during the post-training phase. Four of these parents (50%; 3 mothers) continued to meet the fidelity criterion at follow-up.

More specifically, all parents demonstrated increased skill levels after training, with Parents 1, 2, 4, 6, and 7 meeting the criterion for fidelity post-training. Three parents (Parents 1, 2, and 5) continued to make at least slight gains at follow-up (mean increase of 11.2%, 3.0%, and 14.8%, respectively). The other five parents (Parents 3, 4, 6, 7, and 8) displayed either no change or a slight decrease in fidelity between post-training and follow-up (mean decrease of .6%, 4.4%, 6.7%, 1.5%, and 4.0%, respectively).

Overall, parents' fidelity of implementing PRT techniques improved significantly after training ($Z = -2.25$, $p < .05$, $d = 2.09$; mean change = 27.16%, range = 12.0–44.4%), and this gain was maintained at follow-up ($Z = .0$, $p > .05$, $d = .13$).

Self-efficacy. In general, parents demonstrated high levels of perceived self-efficacy pre-training. However, for the two parents with lower pre-training levels of self-efficacy (Parents 4 and 5, whose scores

were at least one SD below the mean of a clinical sample; Hastings & Brown, 2002), scores increased to within the average range by follow-up ($M = 13.0$ and 20.0, for pre-training and follow-up, respectively). Overall, there was no significant difference in parental self-efficacy scores between pre- and post-training ($Z = -.42$, $p > .05$, $d = .32$; $n = 6$), or between post-training and follow-up ($Z = -.95$, $p > .05$, $d = .06$; $n = 6$).

Parent satisfaction. Overall, parents found the whole training experience to be very helpful ($M = 9/10$). They rated the training sessions as being very helpful ($M = 8.7/10$) and the training manual as fairly helpful ($M = 7.1/10$). Parents rated the training in PRT as being more helpful in increasing their child's language ($M = 7.6/10$) than decreasing disruptive behaviour ($M = 5.2/10$). All of the parents' qualitative comments were very positive. For example, one parent stated 'I found the training very helpful. It made me feel much more confident in what I'm doing.' Another parent said 'I'm amazed at how little effort on our part can create such a big change for our child so far.'

Time implementing PRT. Overall, parents reported spending .5 to 2 hours a day implementing PRT with their children, with a range of 4 to 10 hours a week. Note, however, that parents reported that it was difficult to estimate the amount of time they spent doing PRT, because they were incorporating the techniques into routines throughout the day.

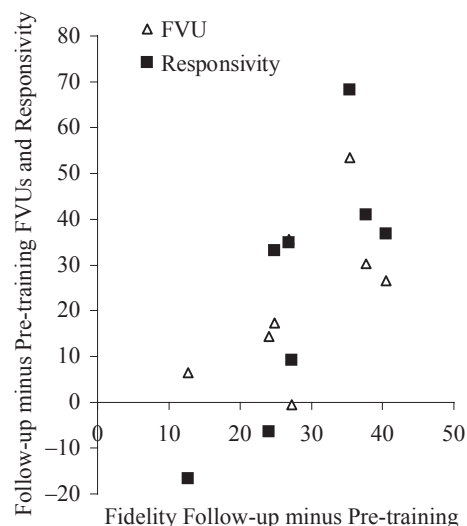


Figure 2 Relationship between change from pre-training to follow-up in mean percentage of intervals during which parents implemented PRT techniques (fidelity), and change in mean percentage of intervals during which the child produced (a) functional verbal utterances (FVUs; triangles) and (b) appropriate child responses (responsivity; squares)

Relationship between parent fidelity and child communication

No significant correlation was found ($r_s = .12$, $p > .05$) between changes in parent fidelity and child FVUs from pre-training to post-training. However, parent fidelity and child FVUs were moderately correlated from pre-training to follow-up ($r_s = .50$, $p < .05$), indicating that as the fidelity of parents' implementation of PRT skills increased, child FVUs also increased (see Figure 2). Similarly, there was no relationship between changes in parent fidelity and changes in child responsivity from pre- to post-training ($r_s = -.05$, $p > .05$). However, there was a strong correlation between pre-training and follow-up ($r_s = .88$, $p < .05$), indicating that the degree to which parent PRT skills improved was related to the extent to which child responsivity increased (see Figure 2).

Discussion

The present study is the first to systematically evaluate the efficacy of brief (6-hour) training in PRT for parents of young children with autism. This was accomplished using a non-concurrent multiple baseline (across-participants) design with eight families. The eight preschoolers (1 girl) were all diagnosed with autism and ranged in cognitive and language ability from mildly to severely impaired, with the majority of children falling in the severe range (e.g., with little or no expressive language).

In terms of communication, the overall frequency of child FVUs increased after training and was maintained at the 2- to 4-month follow-up. This finding is consistent with previous studies that have shown increases in children's communication following parent training in PRT (e.g., Laski, Charlop, & Schreibman, 1988; R.L. Koegel et al., 2002; Openden, 2005). Notable, however, is that despite only 6 hours of training, our average increase in FVUs from pre- to post-training (25.8%) is comparable to that reported by Openden (2005) following 20 hours of group parent training (18.5%).

In the present study, gains in FVUs following training were maintained at follow-up, although this varied across the children with autism. Unlike the other children, Child 6, a very young and cognitively delayed child, made minimal gains from pre- to post-training (a short time); however, her gains at follow-up were large. This finding raises the possibility that very young (under 36 months) cognitively delayed children may take longer to respond to treatment than older preschoolers or preschoolers at a more advanced developmental level. Among the remaining children, two (Children 1 and 5) continued to make gains at follow-up, while the others (particularly Children 2 and 8) did not maintain their post-training gains at follow-up. Child 8 was

sick for one month during the follow-up period, which might account for the decrease in FVUs. For Child 2, there were fewer language opportunities (i.e., times when the parent creates an opportunity for the child to communicate) during follow-up compared to the post-training phase (91 vs. 206, respectively, as coded from videos). Providing fewer language opportunities likely has a major impact on the percentage of FVUs, as the children were making few initiations (i.e., < 22% of their utterances) and communicating primarily when a language opportunity was provided by their parents. Therefore, decreases in FVUs for Children 2 and 8 may not represent 'true' decreases in communication skills. Conversely, it is important to note that increases in communication did not appear to be attributable to increases in the number of language opportunities provided.

The communication changes reported here were explored further by examining the nature of child utterances. After training and at follow-up, the children were more likely to provide an appropriate response to their parents' prompts (responsivity), instead of responding inappropriately or not at all. This pre- to post-training change in more appropriate responding (20.9%) parallels that obtained following a 20-hour group parent training programme (21.0%; Openden, 2005), and again in our study was maintained at follow-up. When looking specifically at the degree to which the children were prompted to respond, there were no overall changes in model-prompted responses, initiations, or inappropriate responses. However, child responses to indirect prompts, which are higher-level than those modelled directly, increased after training and were maintained at follow-up. Some studies have demonstrated increases in child initiations when they are targeted (e.g., L.K. Koegel, Camarata, Valdez-Menchaca, & R.L. Koegel, 1998; L.K. Koegel, Carter, & R.L. Koegel, 2003). However, these studies examined treatment delivered by clinicians, not parents. Laski and colleagues (1988) found an increase in spontaneity for 4/8 children following 5 to 9 sessions of parent training in the natural language paradigm (an earlier version of PRT). Owing to the brevity of the training in the current study, initiations were not specifically targeted. Thus, it was not surprising that verbal initiations did not show significant change. Some parents did report informally that their child was initiating more (primarily requests) following training.

With regard to standardised test performance, two of the 8 children on the PLS-4, and 3 out of the 5 children testable on the PPVT-III, demonstrated age equivalence increases equal to or greater than expected over a 4- to 6-month period (the duration of the intervention). In addition, there was a trend toward an increase in expressive language, which future studies might replicate with larger numbers.

In the present study, increases in communication were not mirrored by decreases in disruptive behaviour. This was likely due to floor effects, as the majority of children displayed minimal levels of disruptive behaviour throughout the study. For the two children who did demonstrate higher levels of disruptive behaviour prior to training, this decreased either immediately after training or by follow-up.

Looking specifically at parent outcomes, the results from this study indicate that parents' ability to implement PRT techniques increased after brief training and was maintained 2 to 4 months following training. On average, parents' fidelity of implementation score increased by 27% following only 6 hours of training. Prior to training, none of the parents met the criterion for fidelity of implementation (>75%). However, following 6 hours of training, this criterion was met by 5 and 4 of 8 parents at post-training and follow-up, respectively. Although pre-training fidelity scores may have been elevated for parents who completed the More than Words parent training programme (which incorporates child choice, one of five main PRT techniques), the two parents (of Children 1 and 2) who did not were not distinguishable on the basis of their PRT fidelity data. However, we acknowledge that it is unknown whether PRT training was enhanced by the parents' previous More than Words experience.

In comparison, Stahmer and Gist (2001) reported that only 4 of 11 parents who completed 12 hours of PRT training without a support group mastered the techniques. Thus, even though the parents in our study received less training (6 vs. 12 hours), more demonstrated mastery of the techniques post-training (62% vs. 36%). It is unclear why these findings are discrepant, as the characteristics of the participants in the two studies are similar. One difference is that the training provided in the present study was more concentrated (i.e., 6 hours over 2 weeks vs. 12 hours over 12 weeks), which may have enhanced parent learning. Other potential contributing factors include the prior completion of the More than Words programme by most parents in the current study, and cross-study differences in training style.

We also note that both mothers ($n = 5$) and fathers ($n = 3$) participated in the present study. Four out of 5 mothers (80%) compared to 1 out of 3 fathers (33%) met the criterion for fidelity of PRT implementation post-training. In related work, Seung, Ashwell, Elder, and Valcante (2006; $N = 8$) reported no difference between mothers and fathers in the acquisition of two skills for promoting their child's social reciprocity. Unfortunately, the interesting issue of possible sex differences in training uptake remains outstanding, as the small samples in both studies preclude any conclusions.

While parents' ability to implement the PRT techniques increased, there was no overall increase in parental self-efficacy following training. However, most of the parents had high levels of parental

self-efficacy throughout the study (which might also have been elevated by their prior participation in parent training). For the two parents who had relatively low parental self-efficacy prior to training (both of whom had completed prior parent training), self-efficacy did increase considerably following training. This suggests that brief parent training in PRT may increase parental self-efficacy for parents who have low self-efficacy from the outset. The lack of change in parental self-efficacy for those remaining could be due to several factors, including a ceiling effect or the use of a questionnaire which focused specifically on parents' perceptions of their ability to handle their child's behaviour problems, which was not the focus of the intervention (and possibly less of an issue in this sample).

Parents reported that the whole training experience was very helpful, particularly in increasing their child's language. The training sessions, which included in vivo feedback, were considered to be more helpful than the manual, which was reported as being fairly helpful. Critical here in planning future training programmes is that parents perceived the training package, particularly the individual sessions, as being highly beneficial. In addition, it will be important for future research to measure parent satisfaction at follow-up as well as immediately after training.

Of the studies that have assessed parent fidelity of implementation, this is one of the few to investigate the relationship between changes in parents' skills and child outcomes. We provide evidence for a relationship between the extent to which parent skill level increased and the magnitude of improvement in child communication following training. This finding, evident on two measures at follow-up, is critical, as it highlights the importance of focusing on fidelity of treatment when providing an intervention or evaluating its impact on children's skill development.

The present multiple-baseline (across-participants) design controls for temporal or developmental effects between pre- and post-training; however, the pre-training phase (3 to 7 weeks) was shorter than the follow-up phase (2 to 4 months). Therefore, development could have contributed to changes between the post-training and follow-up phases. A further limitation is that the design does not allow comparison of brief parent training in PRT to another intervention. Now, with positive preliminary findings, a randomised clinical trial (RCT) would provide stronger evidence for the efficacy of brief parent training in PRT. An RCT would also provide an opportunity to assess the generalizability of our findings, which are based on only 8 parent-child dyads. Most parents who volunteered to participate in this study were of middle to upper-middle socioeconomic status, had previously participated in a parent training programme (i.e., More than Words), and displayed some skill in PRT techniques prior to

training. Therefore, the results may not generalise to other families with preschoolers with autism. However, 8 is considered a large sample for a single-subject design. Moreover, the pattern of changes in both parent and child behaviour, although modest, was fairly consistent across all 8 parent-child dyads, and the compelling relationships between parents' fidelity of treatment and child gains, both strengthen the conclusions drawn from the study.

Finally, the present findings may have implications for clinical practice. In the face of long waiting lists and delays in treatment services, providing parents with early brief training focused on enhancing their children's communication may improve the children's prognosis. We consider these results of parent-implemented PRT to be promising. However, the small effects evident in a recent RCT study investigating another parent training programme are sobering (Green et al., 2010). Future research will help to determine what type and intensity of parent training is required to optimise treatment effects. We are particularly optimistic that training might enhance parents' confidence and self-efficacy in supporting their children's development. Our parent training programme was not resource or time intensive. It might therefore be feasible for families living in both rural and urban areas, and for various professionals who are involved in the care and education of children with autism.

Supplementary material

The following supplementary material is available for this article:

Appendix A. Functional verbal utterance operational definition;

Appendix B. Definitions for the nature of child utterances;

Appendix C. Fidelity of implementation operational definitions (Word document)

This material is available as part of the online article from:

<http://onlinelibrary.wiley.com/doi/abs/10.1111/j.1469-7610.2010.02326.x>

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Key points

- Training parents in pivotal response treatment/training (PRT) has been shown to increase communication in children with autism.
- To date, most studies have evaluated 25 hours of training, although preliminary evidence suggests that less intensive training may still be effective.
- The current study demonstrates that after brief (6-hour) parent training, child communication and parent skills increased, and generally were maintained 2 to 4 months following training.
- Improvements in parents' ability to implement PRT techniques were associated with improvements in child communication.
- Brief parent training promises to provide an immediate cost-effective intervention that could be adopted widely.

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Anexo III

Flippin, M. & Crais, E. (2011). The Need for More Effective Father Involvement in Early Autism Intervention: A Systematic Review and Recommendations. *Journal of Intervention*, 33(1), 24-50. Índice de impacto: JCR (Journal Citation Reports) 2014: 0.828.



The Need for More Effective Father Involvement in Early Autism Intervention

A Systematic Review and Recommendations

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Fathers of children with autism spectrum disorders (ASD) are underrepresented in both early intervention and research. However, fathers have unique interaction styles that make important contributions to the language and symbolic play development of typically developing children. Fathers may make similar contributions to the development of their children with ASD, who struggle with social-communicative deficits, particularly in the areas of language and symbolic play. This article provides a theoretical rationale for enhancing father-child involvement in early autism intervention that may lead to improved outcomes in child communication and symbolic play and have cascading benefits for families in reducing stress and enhancing coping mechanisms. To support this rationale, systematic reviews of the literature were conducted to (a) identify the extent of father involvement in parent training programs for children with autism, (b) identify the contributions of parents to the symbolic play outcomes of their children with ASD and other disabilities, and (c) examine differences in stress and coping experienced by mothers and fathers of children with ASD. Finally, possible barriers to father participation in early autism intervention are discussed and recommendations are offered for making parent-implemented early intervention for children with ASD more amenable to fathers.

Keywords: *autism; fathers; language; play; parent stress*

Over the past three decades, there has been growing interest in fathering and an emerging body of literature on the impact of fathers on child outcomes. Overall, fathers are increasing the amount of time they spend caring for their children and are more directly involved with their children than fathers of past generations, effectively shifting from bread-winning to coparenting roles (Pleck & Masciadrelli, 2004). In fact, according to the U.S. Census Bureau, although the number of stay-at-home fathers is still relatively small (i.e., 1%), fathers are now estimated to be the primary caregivers for 24% of preschool-age children with working mothers. Given the increased evidence of the greater coparenting role and more direct involvement of fathers with their children, one would expect greater participation of fathers in early intervention for their children with autism spectrum disorders (ASD).

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Unfortunately, this does not always appear to be the case. Despite the move to a “family-centered” model (Bruder, 2000) with greater caregiver participation in key components of early intervention (Crais, Poston Roy, & Free, 2006), mothers continue to be the primary and often exclusive participants in both autism research and early intervention service delivery. This one-parent participation model, however, ignores the growing literature that indicates that mothers and fathers each play an early and integral role in the development of their children, perhaps particularly in their social and communicative skills (Clarke-Stewart, 1980; Pancsofar & Vernon-Feagans, 2006; Shannon, Tamis-LeMonda, London, & Cabrera, 2002; Tomasello, Conti-Ramsden, & Ewert, 1990). Therefore, for children with communication and social deficits such as ASD, understanding and enhancing the role of fathers may be an important direction in both research and clinical practice. Moreover, there is evidence that responsive fathering is a strong predictor of better developmental outcomes for children, including improved emotional regulation and cognitive and language development (Shannon et al., 2002; Tamis-LeMonda, Shannon, Cabrera, & Lamb, 2004). If professionals are not involving fathers in early ASD intervention, they may be missing important opportunities to maximize social-communicative gains for these children. Overlooking fathers in intervention and research also may have unintended consequences for families, including increased levels of parental stress and decreased family cohesion. For instance, Tehee and colleagues (Tehee, Honan, & Hevey, 2009) reported high levels of stress in mothers of children with ASD and concluded that these high stress levels may be the result of the challenge of taking on the dual roles of caregiver and intervention provider. Thus, increased father involvement in intervention services may ease the overall workload for mothers and serve to reduce maternal stress. Indeed, enhancing the role of fathers in the development of children with communication and social deficits such as ASD could be an important direction in realizing optimal “family-centered” services for children with ASD and their families (Gable, Crnic, & Belsky, 1994; Magill-Evans & Harrison, 1999; Shannon et al., 2002). There is, however, a paucity of research on father contributions to social communication outcomes for children with ASD, and an added emphasis in this area is strongly needed.

In an effort to influence the field to attend more fully to fathers, we provide in this article a theoretical rationale for more effective father involvement by describing the unique roles of mothers and fathers with their young children in relation to communication, play, parental stress, and family cohesion. To support this rationale, we conducted systematic reviews of the literature to (a) identify the extent of father involvement in parent training programs for children with autism, (b) identify the contributions of parents to the symbolic play outcomes of their children with ASD and other disabilities, and (c) examine differences in stress and coping experienced by mothers and fathers of children with ASD. Finally, to further guide the field, we provide recommendations for future studies of father-child interaction and for making parent-implemented intervention for young children with ASD more amenable to fathers and their unique interactional styles.

Deficits in Social-Communicative Development in Children With ASD

Beginning early in life, children with ASD demonstrate severe deficits in language and social-communicative skills that limit their ability to participate in effective communicative

exchanges (Wetherby, Prizant, & Hutchinson, 1998). These communication deficits are parents' primary concern at time of referral and for many remain a concern throughout the child's school years (Lord, Risi, & Pickles, 2004). Although estimates vary, approximately 25% of children with ASD do not develop functional speech (Volkmar, Lord, Bailey, Schultz, & Klin, 2004). Therefore, for these families, helping the child develop some form of communication is vital. As is the case for children who are typically developing, there is growing evidence that the quality of early parent-child exchanges is particularly important for language acquisition for children with ASD (Siller & Sigman, 2002, 2008). Given the early communicative and social deficits characteristic of ASD, coupled with the fact that acquisition of some functional language before the age of 5 years is a strong predictor of further language development (Venter, Lord, & Schopler, 1992), the issue of effective parent involvement in early intervention for these children becomes paramount. In fact, studies of mother-child interactions (Siller & Sigman, 2002, 2008) have shown that when mothers of preschoolers with ASD use more undemanding utterances, or comments, which reinforce or maintain the child's ongoing activity, their children demonstrate better language abilities throughout adolescence. Although similar studies have not yet been conducted for fathers, and are needed, fathers too make important contributions to a child's language and play development. However, fathers have interaction and communication styles that are unique from those of mothers. Before moving to discuss fathers' roles in early intervention with their child with ASD, it is first helpful to understand fathers' unique contributions to child development as well as fathers' unique needs.

Fathers' Unique Contributions to Language Development in Typically Developing Children

Studies of father-child interactions with children who are typically developing have established that fathers offer unique language models, which make important contributions to children's language development (Clarke-Stewart, 1980; Gleason, 1975). Overall, fathers tend to use a higher level vocabulary and a more complex language model with their children than do mothers. For instance, compared to mothers, fathers use vocabulary that is more varied, rarer, and more abstract (Bernstein-Ratner, 1988; Gleason, 1975; Masur & Gleason, 1980; Pancsofar & Vernon-Feagans, 2006; Rondal, 1980). Fathers also use more lexically challenging syntax. For example, fathers are more likely than mothers to direct questions to their children. Moreover, most fathers' questions are "wh" questions that are more complex than the "yes-no" questions more frequently used by mothers (McLaughlin, Schultz, & White, 1980; Walker & Armstrong, 1995). This higher level language model used by fathers has an important role in communicative outcomes for typically developing children.

In seminal work highlighting fathers' influences, Gleason (1975) hypothesized that fathers' complex language models provided the child with a bridge from the supportive language of home to the more complex linguistic demands of the outside world. In Gleason's model, children were tasked by their fathers with speaking more coherently and clarifying misunderstandings, which helped foster their communicative development. Tomasello and colleagues (1990) found support for this "bridge hypothesis" in their observations that fathers' child-directed speech was closer in form to that of speakers outside the family. Indeed, Tomasello and colleagues also documented that children used higher level language with their fathers,

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when compared to language used with their mothers, as well as with unknown examiners. Although the finding that children used similar language with fathers and strangers may support the "bridge hypothesis," conversely it may also be explained by the possibility that the children had less contact with their fathers (particularly 20 years ago, when this work was published). This lack of contact also may account for the more frequent communicative breakdowns fathers experienced with their children (Tomasello et al., 1990).

There is some evidence, however, that fathers' more linguistically challenging style may indeed support child vocabulary development. In fact, fathers' vocabulary use at 24 months has been shown to predict levels of child expressive language 1 year later at 36 months (Pancsofar & Vernon-Feagans, 2006), whereas mothers' language did not account for a significant portion of the variance. Thus, fathers in current times also have been reported to use more linguistically challenging models with their children. Reciprocally, children have been shown to use higher level language with fathers, including longer and more complex utterances (Masur & Gleason, 1980; Rondal, 1980) and more advanced narratives (Tomasello et al., 1990). Through these transactional exchanges with their fathers, typically developing children develop more complex language, greater awareness of the impact of their communicative signal on others, and an understanding of the need to clarify misunderstood messages. Although it is likely that these father-child exchanges also support communicative development for children with ASD, there are few studies available to provide confirmation.

Fathers' Contributions to Language Development in Children With ASD and Other Developmental Disabilities

Despite the numerous unique contributions of fathers' language models to child language development, paternal language styles have also been reported at times to be more directive than those of mothers (Brachfeld-Child, Simpson, & Izenson, 1988; Malone & Guy, 1982). For typically developing children, directive parental interaction styles often have negative connotations and have been associated with authoritarian parenting styles and poorer developmental outcomes (Baumrind, 1991; Weiss & Schwarz, 1996). For children with disabilities, however, the relationship between directive parent-child interactions and developmental outcomes is not as clear. In general, parents of children with disabilities have been shown to use more directives in interaction with their children as compared to parents of children who are typically developing (Dunst, 1985; Pellegrini, Brody, & Siegel, 1985; Tannock, 1988). There is some debate, however, as to whether the directive language used by parents is facilitative for children with disabilities. For example, Mahoney (1998) reported a negative relationship between the frequency of directives used by parents of children with Down's syndrome and parents' level of responsiveness to their child's communication. On the other hand, Cielinski and colleagues (Cielinski, Vaughn, Seifer, & Contreras, 1995) noted that whereas mothers of children with Down's syndrome were more directive of their child's play, compared to mothers of typically developing children, this directiveness was also significantly correlated with the proportion of time their child was engaged in play. In contrast, for the typically developing children in the study, maternal directiveness was not correlated with sustained play engagement. Thus, there is some evidence that directiveness may be facilitative for children with disabilities.

difficulty these mothers had in establishing a joint focus of attention with their children with ASD. Furthermore, Siller and Sigman (2002) documented that preschool-age children whose mothers used more utterances that referenced the child's focus of attention had superior joint attention and language skills 16 years later, compared to children whose mothers used fewer responsive utterances. Given the impact of maternal follow-in directives, it is likely that some aspects of father directive language also may provide support to children with ASD in learning language; however, little is known about potential differences in directives used by fathers.

A second important factor in examining whether fathers' directive models support the language development of their children with ASD is the degree to which fathers are able to match their language models to their child's level of communicative competence. For example, in studies of interactions between mothers and their children with Down's syndrome, Mahoney (1998) noted that although some types of maternal follow-in directives were indeed facilitative, those follow-in directives that placed the burden on the child to produce behaviors that exceeded his or her current level of development did not elicit the desired response from the child. Matching directive parental language models to child competency levels may be particularly important for fathers, as fathers in general have been shown to use more complex language models with their children than mothers (Bernstein Ratner, 1988; Gleason, 1975; Masur & Gleason, 1980; Pancsofar & Vernon-Feagans, 2006). However, previous studies have not analyzed the types of directives used by fathers to help with this distinction.

Finally, there is also evidence to suggest that fathers' directive communication styles may be facilitative in improving their children's social awareness from a pragmatic standpoint. For instance, Pellegrini, Brody, and Stoneman (1987) reported that although mothers tended to ignore their typically developing child's violations of conversational conventions, fathers used these opportunities to provide feedback to their child through repetition, modeling the correct response and sometimes requesting clarification. For children with ASD who inherently have impaired social awareness of the impact of their communicative signals on other people, this directive, didactic, pragmatic style may support their language development and help them to clarify their message, thus increasing their awareness of the impact of their communication on others. Therefore, although we acknowledge the fact that not all directive language is facilitative of language development, we recognize that some aspects of fathers' direct communication styles may indeed play a supportive role in fostering a child's communication development. However, further research is needed on the language and interaction styles of fathers with their child with ASD to directly examine the correlation between fathers' language models and the child's communicative ability. To investigate the extent to which fathers are currently involved in "parent"-implemented intervention for young children with ASD, we examined the existing literature.

Systematic Review of Fathers' Participation in Parent-Implemented Interventions for Children With ASD

Literature Search Strategy

The studies reviewed were identified for inclusion in this synthesis through a three-step process. First, searches were conducted to identify articles related to parent intervention

with their child with ASD that were published in English, in a peer-reviewed journal, between 1990 and November 2010, in the following databases: Academic Search Premier, PsycINFO, ERIC, and Cumulative Index to Nursing and Allied Health Literature (CINHAL). Search terms entered into the databases included *parent*, *autism*, *training*, *intervention*, *father*, and *mother*. Next, reference lists from articles that met inclusion criteria were examined to identify additional studies. Finally, to identify additional studies that were not captured through previous searches, reference lists were examined from three relevant literature reviews of parent training for children with ASD (i.e., Levy, Kim, & Olive, 2006; McConachie & Diggle, 2007; Schertz, Baker, Hurwitz, & Benner, in press). The systematic search identified 114 articles.

Inclusion Criteria

Only empirical studies (i.e., single-subject experiments and controlled group designs) that met the following criteria were included in the review: (a) participants included at least one child participant with ASD between the ages of 2 and 5 years and their parents, mother and/or father; (b) outcome measures included child social-communicative skills (i.e., verbal or nonverbal communication, imitation, social interaction, joint attention); and (c) parents were the agent of intervention. Studies with outcomes that did not include communication (e.g., problem behaviors, sleep behaviors) and studies in which interventions were primarily delivered by research staff and other professionals with an additional parent component were not included in this review.

Results

A total of 27 articles met criteria for inclusion in this synthesis. Two studies (Elder, Valcante, Yarandi, White, & Elder, 2005; Seung, Ashwell, Elder, & Valcante, 2006), which reported data from the same participants, were considered as a single study for purposes of this review. Table 1 describes the study design and the extent of father involvement reported in each. Of the resulting 26 articles (i.e., 11 controlled group studies and 15 single-subject experiments) examining parent intervention in ASD, four group designs and 10 single-subject experiments explicitly stated that participating parents were mothers. Seven group studies and two single-subject experiments did not specifically report whether fathers were included among the parents participating in intervention. Only three studies (Elder et al., 2005; Rocha, Schreibman, & Stahmer, 2007; Symon, 2005) specifically reported the involvement of fathers in parent training for children with ASD. In a study by Rocha and colleagues (2007), one of the three participating parents was the father of a child with ASD. In the study by Symon (2005), one of the three participating mothers trained a father as a secondary therapy provider, although in that study mothers were the primary intervention agents. In the single-subject experiment conducted by Elder and colleagues (2005), 18 fathers of children with ASD were taught to implement two intervention strategies. In a follow-up analysis of verbal communication outcomes for eight of the child participants in that study, Seung and colleagues (2006) examined the gains in verbal language made by a subset (i.e., 8 out of 18) of participating children.

Table 1
Summary of Parent Training Studies for Young Children With Autism Spectrum Disorder and the Extent of Father Involvement Reported in Each

Reference	Study Design	Father Involvement Reported
Aldred et al. (2004)	RCT	Mothers only
Ben Chaabane et al. (2009)	SSD; MBL × participants	Mothers only
Brookman-Frazee (2004)	SSD; repeated reversal	Mothers only
Drew et al. (2002)	RCT	Not specified
Elder et al. (2005); Seung et al. (2006)	SSD; MBL × strategies; secondary analysis	18 fathers
Gillet & LeBlanc (2007)	SSD; MBL × participants	Mothers only
Ingersoll & Gergans (2007)	SSD; MBL × participants	Mothers only
Jocelyn et al. (1998)	RCT	Not specified
Kaiser et al. (2000)	SSD; MBL × families	Mothers only
Kasari et al. (2010)	RCT	Not specified
Kashinath et al. (2006)	SSD; MBL × strategies	Mothers only
Mahoney & Perales (2005)	Matched groups	Mothers only
Mancil et al. (2009)	SSD; MBL × participants	Mothers only
McConachie et al. (2005)	Group; intervention, wait-list control	Mothers only
Moes & Frea (2002)	SSD; MBL × participants	Not Specified
Oosterling et al. (2010)	RCT	Mothers only
Ozonoff & Cathcart (1998)	Group; matched	Mothers only
Reagon & Higbee (2009)	SSD; MBL × participants	Mothers only
Rocha et al. (2007)	SSD; MBL × participants	"Two mothers and one father participated" (p. 156)
Schertz & Odom (2007)	SSD; MBL × participants	Mothers only
Smith et al. (2000)	Group; random matched pair	Not specified
Stahmer & Gist (2001)	Group (pre-post with control)	Not specified
Symon (2005)	SSD; MBL × participants	For 1 of 3 participating families, mother trained father as secondary therapy provider
Vismara et al. (2009)	SSD; MBL (nonconcurrent)	Not specified
Vismara & Lyons (2007)	SSD; alternating treatments	Not specified
Wong & Kwan (2010)	RCT	Not specified

Note: RCT = randomized controlled trial; SSD = single-subject design; MBL = multiple baseline design.

Recommendations

Although the body of literature on parent-implemented communication intervention for young children with ASD has grown over the past 30 years, only three single-subject experiments reviewed in this synthesis specifically reported that fathers participated in parent-training. In 8 of the 25 studies, the authors did not specify whether fathers participated. An assumption of many "parent-training" studies seems to be that outcomes for mothers also apply to fathers. However, as discussed, fathers have language models that are unique

from those of mothers and therefore may have a unique influence on the communication development of their children with ASD. Thus, the need for greater father involvement in communication intervention and research for children with ASD is clear. Further research is also needed on the communicative contexts within which fathers and their children with ASD interact, which is most often through play. Given that fathers also have unique play-interaction skills, involving them in early play-based intervention may be beneficial for children with ASD who have severe deficits engaging in object play.

Rationale for Involving Fathers in Play-Based Early Autism Intervention

Play is one of the most significant tasks of child development, requiring cognitive, social, and emotional skills, and parents have an integral role in the development of their child's play skills. Symbolic play with objects has been shown to be an important predictor of later language development for typically developing children and those with ASD (Charman et al., 2003; Toth, Munson, Meltzoff, & Dawson, 2006).

In typical development, object play emerges in a generally smooth trajectory over four increasingly sophisticated phases. The first phase, *exploratory play*, emerges between 2 and 10 months. At this stage, the child begins to investigate properties of a toy through indiscriminate actions and simple manipulations. For example the child may hold a ball or mouth a toy. At around 10 to 18 months of age, *relational play* emerges. During this stage, the child starts to combine two or more toys in play. For example the child may stack rings, nest cups, or put toys into a bucket. The third phase, *functional play*, emerges between 12 and 18 months. In this phase, the child begins to use toys and miniatures as intended but without clear evidence of pretense. For example, the child may sweep with a toy broom. Finally, the fourth phase, *symbolic play*, emerges around 18 to 30 months. In this phase, the child starts to substitute one object for another (e.g., a banana for a phone) and begins to engage in more elaborate pretend schemas, imagination, and fantasy play (Casby, 1991; Lifter, Sulzer-Azaroff, Anderson, & Cowdery, 1993; Ungerer & Sigman, 1984).

In contrast to the smooth trajectory in play skills for typically developing children, most children with ASD do not follow this same trajectory of play development (Libby, Powell, Messer, & Jordan, 1998). Rather, children with ASD demonstrate severe deficits in play development. Overall, the play of children with ASD is less elaborate and more repetitive (Williams, Reddy, & Costall, 1996). For instance, children with ASD spend a longer period engaging in exploratory play, past the point at which typically developing children move on to more sophisticated levels of play (Jordan & Libby, 1997). It follows that children with ASD spend less time than their typically developing peers engaged in the more sophisticated levels of functional or symbolic pretend play (Baranek et al., 2005; Jarrold, Boucher, & Smith, 1993). Thus, play represents an important skill for children to acquire, and higher levels of object play skills have been shown to be strong correlates of language ability for both typically developing children and children with ASD (McCune, 1995; Mundy, Sigman, Ungerer, & Sherman, 1987).

Although both mothers and fathers help their children achieve higher level language and symbolic abilities through play, there are qualitative and quantitative differences between parents in play interactions with their children. For instance, father-child play is more

active and rough-and-tumble. Father-child play is also more generative, with fathers being more likely than mothers to engage in play schemas that stretch beyond the physical properties of the toys (Labrell, 1996). Although for most North American families the role of mothers in the family is primarily one of caregiver, the playing role in the family is more frequently associated with fathers (Pleck & Masciadrelli, 2004). As their child's first and primary play partner, fathers have a distinctive role in supporting their child's development through play. The contributions of fathers to their child's symbolic play development, however, have not been fully examined in the ASD literature. Importantly, the work of Kasari and colleagues (Kasari, Freeman, & Paparella, 2006; Kasari, Paparella, Freeman, & Jahromi, 2008) has demonstrated that interventions targeting higher level functional and symbolic play can improve both play and language outcomes for children with ASD; however, the intervention did not specifically target fathers.

Although it is likely that fathers of children with ASD demonstrate play styles similar to those used by fathers in interactions with typically developing children, it may also be the case that the bidirectional impact of a child's ASD affects the type of play fathers typically use. In one study, for example, fathers of children with ASD engaged in less parallel play than mothers while being more directive and less consistently responsive to their child's initiations (Elder, Valcante, Won, & Zylis, 2003). The four fathers in that study also reported being frustrated in not knowing how to play with their children with ASD. From a parental perspective, it may be more difficult to engage in play with a child who continues to play at lower levels than a child who has more complex and perhaps more varied play. However, fathers may be uniquely suited to support the play development of their children with ASD. Moreover, by enhancing play skills, fathers can not only gain more varied contexts within which to interact with their child but also enhance their child's language and social skills.

Systematic Review of the Literature on Parents' Contributions to the Symbolic Play Outcomes of Children With ASD and Other Developmental Disabilities

Given that our search of the literature on parent training in ASD yielded only three studies that specifically reported father involvement, we did not expect to find a study of father-implemented intervention focused on symbolic play outcomes for children with ASD. Therefore, we expanded our search to include studies of mothers and fathers of both children with ASD and children with other developmental disabilities.

Literature Search Strategy

A three-step, systematic search of the literature was conducted following the methods previously described. Search terms included *parent*, *play*, *autism*, *developmental delay*, *mother*, and *father*. The initial search returned 97 articles. Articles were then reviewed to determine whether they met criteria for inclusion described as follows.

Inclusion Criteria

Inclusion criteria included the following: (a) outcome variables included measures of symbolic level of object play and (b) participants were mothers and fathers of children with ASD or other developmental disabilities.

Results

As expected, our search of the literature identified no intervention studies examining fathers' impact on symbolic play outcomes for their children with ASD. The expanded search identified three relevant articles: one observational study examining fathers' contributions to the symbolic play of children with Down's syndrome and two studies that measured symbolic play as an outcome of parent training for children with ASD. Table 2 describes the studies included in the expanded search. In the observational study of 19 children with Down's syndrome and their fathers, de Falco and colleagues (de Falco, Esposito, Venuti, & Bornstein, 2008) reported that children achieved significantly higher levels of symbolic play in interaction with their father than they demonstrated in solitary play. In the two studies of parent-implemented intervention (Kasari, Gulsrud, Wong, Kwon, & Locke, 2010; Wong & Kwan, 2010), children with ASD made gains in the symbolic level of their object play, although neither study reported whether fathers took part in the intervention. The study by Wong and Kwan (2010) examined the effects of an intensive 2-week parent training with 17 newly diagnosed children with ASD and their parents in Hong Kong. The intervention targeted increasing eye contact, gestures, and vocalizations or words. Children showed significant improvement in communication and social interaction as well as significant gains on scores on the Symbolic Play Test (Lowe & Costello, 1995), reflecting that they used a higher degree of symbolic behavior in play following intervention. In the second study (Kasari et al., 2010), results of the effectiveness of mother-implemented intervention on symbolic play skills were mixed. Kasari and colleagues (2010) examined the effects of a parent-implemented intervention aimed at increasing joint attention with 38 children with ASD and their mothers who were assigned to either an immediate treatment or a wait-list control group. Postintervention, children in the immediate treatment group showed more types of functional, but not symbolic, play acts during mother-child play interactions, compared to children in the wait-list group.

Recommendations

Taken together, results from these three studies lend some support to the argument that fathers may make important contributions to the quality of symbolic play for children with ASD and highlight the need for additional studies of father-child play interactions for children with ASD. Play is an important developmental domain, a key context for father-child interaction, and a prime target for early intervention for children with ASD. The contributions of fathers to their child's play development may be especially salient for children with ASD, given the pervasive deficits in play associated with ASD and the link between early play ability and later communicative outcomes (Charman et al., 2003; Toth et al., 2006). By including fathers in early interventions for children with ASD, interventionists

Table 2
Summary of Studies Examining the Impact of Fathers of Children With Developmental Disabilities and Mothers of Children With ASD on Symbolic Play Development.

Reference	Study Design	Participants	Results
de Falco et al. (2008)	Observational; two 10-min sessions (child solitary play; father-child play)	19 children with DS and their fathers	Children with DS showed more high-level symbolic play during father-child than solitary play; father-child dyads with higher emotional availability (EA) scores showed more symbolic play and less exploratory play vs. low EA dyads
Kasari et al. (2010)	RCT intervention: Joint Attention	38 children with ASD; 19 immediate treatment (IT); 19 wait-list (WL) control and their mothers	Children in the IT group displayed significantly more functional play acts but not increased diversity of symbolic play compared to children in the WL control
Wong & Kwan (2010)	RCT intervention: "Autism 1-2-3" vs. Wait-List Control	17 children with ASD and their parents	Intervention targeted (a) eye contact, (b) gesture, and (c) words; children showed gains in communication and social interaction as well as significant improvement in scores on the Symbolic Play Test

Note: ASD = autism spectrum disorder; DS = Down's syndrome; RCT = randomized controlled trial.

capitalize on an important opportunity to recruit the child's primary play partner in targeting social-communicative gains. Indeed, because of fathers' unique interactional styles with their children, they may have a particularly important influence in facilitating play (and language) skills with their young children with ASD. Understanding the unique contributions of fathers to the play skills of their children with ASD may have important service delivery implications for effectively involving all parents in play-based early interventions for children with ASD. One essential step toward effective father involvement is further understanding of the contributions of fathers to the language and play development of children with ASD. In addition, greater father involvement may lead to positive collateral effects for families of children with ASD.

Rationale for the Potential Benefits of Father Involvement on Parental Stress and Family Cohesion

Over the past 30 years, several researchers have documented higher levels of parental stress in families with a child with ASD compared to parents of children who are typically developing as well as those with other developmental disabilities (Dumas, Wolf, Fisman, & Culligan, 1991; Koegel et al., 1992; Sanders & Morgan, 1997). Family systems theory (Turnbull & Turnbull, 1986) would suggest that high levels of parental stress likely have cascading effects on all the relationships in a family. For instance, high levels of parental stress may affect family cohesion, as evidenced by the higher rates of divorce among

families with a child with ASD than among comparison groups (Hartley et al., 2010). This is particularly concerning for the families involved but is also important to interventionists and researchers working with these families. For instance, high levels of parental stress have been shown to reduce the effectiveness of early intervention for children with ASD, particularly for those children receiving more time-intensive interventions (Osborne, McHugh, Saunders, & Reed, 2008). Moreover, there is some evidence that mothers of children with ASD experience even greater levels of stress than fathers of children with ASD (Hastings, Kovshoff, Brown, et al., 2005; Hastings, Kovshoff, Ward, et al., 2005). This may be related to mothers' greater caregiving role (Tehee et al., 2009). Although father involvement in child care is increasing, it continues to be less than mothers (Pleck & Masciadrelli, 2004). Historically within early intervention services, mothers typically played a larger role than fathers because they were more likely at home caring for the children while fathers worked outside of the home and were less available (Murray & McDonald, 1996). It is perhaps a natural extension of their caregiving role that mothers have been the focus of both early intervention services and research in early ASD intervention, despite the move in our field to more "family-centered" models. For example, within the early intervention service system, mothers remain the primary participants in child assessments (Crais et al., 2006) and interventions (Able-Boone, 1993; Polmanteer & Turbiville, 2000).

In focusing primarily on mothers to the exclusion of fathers, however, researchers and interventionists may be placing unstated, unintentional, and unrecognized burdens on mothers. In a qualitative study of mothers participating in the early intervention system, Leiter (2004) reported that interventionists were shown to create a "therapeutic imperative" for mothers, fostering expectations that mothers would learn the therapeutic skills that professionals used with their children and carry these over into the home setting. Furthermore, the mothers who did not perform to the interventionists' expectations were sometimes regarded by the interventionists as "noncompliant." For their part, mothers in the study reported feeling overwhelmed with taking on the role of therapist in addition to their caregiving role and were unsure of their abilities as interventionists. From this study and common current intervention practices, when mothers take on the major responsibilities in early intervention, this may place them in the position of relaying information, potentially "teaching" the other parent techniques, and "monitoring" successes and missteps. In contrast, in his qualitative studies of Australian parents of children with ASD, Gray (2003) theorized that for fathers, the majority of whom worked outside the home, employment provided a respite and may in part explain their lower levels of stress as compared to mothers. Thus, given that fathers of children with ASD appear to experience less overall stress than mothers, involving fathers in early intervention for their children with ASD may have positive outcomes for both children and parents.

Systematic Review of the Literature on Parent Stress and Coping in Mothers and Fathers of Children With ASD

To better understand the differences between fathers' and mothers' experiences of stress and coping, we reviewed the literature on stress and coping for parents of children with ASD.

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Literature Search Strategy

A three-step systematic search of the descriptive and/or qualitative studies of stress and coping in mothers and fathers of children with ASD was conducted using the methods previously described. Search terms included *parent, stress, autism, mother, and father*. The initial search returned 48 articles.

Inclusion Criteria

Articles were examined for the following inclusion criteria: (a) participants included both mothers and fathers of children with ASD ages 2 to 5 years, (b) study outcomes included parental stress and/or coping, and (c) results were reported separately for mothers and fathers.

Results

A total of 17 studies met criteria for inclusion in this synthesis. For the purposes of this review, 2 studies that analyzed data from the same participants (Hastings, Kovshoff, Brown, et al., 2005; Hastings, Kovshoff, Ward, et al., 2005) were considered as a single study. A summary of the 17 included studies is presented in Table 3. Overall, both mothers and fathers of children with ASD were found to have elevated levels of stress compared to parents of typically developing children and parents of children with other developmental disabilities in 4 studies (i.e., Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Brobst, Clopton, & Hendrick, 2009; Dabrowska & Pisula, 2010; Epstein, Saltzman-Benaiah, O'Hare, Goll, & Tuck, 2008). However, results comparing levels of stress experienced by mothers versus fathers of children with ASD were mixed. For instance, mothers and fathers were found to have similar levels of stress in 3 studies (Hastings, 2003; Hastings, Kovshoff, Brown, et al., 2005; Hastings, Kovshoff, Ward, et al., 2005; Ornstein Davis & Carter, 2008). However, in 8 studies, mothers were found to have greater levels of stress than fathers (Dabrowska & Pisula, 2010; Herring et al., 2006; Gray, 2003; Little, 2002; Moes, Koegel, Schreibman, & Loos, 1992; Olsson & Hwang, 2001; Sharpley, Bitsika, & Efremidis, 1997; Tehee et al., 2009). In one study (Twy, Connolly, & Novak, 2007), mothers were also reported to have lower levels of coping compared to fathers. None of the studies included in this synthesis reported that mothers experienced less stress than fathers. Although fathers of children with ASD may have experienced less overall stress than mothers in the majority of included studies, fathers in 2 studies still demonstrated higher levels of stress compared to fathers of typically developing children and children with other disabilities (Herring et al., 2006; Olsson & Hwang, 2001). In contrast, Dabrowska and Pisula (2010) reported that differences in stress levels by gender did not exist for either parents of typically developing children or parents of children with Down's syndrome. Thus, parents of children with ASD may be at risk for elevated levels of stress, with mothers possibly experiencing greater levels than fathers.

Perhaps even more clinically important than examining differences in overall levels of stress of mother and fathers is examining different sources of stress. For instance, in a study by Ornstein Davis and Carter (2008), participating mothers of children with ASD reported problems with their child's regulatory behavior (e.g., sleeping, eating) as their greatest

Table 3
Summary of Studies Comparing Parental Stress and Coping
for Mothers and Fathers of Children With Autism
Spectrum Disorders

Reference	Participants	Findings Reported
Baker-Ericzen et al. (2005)	37 M/F pairs of toddlers with ASD; 23 M/F pairs of TD children	Both mothers and fathers of children with ASD reported significantly higher levels of child and parent-related stress vs. parents of TD toddlers. Following child's participation in inclusion program, mothers of children with ASD reported significant reductions in child-related stress, but no reduction in parent-related stress. For fathers, no changes were reported in either child or parent-related stress. Child's level of social skills was a significant negative predictor of child-related maternal stress for children with ASD.
Brobst et al. (2009)	25 M/F pairs of children with ASD; 20 M/F pairs of TD children	Compared to parents of TD children, parents of children with ASD experienced more intense child behavior problems, greater parenting stress, lower relationship satisfaction (groups did not differ on perceived spousal support, respect for partners, or commitment). For mothers, parental stress was negatively related to relationship satisfaction, spousal support, and commitment. For fathers, parental stress was negatively related only to total social support.
Dabrowska & Pisula (2010)	26M/25F of children with ASD; 27M/F pairs of children with DS; 28M/29F of TD children	Parents of children with ASD had higher levels of stress than parents of children with DS or TD. Mothers of children with autism scored higher than fathers in parental stress; these gender differences were not found in the group of parents of children with DS and TD.
Epstein et al. (2008)	39 Scottish parents of children with AS ages 5–12 years	Both mothers and fathers of children with AS reported elevated levels of parenting stress. For mothers, there was a significant positive correlation between parenting stress and the child's level of impairment, with respect to both executive dysfunction as well as sensory difficulties.
Gray (2003)	Australian parents 32M/21F of children with ASD or AS (53 parents from 21 families)	Different gender roles for mothers and fathers affected the ways they were influenced by child's autism. Mothers were more likely to experience emotional distress and career disruption, to be taking primary responsibility for medical referral process, to have dealt with child's educational problems, and to have primary responsibility for child's behavior both by husband and people outside family. Fathers claimed child's condition did not have significant personal effect on them; fathers believed most serious impact child's ASD had on them was via stress experienced by their wives.
Hastings (2003)	18 M/F pairs of children with ASD	Mothers and fathers did not differ in their levels of stress and depression, but mothers reported more anxiety than fathers. For mothers, stress was associated with teacher ratings of child behavior problems and fathers' mental health. For fathers, neither child behavior problems nor mothers' mental health was associated with stress.

(continued)

Reference

- Hastings, Kovshoff, Brown, et al. (2005); Hastings, Kovshoff, Ward, et al. (2005) Herring et al. (2006)
- Kayfitz et al. (2010)
- Little (2002)
- Moes et al. (1992)
- Olsson & Hwang (2001)
- Ornstein Davis & Carter (2008)
- Sharpley et al. (1997)
- Tehee et al. (2009)
- Twoy et al. (2007)

Note: ASD = autism; NLD = NLD; TD = typical

Table 3 (continued)

Reference	Participants	Findings Reported
Hastings, Kovshoff, Brown, et al. (2005); Hastings, Kovshoff, Ward, et al. (2005)	Sample 1: 26M/20F of school-age children with ASD; Sample 2: 48M/41F of pre-school children with ASD	Comparable levels but different sources of stress in mothers and fathers: for mothers, stress was related to child problem behaviors and fathers' mental health. For fathers, stress was not significantly related to either. Parental stress and positive perceptions were predicted by maternal depression.
Herring et al. (2006)	79M/72F of children with PDD; 38M/34F non-PDD group	Fathers consistently reported less stress than mothers, regardless of whether their child had a PDD or not, though fathers of children with PDD were significantly more stressed than other fathers at Time 2. Partner mental health problems were not a source of stress for mothers or fathers.
Kayfitz et al. (2010)	23 M/F pairs of children with autism ages 5-11 years ($M = 7.39$)	Mothers reported significantly more positive experiences parenting their child with ASD than fathers. Mothers' and fathers' reports of their positive experiences were negatively related to their reports of parenting stress. Fathers', but not mothers', positive experiences were negatively related to their partners' reports of parenting stress.
Little (2002)	103 M/F pairs of children with AS and NLD	Mothers reported significantly higher levels of stress and pessimism for themselves and their family than fathers. Mothers also reported seeking professional help and taking medication for depression more often than fathers.
Moes et al. (1992)	18M/12F of children with ASD	Mothers reported significantly more stress than fathers, with a pattern suggesting that stress may be related to the differing responsibility assigned to child rearing for each parent.
Olsson & Hwang (2001)	216 families of children with ASD and/or ID and 214 control families.	50% of mothers with children with ASD had elevated depression scores. Mothers of children with ASD had higher depression scores than mothers of children with ID without ASD > fathers of children with ASD > fathers of children with ID without ASD > control mothers > control fathers.
Ornstein Davis & Carter (2008)	54 M/F pairs with children with ASD	All parents experienced stress related to children's social relatedness and parent-child relationship problems; however, mothers and fathers are stressed by different child characteristics. Mothers experienced more stress associated with child regulatory problems. Fathers experienced more stress related to child's externalizing behaviors.
Sharpley et al. (1997)	219 Australian parents of children with ASD	Mothers reported significantly more parenting stress, anxiety, depression, and a higher frequency of feeling stretched beyond their limits and greater levels of confidence in handling their child's major problem than fathers.
Tehee et al. (2009)	23M/19F of children with ASD	Mothers were significantly more stressed, were more involved, and reported higher levels of stress and coping related to caregiving than fathers.
Twoy et al. (2007)	29M/22F of children with ASD	Overall, for both mother and fathers, coping levels were within normal limits. Fathers had slightly higher levels of coping than mothers.

Note: ASD = autism spectrum disorder; M = mother; F = father; AS = Asperger's syndrome; ID = intellectual disability; NLD = nonverbal learning disability; PDD = pervasive developmental disorder; DS = Down's syndrome; TD = typically developing.

(continued)

Anexo IV

Ingersoll, B., & Dvortcsak, A. (2006). Including parent training in the early childhood special education curriculum for children with autism spectrum disorders. *Journal of Positive Behavior Interventions*, 8(2), 79–87. Índice de impacto: JCR (Journal Citation Reports) 2014: 1.409.

Including Parent Training in the Early Childhood Special Education Curriculum for Children With Autism Spectrum Disorders



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Abstract: Parent training has been shown to be a very effective method for promoting generalization and maintenance of skills in children with autism. However, despite its well-established benefits, few public school programs include parent training as part of the early childhood special education (ECSE) curriculum. Barriers to the provision of parent training include the need for parent education models that can be easily implemented in ECSE programs and the need for preparation of special educators in parent education strategies. This article describes a parent training model for children with autism developed for use in ECSE programs. The implementation of the program, teacher preparation, and preliminary outcomes and challenges will be discussed.

The importance of training parents as intervention providers for their child with autism was first emphasized by Lovaas and colleagues when they noted that, following intensive treatment, children whose parents were trained to carry on the intervention continued to make gains, whereas children who were returned to an institutional setting lost their previously acquired skills (Lovaas, Koegel, Simmons, & Long, 1973). Since then, parents of children with autism have been successfully taught a variety of intervention techniques to improve the parent-child relationship (e.g., Koegel, Bimbela, & Schreibman, 1996, Mahoney & Perales, 2003), increase communication skills (e.g., Harris, 1986), and decrease inappropriate behavior (e.g., Marcus, Lansing, Andrews, & Schopler, 1978). Teaching parents to provide the intervention has been shown to increase generalization and maintenance of skills over time (e.g., Koegel, Schreibman, Britten, Burke, & O'Neill, 1982). Parent training also improves the quality of life for the family by reducing parental stress (Koegel et al., 1996) and increasing parental leisure and recreation time (Koegel et al., 1982). In addition, parents who participate in parent training programs report more optimism about their ability to influence their child's development (Koegel et al.,

1982), which may help parents sustain their efforts with their child over time.

Even though parent training is now considered an essential component of successful intervention programs for children with autism (National Research Council, 2001), it is rarely included in publicly funded early childhood special education (ECSE) programs (Mahoney et al., 1999; McCollum, 1999). Obstacles to providing parent training mainly relate to issues of dissemination and training. Most evidence-based parent training models are not accessible to teachers, who may not read empirical journals that do not target practitioners. In addition, teachers are rarely trained in how to use parent education strategies. Most special educators, especially those who work with children ages 3 and older, have been trained to work with children, not adults. They lack the knowledge of how adults learn and the techniques for teaching parents specific skills (Mahoney et al., 1999). Finally, there is a lack of fit between current empirically based parent education models and the structure of the majority of ECSE programs for children with Autism spectrum disorders (ASD). Most empirically based parent training models are conducted individually with the parent, child, and parent educator

once to twice a week over many months (e.g., Alpert & Kaiser, 1992; Koegel & Schreibman, 1996; Mahoney, 2004a, 2004b). However, ECSE for children with ASD is typically provided in a classroom setting that allows very little time for teachers to meet individually with the parent and child. This difference makes it difficult for most special educators to envision using these models within their programs.

In order for parent training to be accepted as a legitimate and necessary component in the education of preschool-age children with ASD, researchers need to provide parent training models that can be easily adopted by special educators working within the public system. In addition, special educators need to be provided with explicit instruction in which strategies to teach parents, how to work with families, adult learning strategies, and coaching skills. The purpose of this article is to (a) describe a parent training program for families of preschool-age children with ASD designed for use in public ECSE classrooms, (b) describe the implementation of this model in a preschool classroom and how teachers were trained to use it, (c) describe the outcomes of the pilot program, and (d) discuss the outcomes and implications of implementing this model in the public schools.

Context of Program

This program was implemented as part of the Oregon Statewide Regional Program Autism Training Sites (RPATS). RPATS was established as a collaborative effort among Portland State University, the Oregon State Department of Education, and Oregon Regional and Special Education Programs in an effort to improve the quality of education for students with autism in the state. Several classrooms in each region were selected as model RPATS sites. Teachers at these sites receive intensive, hands-on training in research-based practices for children with ASD. After training, other teachers working with children with ASD in the region can visit the model sites to learn how to implement the interventions in their own classrooms.

RPATS provides an excellent model for disseminating information to teachers across the state. For this reason, we chose to pilot the parent training program in two preschool RPATS classrooms. In the pilot program, the group sessions were conducted in the classroom in the evening. The coaching sessions were conducted in the classroom during the school day. On these days, school was canceled. This format made it possible for the teachers to provide coaching to each family on the same day (the district was very large, making individual home visits for children ages 3 and up who attend a classroom-based program unfeasible). The teachers felt that having the coaching sessions at school during the day would allow them to use this model in the future. The individual parent coaching sessions were written into the Individualized Family Service Plan (IFSP)

of each child in the two classrooms, although some parents chose not to take advantage of the program.

Method

PARTICIPANTS

All families of children participating in the two RPATS ECSE classrooms were asked to participate in the parent training program. Out of a total of 12 families (six children in each classroom), 9 families chose to take part. One family did not participate because they had already received individualized parent training from one of the authors. Another family did not participate because the family was non-English speaking and a translator was not available. The third family did not specify why they did not participate. Of the participating families, 5 attended all group and individual sessions, while the other 3 attended the majority, but not all of the sessions. One family dropped out after the second session because the father had surgery.

All participating children were 3 or 4 years old and had an educational eligibility of ASD. The participating parents ranged in age from early 20s to mid-40s and represented a wide range of educational and income levels. One set of parents had previously received some parent coaching using the same strategies in a toddler classroom offered through the district. None of the other parents had participated in any formalized parent training programs. The participating teachers included two early childhood special education teachers, one speech-language pathologist and one occupational therapist, both of whom consulted to the classrooms, and the regional autism specialist (see Table 1).

Both classrooms used the STAR Curriculum with their students (Arick, Loos, Falco, & Krug, 2004), which is based on the principles of applied behavior analysis and includes three instructional formats: discrete trial training, pivotal response training (PRT), and functional routines. Therefore, the teachers had experience implementing the naturalistic behavioral strategies (via PRT) of the parent program but not the developmental strategies. They had not previously received training in any other parent training programs. The speech pathologist had over 30 years of experience and was trained in the Hanen approach; she was thus familiar with all of the intervention strategies as well as parent training.

CONTENT OF PARENT TRAINING CURRICULUM

The parent training curriculum was developed by the authors for families of young children with ASD. The parent training curriculum focuses on teaching families naturalistic intervention techniques to increase their child's social-communication skills during daily activities and routines. The intervention is composed of two primary teaching

techniques: developmental (e.g., Mahoney, 2004a, 2004b) and naturalistic behavioral (e.g., Kaiser, Yoder, & Keetz, 1992) strategies, which we refer to as *indirect* and *direct* teaching strategies, respectively (see Table 2). These strategies were selected from intervention techniques shown to be effective for teaching social-communication skills to children with autism and other developmental disabilities in a parent training context. A combination of approaches was chosen because developmental and naturalistic behavioral strategies are compatible (both begin with following the child's lead), and each focuses on improving a different set of skills considered important for young children with autism. For example, developmental strategies are specifically focused on improving parent-child interactions, whereas naturalistic behavioral strategies are specifically focused on teaching novel language and play skills. Each teaching strategy is outlined in a parent manual designed for this program that was adapted from the manual used at the Hearing & Speech Institute in Portland, Oregon (Ingersoll & Dvortcsak, 2003).

Indirect Teaching Strategies

The indirect teaching strategies are derived from developmental interventions such as Hanen (Manolson, 1992), Responsive Teaching (Mahoney, 2004a, 2004b), and Floor Time/DIR (Greenspan & Wieder, 1998). Developmental interventions are based on research that indicates a moderate relationship between caregivers' responsivity and their child's level of social-communication development (Prizant, Wetherby, & Rydell, 2000). These strategies have been shown to increase social responsiveness (Mahoney & Perales, 2003) and language skills in children with autism (e.g., Ingersoll, Dvortcsak, Whalen, & Sikora, 2005; Mahoney & Perales, 2003) and other developmental disorders (Kaiser et al., 1996). The indirect techniques are used during child-directed activities to enhance the parent's responsivity to their child's behavior. Teaching follows the child's lead, all communicative attempts are responded to as if they were purposeful, and verbal input is adjusted to facilitate communicative growth (Prizant et al., 2000). These strategies were not currently being used in either classroom.

Direct Teaching Strategies

The direct teaching strategies are derived from naturalistic behavioral interventions such as incidental teaching (Hart & Risley, 1968; McGee, Krantz, & McClannahan, 1985), milieu teaching (Alpert & Kaiser, 1992), and PRT (Koegel, O'Dell, & Koegel, 1987; Koegel et al., 1989). These interventions are based on learning theory and use prompting, shaping, and reinforcement within natural contexts to teach specific social-communication skills. These strategies have been found to be effective for teaching language (see Kaiser et al., 1992, for review), play (Stahmer, 1995), and imitation (Ingersoll & Schreibman, in press) in chil-

Table 1. Participant Demographic Information

Participant	Measure
Children	
Eligible children (children in class)	<i>n</i> = 12
Participating children	<i>n</i> = 9
Average age at program entry	3 years 0 months
Gender	8 boys, 1 girl
Average hours of instruction/week	13 hours
Ethnicity	All Caucasian
Language level	
Nonverbal	22%
Single words	44%
Phrase speech	44%
Complex language	33%
Parents	
One parent	56%
Both parents	44%
Marital status	
Married	89%
Divorced/separated	11%
Education level	
High school diploma/GED	54%
Some college/trade school	0%
College degree	38%
Advanced degree	8%
Sessions attended	
Group	83%
Individual	67%
Teachers	
Special educators	2
Speech-language pathologists	1
Occupational therapists	1
Other	1
Gender	0 men, 5 women
Years of teaching experience	
< 5	20%
5–10	40%
11–20	20%
> 20	20%
School	
Average class size	6 students

dren with autism and developmental delay. These strategies were being used in both classrooms during the PRT portion of the STAR Curriculum.

PARENT TRAINING PROTOCOL

The parent training program was designed to be conducted once a week over 9 weeks in six group sessions of 1½ hours and three individual sessions of 45 minutes each with each parent and child. In the pilot program, all group sessions and the first two parent coaching sessions were conducted by the authors while the teachers observed. The final coaching session was conducted by the teachers with feedback provided by the authors.

Table 2. Parent Training Curriculum

Session	Topic	Reference for techniques
Week 1 (Group)	Overview of the program: (a) research on parent training, (b) goals and format of parent training program, (c) overview of the intervention techniques, (d) social-communication goals	
Week 2 (Group)	Following your child's lead and making it interactive: (a) following your child's lead, (b) joining in your child's play, (c) imitating your child, (d) being animated, (e) engaging in playful obstruction	Greenspan & Wieder, 1998; Ingersoll et al., in press; Ingersoll & Schreibman, in press; Kaiser et al., 1996; Mahoney, 2004b.
Week 3 (Group)	Modeling and expanding language and play: (a) using indirect language stimulation, including self-talk, parallel-talk, and conversational recasts; (b) modeling appropriate play skills; (c) treating actions as purposeful	Camarata, Nelson, & Camarata, 1994; Kaiser et al., 1996; Ingersoll et al., in press; Ingersoll & Schreibman, in press; Prizant et al., 2000.
Week 4 (Individual)	Parent coaching on the use of indirect techniques	
Week 5 (Group)	Environmental arrangement: (a) setting up the environment at home for success; (b) using various environmental arrangement strategies, including in sight-out of reach, inadequate portions, sabotage, assistance, silly situations	Kaiser, Ostrosky, & Alpert, 1993.
Week 6 (Group)	Prompting and reinforcement: (a) using a variety of natural environment prompts including models, choices, mand-model (questions), CLOZE procedure, and time delay; (b) using natural reinforcers	Kaiser et al. 1993; Koegel et al., 1987; McGee et al., 1985.
Week 7 (Individual)	Parent coaching on the use of direct techniques	
Week 8 (Group)	Putting it all together (a) review of the direct techniques, (b) when to use indirect and direct techniques, (c) how to use them together	Kaiser, Hancock, & Nietfeld, 2000.
Week 9 (Individual)	Parent coaching on the use of the entire procedure	

Format of Group Sessions

Each group session consisted of a didactic presentation, videotaped examples, and group discussion and problem solving. The first session consisted of an initial didactic presentation that reviewed the research on parent training for children with autism, an overview of the intervention techniques parents would be learning, and a description of the parent training program. Parents then developed individual goals for their child with the help of the parent educator. Goals were developed by having the parents complete a skills checklist that covered social engagement, language, and play and imitation skills. Parents indicated whether their child used each behavior (a) *usually* (at least 75% of the time), (b) *sometimes, but not consistently*, or (c) *rarely or not yet*. The parent and parent educator then developed the child's goals together by reviewing the parent's checklist and the child's IFSP goals. Parents were asked to select no more than four social-communication goals to target over the 9 weeks.

After the first session, all subsequent sessions began with a 20-minute discussion of the parents' use of the different intervention strategies in the home. After the initial discussion, the parent educator conducted a 60-minute didactic presentation of the next intervention strategies. Indirect teaching strategies were presented first, followed by the direct teaching strategies, with later strategies building upon early strategies. All presentations were augmented with videotaped examples of intervention providers and other parents using the strategies with children with ASD.

At the end of each group session, parents were given homework. The homework consisted of having parents write down one to two of their child's goals, activities they typically did with their child, which intervention technique they would use, and their child's expected response. Parents were then instructed to go home and practice those techniques over the next week with their child and record how their child responded. As new intervention strategies were presented, the homework was updated.

Format of Individual Sessions

Each parent and their child participated in three coaching sessions of 45 minutes each with the parent educator. The coaching sessions were interspersed with the group sessions to provide parents with opportunities to practice techniques covered during the group sessions and receive feedback. In each coaching session, the parent observed as the parent educator modeled the target techniques with the child for 5 to 10 minutes. The parent then practiced the techniques with his or her child while receiving feedback from the parent educator. At the end of each session, the parent educator and the parent discussed how to use the techniques in the home to target the child’s social-communication goals and the parent completed the homework sheet.

TEACHER TRAINING PROTOCOL

The parent and teacher training occurred concurrently to provide teachers hands-on learning opportunities. The teacher preparation consisted of didactic and hands-on training in using the parent training model. The authors conducted an initial 6-hour workshop for all of the teachers in the region who would be using the program. The workshop provided an overview of parent training, research on the effectiveness of parent training for children with ASD and their families, and the intervention strategies. It then focused on specific skills that are involved in presenting information and providing online feedback to parents during coaching sessions (see Table 3).

Teachers participating in the pilot program then received hands-on training in the implementation of the model. These teachers observed the authors conduct all of the evening group sessions with the parents. During the group sessions, the teachers assisted with goal development and participated in the group problem-solving discussions. The teachers also observed the authors conduct the first two parent coaching sessions. During these sessions, the teachers wrote down feedback they would have provided the parents using a parent feedback form designed for this program. During the third coaching session, the teachers modeled the techniques and provided feedback to the families of the children in their class. After these individual coaching sessions, the authors provided feedback to the teachers on their coaching.

The entire training required roughly 50 hours of each teacher’s time, which included the workshop, participation in the group sessions (2.5 hours per group session, which included setup and debriefing, for a total of 15 hours), the full-day individual coaching sessions (7 hours per individual session, which included setup and debriefing, for a total of 21 hours), and an additional 8 hours worth of planning meetings and preparation time. Of this time, roughly 18–20 hours were conducted outside of the typical school day (i.e., evening groups).

FUTURE TRAINING

The teaching staff who participated in the full training will continue to conduct the training with families of the stu-

Table 3. Parent Coaching Strategies

Topic	Description
Building rapport	(a) Make eye contact and use balanced turns in conversation, (b) be competent and confident but do not look better working with the child than the parent, (c) point out what the parent is doing correctly, (d) acknowledge parent’s feelings of guilt and/or frustration, (e) listen to parent’s concerns, (f) remain professional, (g) avoid alliances with one parent against the other.
Reviewing information	(a) Present only a few techniques at a time, (b) give the rationale behind the technique, (c) describe the critical elements of technique, (d) check for understanding, (e) discuss how the technique can be used to target child’s goals.
Modeling techniques	(a) Model the technique with the child while the parent watches, (b) make sure the modeling takes up no more than 25% of the session, (c) use role-playing with the parent if he or she is having difficulty using the technique with the child. Providing feedback
Providing feedback	(a) Provide feedback that is succinct but specific, (b) focus more on positive than corrective feedback, (c) respond to almost everything the parent does (at least one comment every minute), (d) give feedback on only a limited number of techniques per session. Building independence
Building independence	(a) Discuss how to use the technique at home, (b) assign homework, (c) increase the amount of time the parent is working with the child, (d) decrease feedback and proximity to the parent and child, (e) have the parent practice across different settings and activities.

dents in their classrooms in the next school year, and the authors will begin the hands-on training at subsequent RPATS sites across the state. As part of the RPATS, the participating teachers will provide training in the model to additional educators in the region, so that other teachers will be able to implement the parent training program with their students with ASD.

Results

As part of the pilot project, we collected several outcome measures to assess the benefit of the program.

Timmy has difficulty interacting with other people and prefers to play alone. Timmy has some single words and uses several gestures to communicate. His mother is trying to increase Timmy's use of single words and interaction skills. Timmy is playing with a small, red truck on the kitchen floor while Timmy's mom is making popcorn.

1. Select the best example for Timmy's mother to use to get Timmy to engage with her.
 - A. Give Timmy some popcorn.
 - B. Tell Timmy, "Look, I'm making popcorn."
 - C. Give Timmy another truck to play with.
 - D. Block Timmy's play with the truck by standing in his way.**
2. Select the best example of language modeling for Timmy.
 - A. "Hey Timmy, look at the popcorn."
 - B. "Truck. Red truck."**
 - C. "I'm making popcorn."
 - D. "You have a small, red truck."

Khari is eating dinner with her family. Khari is nonverbal and is not yet able to consistently communicate her wants or needs. Her parents are trying to get Khari to indicate what she wants using gestures.

3. Select the best way for Khari's mom to teach her to point.
 - A. Mom offers Khari milk and water and waits for her to reach for one. Then she helps her point.**
 - B. Mom gives Khari milk while saying "milk."
 - C. Mom makes Khari point to the milk while she is drinking it.
 - D. Mom tells Khari, "Point to your nose."
4. Select the best way for Khari's dad to encourage Khari to communicate.
 - A. Dad serves her dinner while saying, "Here is your dinner."
 - B. Dad serves her a small portion of her meal and leaves the rest in the kitchen.
 - C. Dad serves her a small portion of her meal and holds the rest where Khari can see it.**
 - D. Dad asks Khari, "What are you eating?"

Figure 1. Sample pre-post quiz items. (Correct answers appear in boldface.)

INCREASES IN PARENT KNOWLEDGE

To determine whether parent knowledge regarding the intervention techniques increased, we administered a pre-post quiz. The quiz included 10 multiple choice items that addressed how to implement specific treatment strategies in natural contexts (see Figure 1). Prior to training, the parents received an average score of 29% correct (range 0%–60%). After training, the parents received an average score of 75% correct (range 40%–100%).

PARENT SATISFACTION SURVEY

At the end of training, parents were asked to complete a satisfaction survey regarding the program. This survey asked parents to respond to statements about the training using a 7-point Likert-type rating scale (1 = *strongly disagree*; 4 = *neither agree nor disagree*; 7 = *strongly agree*). Overall, parent ratings were positive (see Table 4). Parents felt strongly that their child improved his or her social engagement and communication skills as a result of the program. Parents felt less strongly that they understood what skills their child was working on and why, and how to address different goals they had for their child during everyday activities. On average, parents felt that the time and the format of the program were appropriate and that the different components of the program (i.e., written materials, presentations, homework, and parent coaching) were helpful; parents were least positive about the homework assignments and most positive about the parent coaching. Parents reported that both they and their child enjoyed the program.

TEACHER SATISFACTION SURVEY

Teachers were also asked to complete a satisfaction survey regarding the parent training program at its conclusion. This survey used the same 7-point Likert-type rating scale as the parent satisfaction survey. The teachers' responses were uniformly positive (see Table 5). The teachers felt that both the participating parents' ability to promote their children's skills at home and the children's engagement and communication skills improved. They also felt that the training format was appropriate and the amount of time they spent as part of the training was manageable. In addition, the teachers reported that the training they received adequately prepared them to use the program. Finally, the teachers unanimously agreed strongly that the program was a beneficial addition to the current classroom curriculum, that they could see themselves using this program with the children in their class in the future, and that they would recommend this program to others.

Teachers were also asked to answer three open-ended questions regarding the parent training program: (a) What aspects of this training went well? (b) What aspects of this training would you like to see change? and (c) What barriers

Table 4. Average Ratings on the Parent Satisfaction Survey

Statement	M (range)
I feel my child improved her or his social engagement as a result of this program.	6.2 (4.5–7)
I feel my child improved her or his communication/language skills as a result of this program.	6.3 (5–7)
I understand which skills my child was working on and why.	5.7 (3–7)
I understand how to use the techniques at home during everyday activities to address different goals I may have for my child	5.3 (3–7)
The written material was clear, understandable, and helpful.	5.9 (5–7)
The presentations were clear, understandable, and helpful.	6.1 (6–7)
The homework assignments were clear and manageable.	5.7 (4–7)
The parent coaching was clear, understandable, and helpful.	6.7 (6–7)
The format of the program was appropriate (6 group sessions, 3 individual sessions).	5.9 (4–7)
The time of the program was appropriate (evening group, daytime coaching).	6.7 (6–7)
The trainers were knowledgeable.	6.7 (6–7)
I enjoyed this program.	6.7 (6–7)
I feel my child enjoyed this program.	6.4 (5–7)

Note. 1 = strongly disagree; 4 = neither agree nor disagree; 7 = strongly agree.

Table 5. Average Ratings on the Teacher Satisfaction Survey

Statement	M (range)
The participating parents improved their ability to promote their child's learning at home as a result of this program.	6.3 (6–7)
The participating children improved their engagement and communication skills as a result of this program.	6.0 (5–7)
The written material was clear, understandable, and helpful.	7
The presentations were clear, understandable, and helpful.	7
The parent coaching was clear, understandable, and helpful.	6.7 (6–7)
The format of the program was appropriate (6 group sessions, 3 individual sessions).	6.3 (6–7)
The time of the program was appropriate (evening group, daytime coaching).	7
The training I received (initial workshop, observing group and coaching sessions, meetings with trainers, coaching on giving feedback) adequately prepared me to use this program.	6.7 (6–7)
The amount of time I spent as part of this training was manageable.	7
This program is a beneficial addition to the current classroom curriculum I use.	7
I can see myself using this program with children in my class in the future.	7
The trainers were knowledgeable.	7
I would recommend this program to others.	7

Note. 1 = strongly disagree; 4 = neither agree nor disagree; 7 = strongly agree.

ers do you see to using this program in your classroom in the future? In response to the first question, teachers felt that the information presented was relevant for families, improved the parents' skills, and helped with the children's generalization of skills to the home. Teachers also reported that they enjoyed the teaching format and found the parent coaching and consultation time with the trainers to be

highly valuable. Further, all teachers indicated that they would prefer longer and possibly more parent coaching sessions, as they felt that the parent coaching led to the greatest improvements in the parents' skills. Finally, in response to what barriers the teachers saw to using this program in their classroom in the future, all teachers reported that their main concern was consistent parent attendance.

Discussion

Despite the generally positive responses we received, several issues arose during the implementation of the pilot project that should be addressed. First, although several accommodations were made to encourage parent participation, including providing both evening and day sessions, only 75% of the families chose to participate at all and, of these, only 56% participated in the entire program. Participating teachers indicated lack of parent participation as a significant impediment to the success of this program. This project did not provide childcare during the evening groups, which may have prevented some families from participating on a regular basis. Although it would be difficult to find a time in which all parents could (and would) attend, it is likely that offering childcare might increase the attendance rates of families.

Second, all of the individual coaching sessions were held at the school on the same day to facilitate teacher use of the intervention model. Given the size of the district, home visits were viewed by teachers as a barrier to their ability to implement the program in the future. However, parents were least positive in their response that they understood how to use the techniques at home during everyday activities. This response suggests that coaching provided in the home may be more effective than in the school. Home visits are more manageable in smaller than in larger districts. One option is to include in the video clips shown during group training sessions examples of parents using the techniques during daily routines in the home, rather than just during play.

Third, it is unknown whether this parent training model, which includes a significant portion of group instruction, is equivalent to parent training models that are conducted individually with the parent, child, and parent educator. Indeed, all teachers and one parent reported that more coaching sessions would have resulted in better parent learning. Our choice of providing three coaching sessions was based on the preferences of school administrators, who were concerned about canceling more than 3 days of instruction. As with any program, the needs of those receiving the service (children and their families) must be balanced with the needs of those providing it (teachers and school administrators). Therefore, although additional coaching sessions and conducting coaching in the home might be more effective for families, they might also limit teachers' ability or willingness to use the model over time. With this in mind, we feel that the addition of one extra coaching session after the second group session and the provision of the final coaching session in the home would increase parent performance and still remain acceptable to teachers and administrators. Future research should investigate optimal parent training formats for school programs, in terms of both gains in parent knowledge and teacher implementation.

Fourth, this model was conducted at a site that may have been atypical of ECSE classrooms in that significant hands-on training in the use of research-based practices for children with autism had occurred there. In addition, this classroom was designed for children with autism and had small student numbers. In classrooms with less teacher expertise in autism interventions, the teachers may need to receive initial training in the intervention strategies themselves prior to receiving training on how to conduct parent coaching. In classrooms with higher student numbers, the course could be offered more than once throughout the year, so that all families would have the opportunity to participate. Given that the parent coaching strategies are appropriate for children with a range of disabilities, we believe that the use of this model with a mixed-disabilities classroom would still be appropriate.

Finally, the number of hours each participating teacher invested in this program was significant (50 hours). Trained teachers will spend roughly 36 hours to implement the program in the future, 15 of which will be outside of the regular workday. In addition, as this program is part of the RPATS program, teachers who have already been trained in the model will have the responsibility to train new teachers, which will require significantly more time than implementing the program with parents. Although all participating teachers felt strongly that they would use this program again in the future, most expressed concern about the amount of time that training other teachers would take.

In summary, we have described a model for training parents to use empirically validated intervention techniques with their child with ASD that can be implemented by educators within a publicly funded ECSE program. We were encouraged by both the teachers' and parents' enthusiasm for the program and the benefit they felt this program added to the children's education. However, since we did not measure changes in actual parent or teacher behavior, the utility and cost-effectiveness of implementing this model is unknown. Future empirical study is needed to determine both the short- and long-term effects of adding such a program to the special education curriculum for preschool-age children with ASD.

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AUTHORS' NOTES

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Anexo V

Ingersoll, B., & Gergans, S. (2006). The effect of a parent-implemented imitation intervention on spontaneous imitation skills in young children with autism. *Research in Developmental Disabilities, 28*(2), 163–175. Índice de impacto: SJR (SCImago Journal Rank) 2014: 0.986.



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The effect of a parent-implemented imitation intervention on spontaneous imitation skills in young children with autism

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Abstract

Children with autism exhibit significant deficits in their ability to spontaneously imitate the play actions and descriptive gestures of others. Reciprocal imitation training (RIT) is a naturalistic imitation intervention designed to teach spontaneous imitation skills during play. This study assessed the effectiveness of parent-implemented RIT using a multiple-baseline design across three young children with autism and their mothers. After an initial baseline, mothers were taught to implement RIT techniques with their child twice a week for 10 weeks in a clinic setting. Two mothers were taught to use RIT to teach object imitation. The third mother was taught to use RIT to target both object and gesture imitation in a multiple-baseline design across behaviors. Generalization was assessed in the families' homes at the end of treatment and a 1-month follow-up. Parents learned to use the intervention strategies and their children exhibited increases in spontaneous imitation. These findings replicate the results from previous studies, indicating that RIT is effective for teaching imitation skills to young children with autism in a naturalistic setting and extend the findings to parents.

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Keywords: Autism; Intervention; Parent training; Social communication; Imitation

A growing body of literature has demonstrated the effectiveness of teaching parents to provide intervention to their children with autism. Parent training offers several important benefits for the child and family. First, researchers have found that parent-implemented intervention leads to better generalization and maintenance of skills than therapist-implemented intervention (Koegel,

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Schreibman, Britten, Burke, & O'Neill, 1982) and may lead to more child gains in overall (Drew et al., 2002). Second, parent training has been shown to improve the quality of life for the family by decreasing parental stress (Koegel & Schreibman, 1996) and increasing leisure and recreation time (Koegel et al., 1982). Third, parent training can increase parents' optimism about their ability to influence their child's development (Koegel et al., 1982), which may help them sustain their efforts with their child over time. Finally, parent training can be very cost effective because it requires fewer hours of direct service. This benefit cannot be understated given the significant cost required to educate this population (Jacobson, Mulick, & Green, 1998). Indeed, parent training is now considered to be an essential component of quality early intervention programs for young children with autism (National Research Council, 2001).

The majority of research on parent training for children with autism has focused on interventions which teach verbal language skills (e.g., Harris, 1986; Hemmeter & Kaiser, 1994; Koegel & Schreibman, 1996). Recently, there has been an interest in training parents to teach earlier emerging, non-verbal social-communication skills to their children (Drew et al., 2002; Mahoney & Perales, 2003). This interest has been driven by developmental research indicating a relationship between non-verbal social-communication skills, particularly joint attention, and later language development (e.g., Bates, 1976; Schertz & Odom, 2004). Imitation is non-verbal social-communication skill, which is significantly impaired in young children with autism (e.g., Smith & Bryson, 1994). Imitation also emerges early in development and plays a crucial role in the development of more complex cognitive and social skills (Stern, 1985; Uzgiris, 1981). In children with autism, research has shown imitation ability to be associated with language (Stone & Yoder, 2001), play (Stone, Ousley, & Littleford, 1997), and joint attention (Carpenter, Pennington, & Rogers, 2002). Given this association, researchers have suggested that targeting imitation in young children with autism may assist in the development of social communication more broadly (Carpenter et al., 2002; Rogers, 1999; Rogers & Bennetto, 2000).

Reciprocal imitation training (RIT) is a naturalistic intervention that targets generalized, spontaneous imitation skills in young children with autism during ongoing play interactions. Previous research has demonstrated that RIT is effective for teaching both object (Ingersoll & Schreibman, *in press*) and gesture imitation (Ingersoll, Lewis, & Kroman, *submitted for publication*; Ingersoll & Schreibman, 2004). Imitation skills generalize to novel settings, materials, and therapists and maintain over time. This intervention is especially promising because it also leads to changes in other social-communication skills including language, pretend play, joint attention (Ingersoll & Schreibman, *in press*), and spontaneous gesture use (Ingersoll et al., *submitted for publication*). Given the effectiveness of RIT for teaching a broad range of social-communication skills, it appears to be an appropriate strategy to teach parents to use with their young children with autism.

The aims of this study were to assess whether parents could be taught to implement RIT with their children with autism and to determine the effectiveness of the intervention for increasing spontaneous object and gesture imitation in young children with autism.

1. Method

1.1. Participants

Three young children with autism and their mothers participated. The children were diagnosed by an outside professional with expertise in autism. Diagnoses were confirmed by the

Table 1
Participant characteristics at intake

Child	Chron. age (months)	Mental age (months)	Language age ^a (months)	Autism severity ^b (mild-mod)	Object imitation ^c (%)	Gesture imitation ^c (%)	Treatment phase
Conrad	31	15 ^d	<8	33	13	6	I & II
Alicia	37	15 ^e	<8	31	19	13	I & II
Luke	42	22 ^e	17	32.5	88	81	I, II, & III

^a MacArthur-Bates Communicative Development Inventory.

^b Childhood Autism Rating Scale.

^c Motor Imitation Scale.

^d Mullen Scales of Early Learning.

^e Bayley Scales of Infant Development, 2nd ed.

first author using DSM-IV-TR criteria (APA, 2000). At intake, the children were administered the Bayley Scales of Infant Development, 2nd ed. (Bayley, 1993) or Mullen Scales of Early Learning (Mullen, 1995) to determine developmental age and the Motor Imitation Scale (MIS; Stone et al., 1997) to determine imitation performance in a structured setting. The children's primary caregivers completed the MacArthur-Bates Communicative Development Inventory (CDI; Fenson et al., 1993) to determine expressive language age and the Childhood Autism Rating Scale (Schopler, Reichler, DeVellis, & Daly, 1980) to determine severity of autism (see Table 1). Participants were recruited via flyers and word of mouth from service providers in the area.

Conrad was 2 years, 7 months at intake. He had a mental age of 15 months on the Mullen and a language age of less than 8 months on the CDI. He did not consistently use sounds and relied mainly on hand-leading to make his needs known. On the MIS, Conrad received an object imitation score of 13% and a gesture imitation score of 6%. Based on his difficulty with imitation of actions with objects in a structured setting, Conrad's mother was taught to use RIT to target object imitation only (Phases I and II). Conrad lived with his older brother and parents. Conrad's mother had attended 2 years of college and was currently staying at home to raise her children. During his participation in this study, Conrad received 1 h of early intervention services in the home per week. Conrad's mother had not received any parent training prior to participation in this study. She received one individual coaching session in relationship development intervention (RDI; Gutstein & Sheely, 2002) from an educational specialist towards the end of treatment.

Alicia was 3 years, 1 month at intake. Her mental age on the Bayley was 15 months and her language age on the CDI was less than 8 months. Alicia communicated mainly through gestures and used several basic signs. On the MIS, Alicia received an object imitation score of 19% and a gesture imitation score of 13%. Based on her difficulty imitating actions with objects in a structured setting, Alicia's mother was taught to use RIT to target object imitation only (Phases I and II). Alicia lived with her older brother and parents. Alicia's mother was a registered nurse and returned to work part-time halfway through their participation in the study. During the study, Alicia received 10 h of early intervention services per week in a group setting. Alicia's mother had not received any parent training prior to or during the study.

Luke was 3 years, 6 months at intake. His developmental age on the Bayley was 22 months and his language age on the CDI was 17 months. Luke primarily communicated with single words to request desired items. On the MIS, Luke received an object imitation score of 88% and a gesture imitation score of 81%. Based on his ability to imitate actions with objects in a structured setting, Luke's mother was taught to use RIT to target both object and gesture imitation (Phases I,

II, and III). Luke lived with his parents and younger sister. His mother had received a Masters in social work, but stayed at home with Luke and his sister. At the conclusion of the study, she returned to work part-time. Throughout this study, Luke received early intervention services, which consisted of 10 h in a group setting and 1 h of private speech–language therapy per week. Luke’s mother had previously received coaching in DIR/Floor Time techniques (Greenspan & Wieder, 1998) from her son’s speech therapist.

1.2. Setting and materials

All baseline and treatment sessions were conducted in a small treatment room at an intervention center specializing in the treatment of children with communication disorders or at a college research laboratory. Rooms had a one-way mirror through which treatment was filmed. Five to 10 pairs of toys were provided by the parent trainer for each session. Generalization sessions were conducted in the families’ homes with their own toys.

1.3. Procedure

A single-subject, multiple-baseline design was conducted across participants (Hersen & Barlow, 1976). A multiple-baseline design was also used across behaviors (object imitation and gesture imitation) for Luke and his mother. Participants attended the research laboratory 2 days per week during baseline and treatment. Baselines lengths were chosen a priori and were 2, 4, or 6 weeks. Participants were randomly assigned to different baseline lengths, and then received 10 weeks of parent training in RIT. Participants were filmed in their home twice during baseline and treatment and at a 1-month follow-up to determine generalization and maintenance of skills.

1.4. Baseline

During the baseline phase, caregivers were provided with pairs of identical play materials and asked to play with their child as they did at home for 10 min.

1.5. Treatment

During the treatment phase, the parent trainer, who was the first author, worked with each parent–child dyad during 30–40 min sessions to teach the parents how to use RIT techniques. At the beginning of treatment, the parent was provided with a training manual, which outlined the individual techniques of RIT. At the beginning of each session, the parent trainer presented a treatment technique. When reviewing the technique the parent trainer described the rationale behind the technique, the critical elements of the procedures, how the technique could be used at home, and answered the parent’s questions. After presenting the technique, the parent trainer modeled the procedures with the child for 5–10 min while the parent watched. While modeling, the parent trainer described what she was doing and how the child responded. After watching the parent trainer for several minutes, the caregiver took over and practiced the techniques with her child. The parent trainer provided positive and corrective feedback to the parent while the parent practiced. As training progressed, the sessions consisted mainly of parent practice and feedback.

RIT includes strategies designed to increase parent–child reciprocity and to teach the child to imitate. The intervention was implemented in three phases. During Phase I, the parent was taught to use intervention strategies designed to increase reciprocity. These strategies included

contingent imitation, in which the parent was taught to imitate her child's actions with toys, gestures/body movements, and vocalizations, and linguistic mapping, in which the parent was taught to describe objects and actions that were the focus of her child's attention using simplified language.

In Phase II, which was introduced after one week of treatment, the parent was taught to use imitation training strategies to increase object imitation while continuing to use reciprocity strategies. The parent was taught to model an action with a toy related to her child's play every minute up to three times. Models were combined with a verbal marker that described the action. The parent was also taught to prompt her child to complete the action using physical guidance, a verbal command, or gestural prompt if her child did not spontaneously imitate after the third model. Finally, the parent was taught to praise her child after the child imitated and allow her child continued access to the toys. All parent–child dyads participated in Phases I and II.

Luke and his mother also participated in Phase III, which was introduced after 4 weeks of treatment. In this phase, Luke's mother was taught to use imitation training strategies for teaching gesture imitation while continuing to target object imitation. Strategies for teaching gesture imitation were similar to those for teaching object imitation. However, the parent modeled gestures directly related to the child's play. For example, if the child threw a ball, the parent might model a pointing gesture and say, "The ball went over there."

1.6. Generalization probes

Twice during baseline and at the end of treatment, and once at a 1-month follow-up, sessions were conducted in the families' homes to determine generalization and maintenance of skills to the home environment. During these sessions, the parent was instructed to play with her child as she typically did at home for 10 min.

1.7. Dependent measures

All sessions were videotaped for later scoring. For baseline and generalization sessions, the entire 10 min was taped without the trainer present. For treatment sessions, the parent trainer left the room after training was complete and taped the parent while she played with her child for 10 min. Videotapes were scored for the parents' use of the RIT strategies and the children's use of spontaneous imitation. Contingent imitation and linguistic mapping were scored using 30 s interval scoring. Modeling, prompting, and reinforcement, as well as the child's use of spontaneous object and/or gesture imitation were scored using frequency data. These data were converted to a rate per minute by dividing the number of behaviors by the number of minutes observed (see [Table 2](#)).

1.8. Reliability

Reliability data were collected on 25% of the observations. Cohen's Kappa was used to calculate reliability for the measures using interval data. Reliability for contingent reinforcement was .58 and it was .62 for linguistic mapping. These Kappa scores are considered fair and good, respectively. Pearson's r was used to calculate reliability for measures using frequency data. All correlations were significant at $p < .01$. The correlation for object imitation was .64, gesture imitation was .99, imitation training was .81, modeling was .72, prompting was .73, and reinforcement was .81.

Table 2
Behavioral definitions

Parent behaviors	
Contingent imitation	The parent imitates the child's actions with toys, gestures/body movements, and vocalizations at the same time as the child
Linguistic mapping	The parent describes what the child is attending to and/or doing using simplified language (e.g., "Dog is walking") or sound effects
Imitation training	The parent implements all three imitation training strategies correctly within a single trial
Modeling actions	The parent models an action with a toy (or a gesture) related to the child's play up to three times. Actions are paired with a verbal marker that describes the action
Prompting	The parent uses physical guidance, a verbal command, or gestural prompt to encourage the child to imitate the modeled action if the child does not spontaneously imitate after the third model
Reinforcement	The parent praises the child after imitating and allows continued access to the toys
Child behaviors	
Object imitation	The child imitates the parent's model of an action with a toy without physical guidance, verbal command, or gestural prompt within 10 s of the model
Gesture imitation	The child imitates the parent's model of a gesture without physical guidance, verbal command, or gestural prompt within 10 s of the model. Gestures include conventional, descriptive, or affective actions

Table 3
Parent satisfaction survey results

Intervention was simple and easy to use	7.0
Child's object imitation skills improved	6.7
Child's social engagement improved	6.7
Child's play/object interaction skills improved	6.3
Child's communication/language skills improved	6.7
Child enjoyed intervention	6.7
Parent enjoyed using intervention with child	6.7
Parent used intervention at home on regular basis	6.7
Parent would recommend intervention to others	7.0

1 = Strongly disagree; 4 = neither agree nor disagree; 7 = strongly agree.

1.9. Social validity

Parents of the participating children were asked to complete a parent satisfaction questionnaire at the conclusion of treatment to assess their opinion of the effectiveness of the intervention for their child (see Table 3).

2. Results

2.1. Parent behavior

2.1.1. Reciprocity strategies

During baseline, Conrad's and Alicia's mothers rarely used contingent imitation, while Luke's mother used a moderate amount. All three mothers used a moderate amount of linguistic mapping

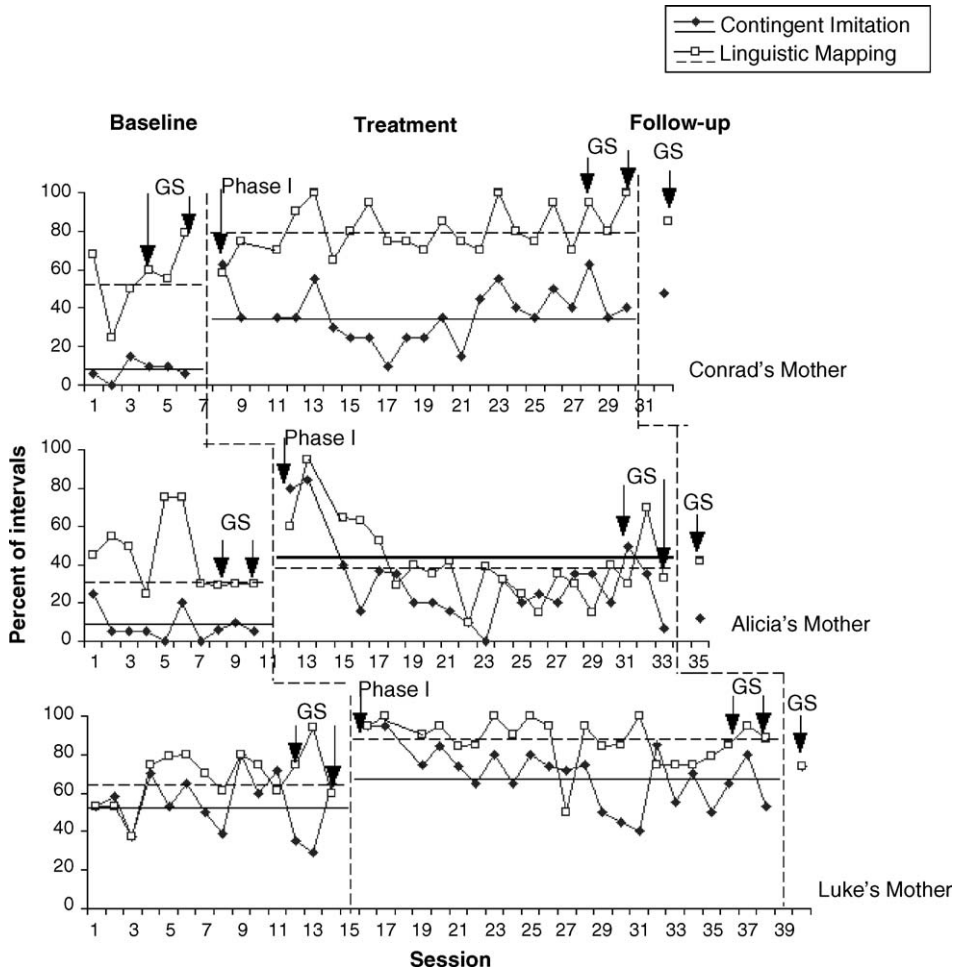


Fig. 1. Parents' use of reciprocity strategies. GS: generalization session.

prior to training. With the onset of Phase I of treatment, all three mothers increased their use of contingent imitation. Conrad and Alicia's mothers maintained this higher rate throughout treatment, while Luke's mother returned to baseline rates in Phase II. All mothers also increased their use of linguistic mapping. Conrad and Luke's mothers maintained this higher rate throughout treatment, while Alicia's mother returned to baseline rates of linguistic mapping in Phase II. At follow-up, Conrad's mother continued to use higher rates of contingent imitation and linguistic mapping, while Alicia's and Luke's mothers' use of these strategies fell between their baseline and treatment rates (see Fig. 1).

2.1.2. Imitation training

During baseline, Alicia's mother rarely implemented the imitation training procedure correctly. Conrad's and Luke's mothers did so at a low- to -moderate rate for object imitation. However, Luke's mother did not target gesture imitation at all. With the onset of Phase II, all

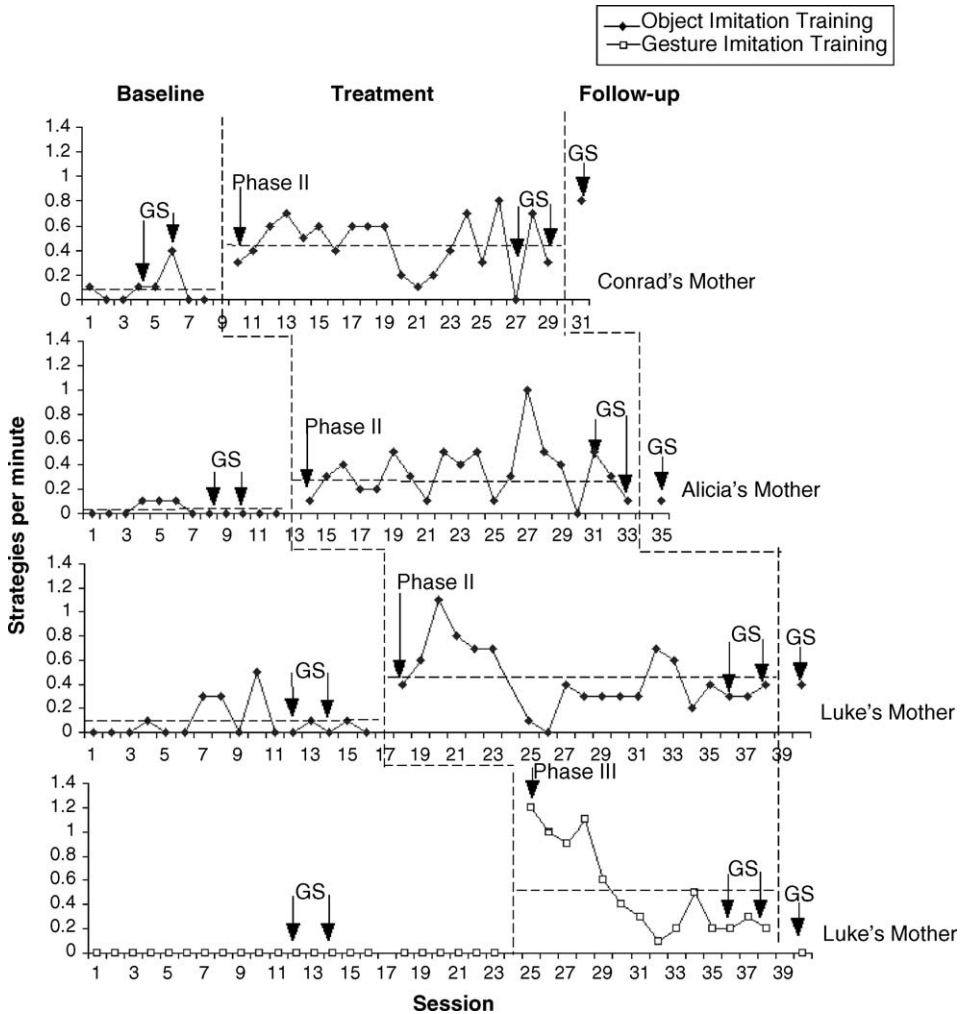


Fig. 2. Parents' use of imitation training procedure. GS: generalization session.

parents exhibited a substantial increase in their correct implementation of imitation training procedure for teaching object imitation (see Fig. 2). Alicia's mother showed a substantial increase in her use of all three individual strategies (see Fig. 3). Conrad's and Luke's mothers showed a substantial increase in their use of modeling and reinforcement and a smaller increase in their use of prompting.

With the onset of Phase III, Luke's mother increased her correct implementation of the imitation training procedure for targeting gesture imitation. During this time, she decreased her rate of object imitation trials as she focused on targeting gesture imitation. As Phase III progressed, her rate of gesture imitation trials decreased and her use of both types of trials became more balanced.

All three mothers generalized their use of the imitation training procedure to the home. Their use of the object imitation procedure maintained at follow-up; although, Alicia's mother's rate at

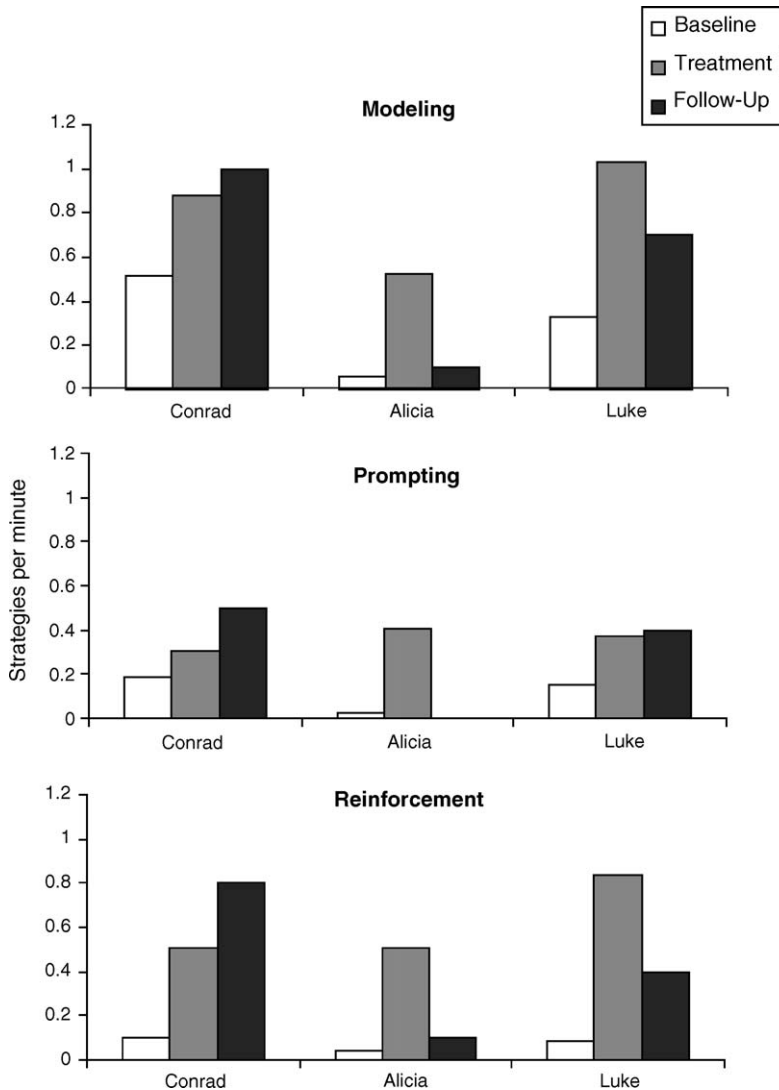


Fig. 3. Parents' average use of individual imitation training strategies for baseline, treatment, and follow-up.

follow-up was lower than that during the treatment. Luke's mother did not maintain her use of gesture imitation training at follow-up.

2.2. Child behavior

2.2.1. Object imitation

During baseline, all three children had low rates of spontaneous object imitation, imitating, on average, less than one action per 10 min session. With the onset of Phase II, all three children increased their spontaneous object imitation concurrent with their mothers' use of object

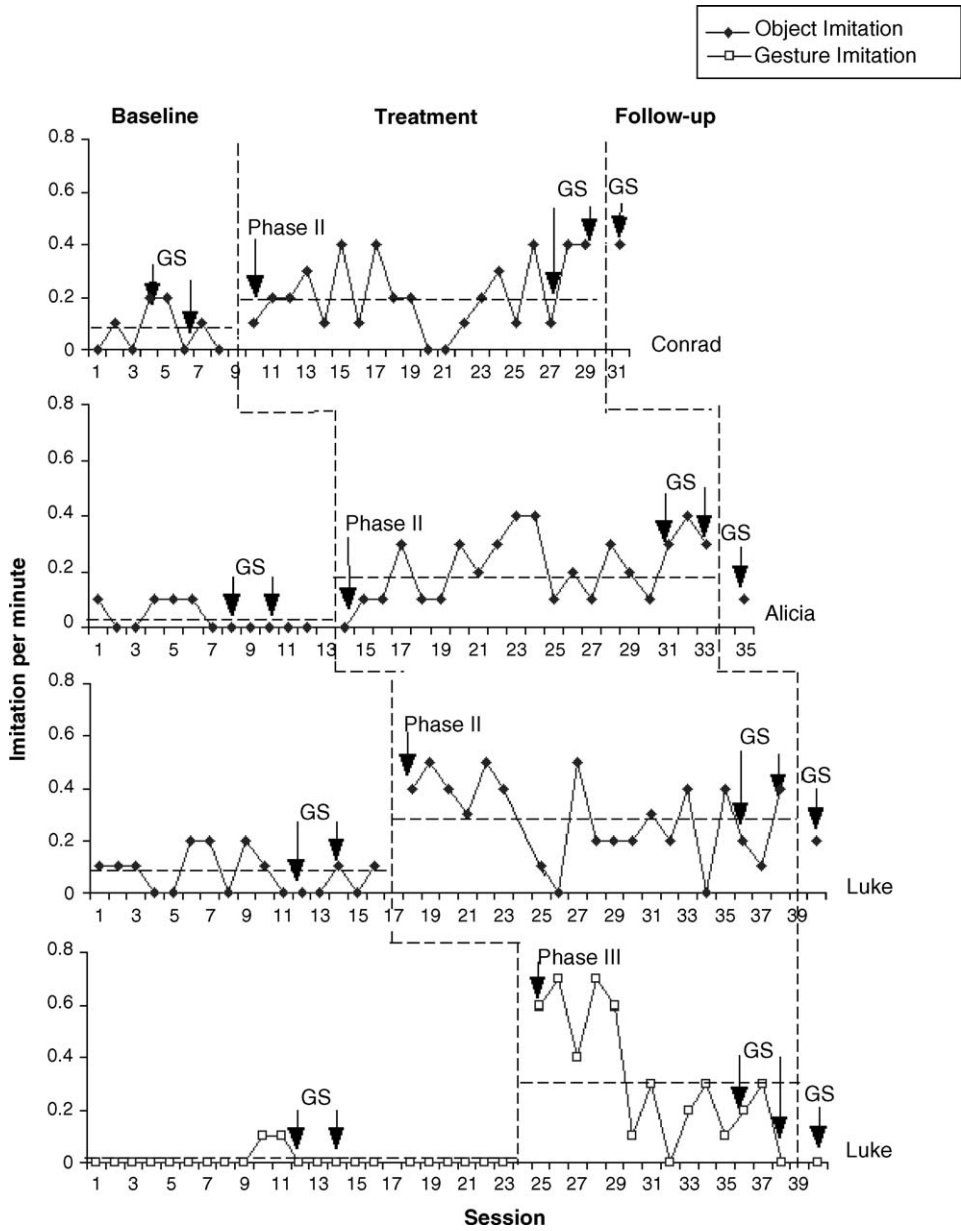


Fig. 4. Children's use of spontaneous imitation. GS: generalization session.

imitation training. All children generalized their object imitation skills to their homes and maintained their object imitation at follow-up.

2.2.2. Gesture imitation

Luke rarely imitated gestures during baseline or Phase II. During Phase III, when his mother was taught to use gesture imitation training, Luke increased his rate of gesture imitation

substantially. He initially exhibited a very high rate of gesture imitation concurrent with his mother's increased use of the gesture imitation training procedure. As treatment progressed and his mother began to balance her use of object and gesture imitation training trials, his spontaneous imitation with objects and gestures also became more balanced. Luke's use of gesture imitation generalized to the home during one treatment generalization session; however, it did not maintain at follow-up (see Fig. 4).

2.3. Parent satisfaction survey

All three parents responded favorably on the Parent Satisfaction Survey, indicating that they found the intervention easy to use and enjoyable. They reported using the intervention at home and felt it improved their child's social-communication skills (see Table 3).

3. Discussion

Parents of young children with autism can be taught to use RIT to enhance their children's spontaneous imitation skills. All parents increased their use of the intervention strategies in the clinic setting and the home, and maintained these skills at the 1-month follow-up. All children increased their object imitation and Luke increased his gesture imitation. The parents reported high levels of satisfaction with the outcomes of the intervention and the training procedure itself.

This study contributes to the parent training literature by providing additional support for parent-implemented interventions that target non-verbal social-communication skills. As improvements in diagnosis allow for earlier identification, interventions which are designed to teach earlier emerging social-communication skills are necessary. Imitation is a critical skill for young children with autism and may lead to broad improvements in social communication (Rogers, 1999). The parents in this study reported that the intervention led to positive changes in social engagement, play skills, and communication/language. Future research that demonstrates this finding empirically would provide additional support for the idea that parent-implemented RIT may lead to wide-ranging effects on social-communicative functioning.

In this study, object imitation was targeted before gesture imitation for several reasons. First, researchers have indicated that imitating actions with objects is substantially easier than imitating body movements or gestures, perhaps due to the limited range of movement that objects allow (DeMyer et al., 1972; Stone et al., 1997). Second, researchers have found that tasks which involve a direct response–reinforcer relationship are more motivating and thus easier to learn (Koegel, O'Dell, & Koegel, 1987). Imitation with objects is more likely to result in a direct response–reinforcer relationship, in that the modeled action involves the manipulation of an object and thus may be reinforcing in itself. In contrast, gesture imitation is less likely to result in such a relationship, since the modeled action does not involve an object directly. However, it is unknown whether targeting object imitation first confers any benefit over targeting object and gesture imitation simultaneously from the beginning or starting with gesture imitation. Future research should be designed to examine whether the pattern of introducing different targets affects learning outcomes for parents or children.

Although the children in this study made significant gains in their imitation skills, it is unknown whether parent-implemented RIT would lead to similar outcomes as therapist-implemented RIT. On one hand, parents spend substantially more time with their children and are thus able to implement the intervention throughout their daily interactions, increasing the number of learning opportunities. On the other hand, parents may prefer to engage in a variety of different

interactions with their child, which may, in turn, limit the number of imitation opportunities available. Indeed, the parents in this study used lower rates of reciprocity strategies and modeled fewer actions than therapists in previous studies of RIT (Ingersoll & Schreibman, in press). Future research should compare the effectiveness of RIT as implemented by trained therapists and parents to determine if one approach leads to better child outcomes.

There are several limitations to this research. First, only Luke's mother was taught to target gesture imitation due to the other children's difficulty with object imitation on the structured assessment. Thus, it is unknown whether the other mothers would have been able to learn the procedure or whether Conrad and Alicia would have been able to learn gesture imitation had it been targeted. This decision limits the conclusions that can be drawn regarding the effectiveness of parent-implemented RIT for teaching gesture imitation. Future research should examine the ability of children with different intake characteristics to learn both object and gesture imitation via RIT.

Second, although our findings indicate that generalization and maintenance were strong for object imitation, Luke's mother did not maintain her use of gesture imitation training after the treatment was discontinued. Consequently, Luke did not maintain his use of gesture imitation. This finding stands in contrast to a previous study on RIT which indicated that gesture imitation maintained over time when implemented by trained therapists (Ingersoll et al., submitted for publication; Ingersoll & Schreibman, 2004). This result may indicate that gesture imitation is more difficult for parents to implement in the natural environment or that gesture imitation requires more intervention than object imitation in order to maintain over time.

Third, given that this intervention has multiple components, it is unknown which aspects were necessary for teaching imitation. For example, during baseline, parents were instructed to play with their child as they do at home. Parents thus differed significantly in the number of actions they modeled during baseline. Once parents were taught to use RIT, they all increased the number of models they provided. This finding was especially true for Alicia's and Luke's mothers, who, during baseline, provided minimal opportunities to imitate actions with objects and gestures respectively. Therefore, it is possible that simply providing more opportunities may have increased imitation. Future research should examine which intervention components are necessary for improving imitation skills.

In conclusion, this research offers a promising intervention option that is simple and effective and can be implemented easily by parents of young children with autism. Clearly, additional studies involving more participants that represent a wider range of ages and abilities are needed to further validate the efficacy of this approach.

Acknowledgment

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Anexo VI

Kasari, C., Gulsrud, A., Paparella, T., Hellemann, G., & Berry, K. (2015). Randomized comparative efficacy study of parent-mediated interventions for toddlers with autism. *Journal of Consulting and Clinical Psychology, 83*(3), 554–563. Índice de impacto: ISI Journal Citation 2014: 5.279.

Randomized Comparative Efficacy Study of Parent-Mediated Interventions for Toddlers With Autism

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University of California Los Angeles

Objective: This study compared effects of two parent-mediated interventions on joint engagement outcomes as augmentations of an early intervention program for toddlers with autism spectrum disorder (ASD). **Method:** Participants included 86 toddlers (range 22–36 months) with ASD and their primary caregiver. Caregiver-child dyads were randomized to receive 10 weeks of hands-on parent training in a naturalistic, developmental behavioral intervention (joint attention, symbolic play, engagement and regulation—JASPER) or a parent-only psychoeducational intervention (PEI). Dose was controlled in terms of researcher-parent contact and early intervention services received by the child. **Results:** Results yielded significant effects of the JASPER intervention on the primary outcome of joint engagement. The treatment effect was large (Cohen's $f^2 = .69$) and maintained over the 6-month follow-up. JASPER effects were also found on secondary outcomes of play diversity, highest play level achieved, and generalization to the child's classroom for child-initiated joint engagement. The PEI intervention was found to be effective in reducing parenting stress associated with child characteristics. All secondary effects were generally small to moderate. **Conclusions:** These data highlight the benefit of a brief, targeted, parent-mediated intervention on child outcomes. Future studies may consider the combination of JASPER and PEI treatments for optimal parent and child outcomes. Trial registry no. NCT00999778.

What is the public health significance of this article?

To improve outcomes associated with core impairments of toddlers with ASD, this study highlights the impact of direct, hands-on parent coaching of techniques to facilitate child social development. Parents also benefit from expert-delivered educational consultation, as shown by reduced parenting stress, but this treatment is less likely to improve child outcomes.

Keywords: autism toddlers, early intervention, parent training, JASPER, parenting stress

Young children with autism spectrum disorder (ASD) display significant impairments in early social communication skills. These include the initiation of joint attention gestures (e.g., showing toys to others, pointing to share, and coordinated eye gaze

between objects and people) and the ability to jointly engage in social interactions with others (Adamson, Bakeman, & Deckner, 2004; Kasari, Freeman, & Paparella, 2006; Sigman, Mundy, Sherman, & Ungerer, 1986). These impairments uniquely discriminate children with ASD from children with other developmental delays and typical children of similar mental age (Mundy, Sigman, Ungerer, & Sherman, 1987). Given the large amount of literature on the importance of these skills as predictors of later development, early interventions have increasingly targeted these skills, especially for very young children (Kasari et al., 2005).

The foundational nature these skills play in the child's ability to develop relationships with others leads researchers to consider parents as important mediators of change and potential targets of intervention. However, the current evidence for parent-mediated interventions for children with ASD is mixed. For example, experimental low intensity, three month, short-term parent-mediated interventions for very young children who are at risk for ASD have not demonstrated significantly greater change in parent and child outcomes relative to community-based treatment-as-usual interventions (Carter et al., 2011; Rogers et al., 2012) whereas longer term interventions of nine months have shown greater effects (Wetherby et al., 2014). For older children with confirmed diagnoses of ASD, these same types of interventions of 12–24 sessions

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over three to six months have improved parent responsiveness and child outcomes to a significantly greater extent when compared with treatment-as-usual community groups (Green et al., 2010; Kasari, Gulsrud, Wong, Kwon, & Locke, 2010) or an alternative treatment (Kasari et al., 2014).

What might account for these age-related differences? One notion is that older children display more readily apparent delays relative to younger children. Thus, parents are better able to recognize the specific needs of older children. Another speculation is that children who have confirmed diagnoses are often receiving a range of intervention services in the community: thus an absolute dose of intervention may be needed to obtain effects from parent-mediated interventions. Currently, we are unclear on the absolute dose needed and the best methods for teaching parents to achieve the most optimal child outcomes.

Other factors may also affect parent and child outcomes. Increased stress and worry have been well documented for parents of children with ASD and suggest the need for specific interventions to address parental mental health concerns (Schieve, Blumberg, Rice, Visser, & Boyle, 2007). The increased stress may result from many sources: distress from the impact of their child's diagnosis, the strain of additional parenting roles and demands, including expectations that they deliver interventions to their young child, as well as time lost from work and increased medical costs associated with caring for a child with ASD (Cidav, Marcus, & Mandell, 2012). Early interventions that provide parenting strategies through psychoeducational programs have significantly decreased parental stress in these families (Feinberg et al., 2014; Tonge et al., 2006). Although effects of psychoeducational approaches on child outcomes are rarely tested, a recent study found that a parent education and counseling program that included behavior management strategies helped to improve child adaptive behaviors (Tonge, Brereton, Kiomall, Mackinnon, & Rinehart, 2014). Thus, the combination of counseling and education for ASD-specific parenting strategies may be effective for improving both parent and child outcomes.

Individual child characteristics can also affect treatment outcomes. These individual characteristics may include a wide range of features such as language ability, cognition, and severity of ASD. This heterogeneity may account for findings that parent-mediated interventions have had very limited effects on child outcomes. Child treatment gains have been limited to particular subgroups, such as those entering the intervention with the greatest impairment, or those identified as displaying greater preintervention object interest (Carter et al., 2011; Siller, Hutman & Sigman, 2013). Overall, there is a need to identify other parent-mediated interventions for young children with ASD that are more robust in significantly improving parent and child outcomes.

This comparative efficacy study attempts to advance intervention research by testing whether a parent-mediated intervention involving direct parent coaching with the child is more efficacious than a parent-education model (without direct involvement of the child) in improving parent and child outcomes. The study treatments were added to existing early intervention services, controlling for type and dose of these services. All of the children were toddlers with ASD, between the ages of 22 and 36 months, and attended the same 30 hr/week early intervention program.

Families attending the early intervention program were randomized to receive either 1 hr/week of parent training based on a

manualized parent psychoeducation program for parents of children with autism (PEI; Brereton & Tonge, 2005) or a hands-on manualized, parent-mediated program aimed at improving core deficits in their toddlers (Joint Attention Symbolic Play, Engagement, and Regulation-JASPER, UCLA, 2005). Controlling for the overall dose of intervention, we compared the approaches on the primary outcome of joint engagement between parent and child. Joint engagement, as defined, requires the active and reciprocal engagement of both parent and child. Secondary measures included child-initiated joint attention, functional and symbolic play types (reflecting play flexibility and diversity), play level, and generalization of joint engagement to the child's classroom. We hypothesized that improvements in child engagement with objects and people, joint attention gestures, and play skills would be significantly greater in the JASPER condition as compared with the PEI condition. Because one focus of the PEI condition is on reducing parent stress, we also hypothesized that stress would be reduced to a greater extent for parents in the PEI condition relative to the JASPER condition. Child and parent measures were collected prior to intervention (pretreatment), at the end of intervention (posttreatment), and at six month follow-up.

Method

Participants

Participants were recruited from the same outpatient early intervention (EI) program consisting of 30 hr/week of a combination of behavioral, speech, and occupational therapies for 10 weeks. A University Institutional Review Board approved the study and parents provided written consent. Children were included if they were younger than 36 months, had a clinical diagnosis of ASD confirmed by independent testers with the Autism Diagnostic Interview-Revised (ADI-R; Lord, Storoschuk, Rutter, & Pickles, 1993) and the Autism Diagnostic Observation Schedule (ADOS; Lord, Rutter, DiLavore, & Risi, 2001), had no significant physical disabilities, and parent and child were available for follow-up assessments (e.g., not international residents). A total of 86 parent-child dyads enrolled in the study. Children were, on average, 31.5 months. See Table 1 for participant characteristics.

A random numbers list was used to randomize participants. Participants were randomized to one of two treatment conditions – JASPER-parent-mediated or psychoeducational PEI – in addition to the 30-hr early intervention program. Randomization and analyses were conducted by an independent data-coordinating center. Testing for the success of randomization showed that the two groups were matched on demographics (see Table 1) except for age of entry, in which the JASPER group, with an average entry age of 31 months, was statistically significantly younger than the PEI group with an average entry age of 32 months. Three dyads discontinued treatment and another ten did not complete follow-up assessments. See the participant flow chart in Figure 1.

Due to the intensity of the EI program, families discontinued outside early intervention services during the 10-week program. During the follow-up period all children continued early intervention services. A large percentage (76%) maintained full time services (>30 hr/week). There was no significant difference in service utilization between the JASPER group (73%) and the PEI group (79%, $p = .56$) during the follow-up period.

Table 1
Participant Characteristics

Child and parent characteristics: <i>N</i> (%)	JASPER (<i>N</i> = 43)	PEI (<i>N</i> = 43)	Total	Test	<i>p</i>
Chronological age (months): Mean (<i>SD</i>)	30.7 (3.5)	32.3 (2.7)	31.5 (3.2)	$F(1, 84) = 6.3$.01*
Gender					
Female	8 (19%)	8 (19%)	16 (19%)	$\chi^2(1) = 0.0$	1.00
Race/ethnicity					
African American	0 (0%)	2 (5%)	2 (2%)	$\chi^2(4) = 4.5$.34
Caucasian	27 (63%)	26 (60%)	53 (61%)		
Hispanic	3 (7%)	4 (9%)	7 (8%)		
Asian/PI	4 (9%)	6 (14%)	10 (12%)		
Other	9 (21%)	5 (12%)	14 (17%)		
Mullen age equivalency (months): Mean (<i>SD</i>)					
Developmental quotient	68.0 (20.3)	68.1 (20.6)	68.0 (20.3)	$F(1, 84) = 0.0$.98
Age of mother	36.9 (4.4)	34.9 (4.7)	35.9 (4.6)	$F(1, 83) = 3.9$.05
Maternal education					
Years of education	17.2 (2.3)	16.4 (2.6)	16.8 (2.4)	$F(1, 84) = 2.6$.11

Note. JASPER = joint attention, symbolic play, engagement and regulation; PEI = psychoeducational intervention.

* $p < .05$.

Interventions

Each intervention model involved one hour of interventionist contact per week.

Psychoeducational intervention (PEI). The aim of the PEI intervention is to provide individual education and support to parents of young children with autism (Brereton & Tonge, 2005). This intervention provided 1:1 interventionist meetings with the parents in informational sessions of 1 hr/week for 10 weeks. Sessions covered specific topics each week and parents were able to ask questions specific to their own child's development directly with their therapist. The content of the manualized intervention included information on autism, details of specific behavioral impairments, principles of managing behavior, strategies for teaching new skills, improving social interaction and communication, service availability, managing parental stress, and sibling, family, and community responses to autism.

JASPER parent-mediated model. The JASPER model included the parent and his or her child for 1 hr/week for 10 weeks (two sessions of 30 min per week) with active coaching of the parent by a trained interventionist. A total of 20 sessions were completed, delivering an equivalent amount of therapist contact as the PEI condition per week (1 hr total of interventionist contact) to control for this variable.

JASPER is an empirically supported and manualized treatment for toddlers and preschoolers with a primary focus on sustaining periods of joint engagement and increasing joint attention gestures and play skills (Kaale, Smith, & Sponheim, 2012; Kasari et al., 2006; Kasari, Gulsrud, Freeman, Paparella, & Hellemann, 2012; Kasari et al., 2010; Kasari et al., 2014; Kasari, Paparella, Freeman, & Jahromi, 2008; Lawton & Kasari, 2012). Intervention sessions were based on developmental and behavioral principles consistent with JASPER. Parents were first taught to recognize the child's current developmental level of play and use of social-communication gestures. Capitalizing on the child's current level of play and interests, caregivers provided opportunities for the child to initiate interest in a toy/activity and to establish jointly engaged play routines. Parents used a number of strategies to keep children engaged while also improving their frequency of social

communication gestures, spoken words, and play acts. Parents were taught to use these strategies in a structured sequence that has been previously tested (Kasari et al., 2010, 2014).

Therapists, Supervision, and Treatment Integrity

A postdoctoral clinical psychologist supervised all interventionists, and the majority of therapists were PhD candidates in Human Development and Psychology. Three of the eight different therapists were BA level therapists, all in the JASPER arm. Prior to beginning study treatments, therapists were required to demonstrate >90% fidelity on a PEI or JASPER-specific measure of fidelity with practice children, typically requiring two to six months of training. Supervision of active cases was conducted weekly.

The project coordinator used a random numbers list to select sessions for fidelity ratings. To maintain blinding, the sessions were observed through a one-way observation window. Twenty percent of sessions were rated for treatment integrity with average ratings for PEI of 92.7% (78.6%–100%) and for JASPER, 91.4% (75%–100%).

Measures

Examiners blind to treatment status conducted all pretreatment, posttreatment, and follow-up assessments. Separate video coders were also blind to treatment condition.

The primary outcome was a measure of joint engagement coded from the *parent-child interaction*. A 10-min interaction recorded between parent and child was collected pretreatment, posttreatment, and at the 6-month follow-up. Parents were asked to engage in free play with their toddler as they normally would at home using a standard set of toys (including dolls, dishes, puzzles, trucks, shape sorter, and blocks). Children's joint engagement was coded using an adapted coding system from Adamson and colleagues (2004) where time jointly engaged included time in supported joint engagement and coordinated joint engagement, with or without symbols. Supported joint engagement was coded if the child demonstrated awareness of the parent's participation (e.g.,

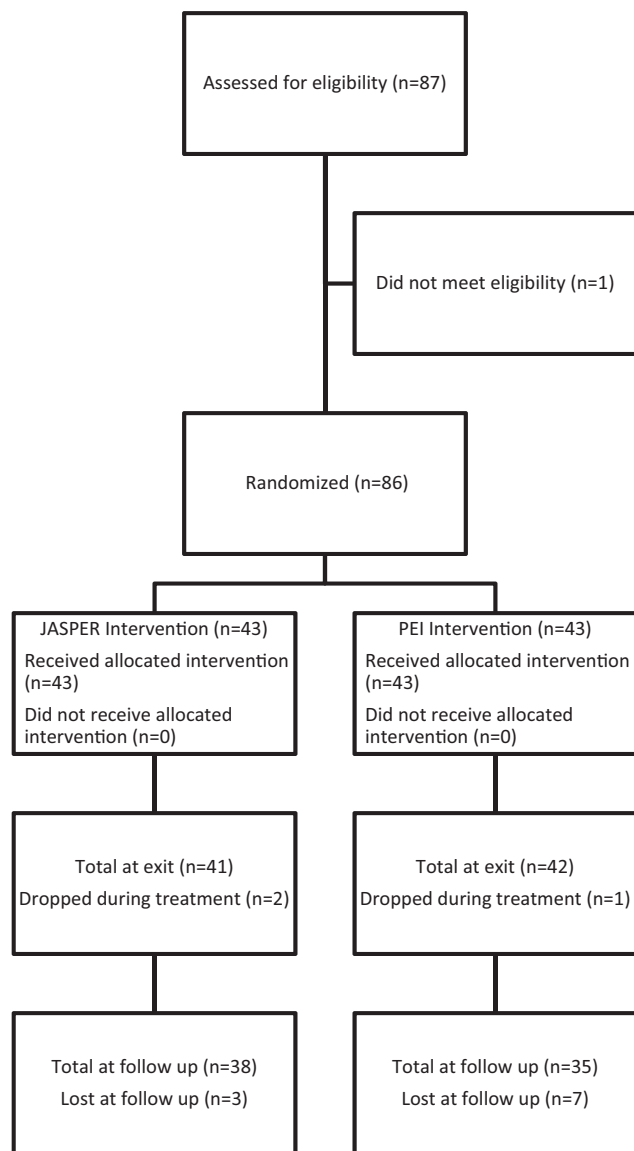


Figure 1. Recruitment flow diagram. JASPER = joint attention, symbolic play, engagement and regulation; PEI = psychoeducational intervention.

takes turns with the same object, follows parent suggestion in play with the object) while coordinated joint engagement was coded when the child directly acknowledged the partner through triadic eye gaze, language, and/or gesture. Instances of supported joint and coordinated joint engagement were coded as symbol infused if the child followed or showed evidence of attending to parent language or used language him/herself. For the purposes of this study, we combined supported joint and coordinated joint with and without symbols into a single variable of joint engagement consistent with previous studies (Kasari et al., 2010, 2014).

Secondary outcomes from the parent-child interaction included *child play skills, play level, and joint attention*. The child's play behaviors recorded during the mother-child interaction were coded for types (i.e., diversity) of functional and symbolic play acts

(Kasari et al., 2006). *Functional play types* involved counting the number of different novel forms of functional play from "relational" to "child directed play with dolls." *Symbolic play types* included counting all novel symbolic play types from "substitutions" through "multiple schemes" (Lifter, Sulzer-Azaroff, Anderson, & Cowdery, 1993). In addition, the *highest play level* that the child was observed to maintain during the interaction was assigned a numerical value for subsequent analyses. Highest play level achieved is a function of functional and symbolic play acts.

Child's frequency of initiating joint attention skills was also coded in the parent-child interaction (e.g., coordinated joint looks, pointing to share attention, and showing). We collapsed the frequency of joint attention skills that were *spontaneously initiated* into a summary variable of initiating joint attention.

Graduate students, not involved in other aspects of the study and blind to child treatment condition, coded the videotapes according to a protocol used in several other studies (Harris, Kasari, & Sigman, 1996; Kasari et al., 2006; Kasari et al., 2008). The reliability of the observational variables of interest, including total time jointly engaged (ICC = .95), initiating joint attention skills (ICC = .97), and number of functional (ICC = .95) and symbolic (ICC = .98) play types was excellent.

Other secondary outcome measures included *cognitive and language assessments, parenting stress, and an observational measure of joint engagement in the classroom*. The Mullen Scales of Early Learning (MSEL; Mullen, 1989) was used to assess general cognitive ability. The MSEL yields an early learning composite score based on scores for visual reception, gross motor, fine motor, and receptive and expressive language. This measure was collected pretreatment and at the 6-month follow-up. The Reynell Developmental Language scales (Reynell & Curwen, 1977) were used to assess the receptive and expressive language abilities of children in the sample. The scales yield raw scores on Expressive Language and Verbal Comprehension, and these raw scores were transformed into age equivalencies. The Reynell was administered pretreatment and at the 6-month follow-up.

The Parenting Stress Index (PSI; Loyd & Abidin, 1985) was used to obtain a measure of parent-reported stress. The PSI consists of two domains: one associated with parent characteristics and the other with child characteristics. The parent domain consists of items targeting sources of stress in the parent-child system related to parental functioning and consists of seven subscales (e.g., Parental Attachment, Sense of Competence, Relationship With Spouse, and Depression). The child domain consists of items reflecting perceptions of child characteristics that make it difficult for parents to fulfill their parenting role and consists of six subscales (e.g., child distractibility, demandingness, and child mood). Items are rated on a Likert-type scale and summed with higher scores reflecting greater dysfunction. The PSI was administered pre- and posttreatment and at the 6-month follow-up.

Classroom observations. Children were observed in their classrooms playing with their teacher for 15-min at pre- and posttreatment. During the 15-min play interaction, the classroom teacher, who was blind to treatment status, was instructed to engage in structured play with the child. Since videotaping was not permitted in the classroom, independent observers coded the classroom play interactions in 1-min intervals and coded the child's predominant engagement state. The engagement states consisted of six mutually exclusive categories: unengaged, onlooking, object

engaged, person engaged, supported joint engagement, and coordinated joint engagement (Adamson et al., 2004). The variable of interest was *time in joint engagement*, and consistent with coding from the parent-child interaction, supported joint engagement and coordinated joint engagement with and without symbols were collapsed into one variable of joint engagement. Six observers were trained to conduct the classroom observations over the course of the study (average $\kappa = .81$, range .73–.97).

Statistical Methods

One of the challenges of this study was the inherent structure of the behavioral measures. The majority of the variables of interest were right-skewed, and some of these behaviors were comparatively rare in this population (e.g., only 6% of the children in the sample showed any joint attention skills at baseline). To avoid potential bias or inflation of Type-I errors, we used a conservative approach. First, we determined whether the variable was zero inflated, as suggested by Min and Agresti (2005). Then, using the Heilbron (1994) approach, we tested if there was a strong enough floor effect to suggest that the measure was too difficult for part of the population. If this was the case, the variable was estimated using a Poisson hurdle model, in which the effect of the intervention was estimated simultaneously, but separately for the participants who were and were not yet in the range of ability covered by the scale. If there was no significant floor effect, we analyzed the data using a generalized linear mixed model (GLMM) with time, treatment assignment, and the Time \times Treatment interaction as fixed effects and participants as random effects to account for individual differences. The main effect of interest is the interaction between time and treatment in order to test for differences in the degree of change over time associated with the treatment condition. We chose either a Poisson GLMM or a linear GLMM depending on which model fit the data better based on the Bayesian information criterion.

To identify maintenance of, or changes in, treatment gains (i.e., if there are significant differences at the follow-up point), we used the same model previously employed to analyze the primary outcome point in order to maximize comparability of the results. In all follow-up assessments, the main outcome of interest (the Time \times Treatment interaction) was reported. In cases lacking an interaction effect and interpretable main effects, the main effect of time was also reported (i.e., if participants changed overall from baseline to the measurement point).

In every analysis we controlled for age to account for the difference between the JASPER and PEI groups at baseline. Age was not a significant factor in any of the models tested.

Lastly, we reported the effect size using Cohen's f^2 where effect sizes of 0.02, 0.15, and 0.35 are generally regarded as small, moderate, and large, respectively (Cohen, 1988).

Results

Means, standard deviations, and effect sizes are presented in Table 2 for primary and secondary outcomes.

Primary Outcome

Duration of joint engagement. The distribution of this variable was sufficiently close to normal to allow the use of a standard

GLMM (Akaike information criterion [AIC] of the linear GLMM = 1964, AIC of the Poisson GLMM = 4599). There was a significant group by time interaction [187.42 , 95% CI: (138.26, 236.58), $F(1, 83) = 57.50$, $p < .01$], showing that there was a significant increase in the length of time spent jointly engaged for the JASPER treatment compared with the PEI condition. Joint engagement more than doubled from entry to week 10 for the JASPER group, with a large effect size (Cohen's $f^2 = .69$).

The increase in the length of time spent jointly engaged was maintained at the 6-month follow-up and significant for the JASPER group compared with the PEI group [63.79 , 95% CI: (36.12, 91.45), $F(1, 83) = 21.03$, $p < .01$] with a moderate effect size (Cohen's $f^2 = .26$). See Figure 2.

Secondary Outcomes

Initiating joint attention. This variable was zero inflated since there were participants whose initiations of joint attention fell below the measurement range of the measure [$F(1, 85) = 30.37$, $p < .01$]. Using the hurdle model, there was no difference in the rate that participants who were below the measurement range entered onto the measurement range [-1.59 , 95% CI (-4.55, 1.36), $F(1, 83) = 2.86$, $p = .28$], and there was no difference in the rate that participants who were in the measurement range improved their initiations of joint attention after treatment [0.098 , 95% CI: (-0.268, 0.465), $F(1, 84) = 0.28$, $p = .60$]. There was an overall effect of time, in that the number of participants within the measurement range increased over time [3.80 , 95% CI (0.40, 6.91), $F(1, 83) = 5.94$, $p = .02$], and the mean score of the participants within the measurement range also increased [0.54 , 95% CI (0.29, 0.80), $F(1, 83) = 18.38$, $p < .01$].

At follow-up, there was no difference in the rate that participants who were below the measurement range entered onto the measurement range [0.76 , 95% CI (-0.45, 1.98), $F(1, 83) = 1.56$, $p = .22$], and there was no difference in the rate that participants who were in the measurement range improved their initiations of joint attention after treatment [0.15 , 95% CI (-0.04, 0.34), $F(1, 83) = 2.52$, $p = .12$]. The number of participants crossing the hurdle did not increase significantly from baseline to follow-up [0.73 , 95% CI (-0.14, 1.61), $F(1, 83) = 2.76$, $p = .10$], but the mean score increased significantly for participants who crossed the hurdle [0.28 , 95% CI (0.14, 0.42), $F(1, 83) = 16.57$, $p < .01$].

Number of functional play types. The number of functional play types did not show zero inflation [$F(1, 84) = 0.25$, $p = .61$]; however, due to the variable's skew, it was modeled best using a Poisson GLMM (AIC = 694) over a linear GLMM (AIC = 789). There was a significant group by treatment interaction indicating that the JASPER group increased more in types of functional play than the PEI group [0.45 , 95% CI (0.06, 0.83), $F(1, 83) = 5.35$, $p = .02$] with a small effect size (Cohen's $f^2 = .06$).

At the follow-up time point, there was no significant interaction effect of group and treatment [0.12 , 95% CI (-0.09, 0.33), $F(1, 83) = 1.23$, $p = .27$], and there was no increase from baseline [0.03 , 95% CI (-0.12, 0.19), $F(1, 83) = 0.16$, $p = .69$].

Number of symbolic play types. The number of symbolic play types revealed zero inflation [$F(1, 84) = 4.48$, $p = .04$]. Consequently, we modeled it using a hurdle model. The hurdle model did not reveal group differences in the change from below

Table 2
Descriptives and Effect Sizes for Primary and Secondary Outcomes

	JASPER (<i>N</i> = 43)		PEI (<i>N</i> = 43)		Effect sizes for group differences in change from baseline	
	Proportion not on scale	Mean (<i>SD</i>)	Proportion not on scale	Mean (<i>SD</i>)	<i>f</i> ² for proportions	<i>f</i> ² for means
Time joint engaged						
Entry		147.49 (99.93)		161.02 (123.84)		
Exit		325.17 (120.20)		159.72 (113.51)		.69
Follow-up		363.66 (132.50)		266.71 (119.90)		.26
Initiating joint attention						
Entry	23/42 (55%)	4.84 (4.62)	19/42 (45%)	4.61 (4.40)		
Exit	17/41 (41%)	8.08 (7.23)	7/41 (17%)	7.00 (6.12)	.03	.00
Follow-up	9/38 (24%)	8.66 (8.58)	10/34 (29%)	6.79 (5.72)	.02	.03
Functional play						
Entry		2.00 (2.01)		2.24 (2.03)		
Exit		4.05 (3.25)		2.85 (2.79)		.06
Follow-up		2.79 (2.17)		2.61 (2.36)		.01
Symbolic play						
Entry	38/42 (90%)	2.25 (2.50)	35/42 (83%)	2.00 (1.29)		
Exit	31/41 (76%)	3.60 (1.95)	31/41 (76%)	1.80 (1.55)	.01	.01
Follow-up	26/38 (68%)	4.75 (2.83)	20/33 (61%)	3.08 (1.98)	.00	.00
Highest play level						
Entry		5.77 (3.41)		7.20 (3.11)		
Exit		7.94 (3.43)		7.00 (3.77)		.11
Follow-up		8.18 (3.92)		8.18 (4.05)		.03
Receptive language						
Entry		16.09 (9.12)		16.47 (9.58)		
Exit		20.87 (11.85)		23.17 (13.02)		.02
Follow-up		32.74 (15.24)		33.38 (16.00)		.03
Expressive language						
Entry		14.09 (6.84)		14.98 (7.02)		
Exit		18.42 (8.03)		19.83 (7.84)		.01
Follow-up		24.26 (9.34)		24.59 (8.82)		.01
PSI child						
Entry	30/43 (70%)	62.31 (24.80)	30/41 (73%)	65.00 (24.70)		
Exit	22/39 (56%)	61.23 (25.62)	25/37 (68%)	47.08 (27.91)	.01	.05
Follow-up	17/37 (46%)	59.30 (24.33)	15/32 (47%)	62.41 (24.73)	.00	.00
PSI parent						
Entry	6/43 (14%)	47.35 (28.13)	9/41 (22%)	42.56 (24.16)		
Exit	4/39 (10%)	47.74 (27.93)	5/37 (13%)	39.31 (30.68)	.00	.00
Follow-up	7/37 (19%)	50.73 (27.60)	10/32 (31%)	35.86 (27.63)	.00	.01
Classroom observation						
Entry		5.77 (3.97)		6.81 (3.51)		
Exit		8.14 (4.03)		7.33 (4.32)		.06

Note. Guidelines for *f*² (Cohen, 1988): small = .02, medium = .15, large = .35. JASPER = joint attention, symbolic play, engagement and regulation; PEI = psychoeducational intervention; PSI = Parenting Stress Index.

the hurdle to over the hurdle [0.14, 95% CI (-.84, 1.14), *F*(1, 82) = 0.57, *p* = .45], nor did it reveal group differences in the change of the observed level of symbolic play from baseline to the end of the study for participants who were within the measurement range [0.07, 95% CI (-0.56, 0.69), *F*(1, 82) = 0.84, *p* = .36]. In addition, we tested for overall changes over time since the interactions were not significant. There were no overall changes for the participants below the hurdle [0.97, 95% CI (-0.61, 2.57), *F*(1, 82) = 1.49, *p* = .22], and the mean score for participants above the mean did not change [-0.04, 95% CI (-1.03, 0.95), *F*(1, 82) = 0.01, *p* = .93].

At the follow-up time point, there was no difference between the groups in the number of children that moved from out of the measurement range into the measurement range [0.14, 95% CI (-0.84, 1.13), *F*(1, 82) = 0.08, *p* = .77]; however, there was a

significant increase over time of the proportion of children in the measurement range [0.84, 95% CI (0.10, 1.59), *F*(1, 82) = 5.10, *p* = .02]. Although there was no overall difference between groups in the increase of the scores for children who were within the range of the measurement [0.07, 95% CI (-0.56, 0.69), *F*(1, 82) = .05, *p* = .82], some results revealed increased scores between baseline and follow-up [0.35, 95% CI (-0.06, 0.76), *F*(1, 82) = 2.85, *p* = .09].

Highest play level achieved. Highest play level achieved did not show significant zero inflation [*F*(1, 84) = 0.39, *p* = .53], but the skew of the data led to a best-fit model of a Poisson distribution (AIC = 833) rather than a normal distribution (AIC = 839). Using the Poisson model, there was a significant treatment by time interaction for the highest play level achieved [0.36, 95% CI (0.11, 0.61), *F*(1, 84) = 9.07, *p* < .01], such that the JASPER group

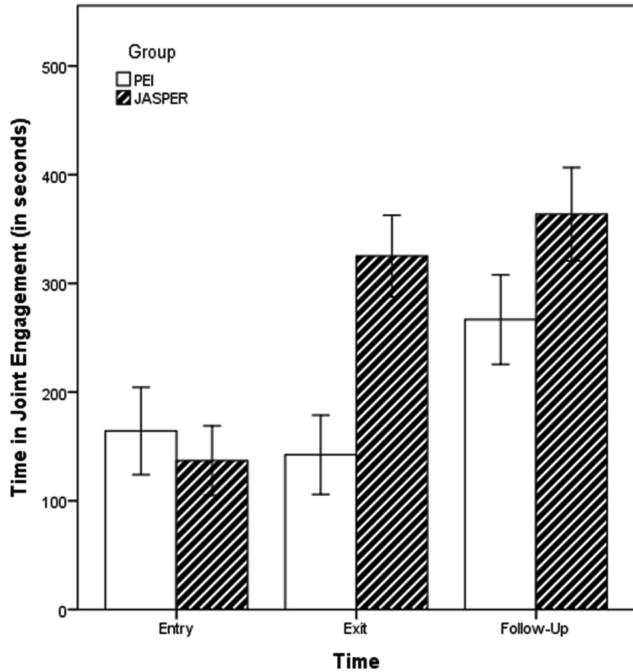


Figure 2. Time in joint engagement (in seconds). JASPER = joint attention, symbolic play, engagement and regulation; PEI = psychoeducational intervention.

increased more than the PEI group in highest play level achieved, although the effect size was small (Cohen's $f^2 = .11$).

At follow-up, the difference between the treatment groups was no longer significant [0.10, 95% CI (-0.02, 0.22), $F(1, 83) = 2.91$, $p = .09$], and there were no overall sustained treatment gains from baseline across the groups [0.07, 95% CI (-0.02, 0.16), $F(1, 83) = 2.54$, $p = .11$].

Reynell receptive language. This variable did not show zero inflation [$F(1, 84) = 0.00$, $p = .98$]. The skew of the data led to a best-fit model of a Poisson distribution (AIC = 1,137) rather than a normal distribution (AIC = 1793). There was no significant treatment effect on the rate of change [-0.11, 95% CI (-0.31, 0.08), $F(1, 84) = 1.35$, $p = .25$], but there was an overall increase of receptive language over time across both groups [1.23, 95% CI (1.09, 1.38), $F(1, 84) = 278.59$, $p < .01$].

This same pattern was obtained at follow-up, with an overall significant increase from baseline [0.62, 95% CI (0.54, 0.69), $F(1, 84) = 278.59$, $p < .01$], but no differences were found between the treatment groups in the degree of change [-0.06, 95% CI (-0.16, 0.04), $F(1, 84) = 1.35$, $p = .25$]. Both groups increased in receptive language by nearly 17 months over the 9-month study.

Reynell expressive language. This variable did not show zero inflation [$F(1, 84) = 0.00$, $p = .99$]. A Poisson distribution (AIC = 1047), rather than a normal distribution (AIC = 1,067), was used to address the skew of the data. There was no significant treatment effect on the rate of change [0.10, 95% CI (-0.13, 0.33), $F(1, 84) = 0.74$, $p = .39$], but there was an overall increase in rate of change over time across both groups [0.91, 95% CI (0.75, 1.08), $F(1, 84) = 122.90$, $p < .01$].

At follow-up, a similar pattern emerged with a significant increase from baseline in expressive language [0.46, 95% CI (0.37,

0.54), $F(1, 85) = 122.90$, $p < .001$] and no significant difference between the treatment groups in the degree of change [0.05, 95% CI (-0.06, 0.16), $F(1, 85) = 0.74$, $p = .39$]. Both groups increased an average of 10 months in expressive language over the 9-month study.

PSI, child domain. Since the stress variables were notably left-skewed with a large proportion of the respondents having extremely high stress scores (>90), we decided to invert this scale to use the zero-inflation framework that requires the data to be right-skewed. The inverted variable indicated significant zero inflation [$F(1, 84) = 15.5$, $p < .01$], a significant overrepresentation of extremely highly stressed respondents, which led to analyses using a zero-inflated Poisson model. The amount of change in the child-domain stress variable significantly differed across treatment groups [-0.76, 95% CI (-1.52, -0.00), $F(1, 82) = 3.99$, $p = .049$] in that parents in the PEI group experienced a larger reduction in child-related stress over time as compared with the parents in the JASPER group but with a small effect size (Cohen's $f^2 = .05$). There was no difference in the ratio of participants on the scale over time [0.72, 95% CI (-1.22, 2.67), $F(1, 82) = 0.46$, $p = .46$].

Overall, more scores moved onto the measurement scale at follow-up, indicating decreased stress [0.70, 95% CI (0.05, 1.35), $F(1, 82) = 4.65$, $p = .03$], yet there was no group difference in this decrease [0.01, 95% CI (-0.82, 0.79), $F(1, 82) = .0$, $p = .97$]. For respondents on the measurement scale, there was no significant change in stress over time [0.42, 95% CI (-0.64, 1.49), $F(1, 82) = .41$, $p = .52$] and no difference between the treatment groups in this change [-0.03, 95% CI (-0.11, 0.05), $F(1, 82) = .34$, $p = .55$].

PSI, parent domain. This variable also displayed zero-inflation [$F(1, 84) = 12.9$, $p < .01$]. There was no difference between the groups in the change over time [-0.11, 95% CI (-0.44, 0.22), $F(1, 82) = 0.44$, $p = .51$], and no overall change over time [0.13, 95% CI (-0.10, 0.36), $F(1, 83) = 1.26$, $p = .26$]. The proportion of parents on the scale also did not change overall [0.75, 95% CI (-0.85, 2.36), $F(1, 82) = 0.87$, $p = .35$], nor was it group dependent [0.00, 95% CI (-2.29, 2.29), $F(1, 82) = 0.00$, $p = .99$]. Similarly at follow-up, there was no difference between groups in change over time [-0.08, 95% CI (-0.27, 0.10), $F(1, 82) = .85$, $p = .36$], nor an overall change over time [0.04, 95% CI (-0.09, 0.17), $F(1, 82) = .35$, $p = .55$]. There was also no difference between groups in the rate that people moved off the scale [0.40, 95% CI (-0.19, 0.62), $F(1, 82) = .34$, $p = .56$], nor was there an overall trend of people moving off the scale [-0.70, 95% CI (-1.76, 0.35), $F(1, 82) = 1.75$, $p = .19$].

Classroom observations. Results indicated a significant interaction effect for joint engagement [2.62, 95% CI (0.38, 4.86), $F(1, 84) = 5.4$, $p = .02$]. The children in the JASPER group improved significantly more than the PEI group in the amount of time spent jointly engaged with the teacher in the classroom environment. The time spent jointly engaged increased for the JASPER group from 5.7 min to 8.9 min within the 15-min observation interval, while the PEI group only increased from 6.9 min to 7.4 min within the same observation period. This difference translated to a small effect size (Cohen's $f^2 = .06$). See Figure 3.

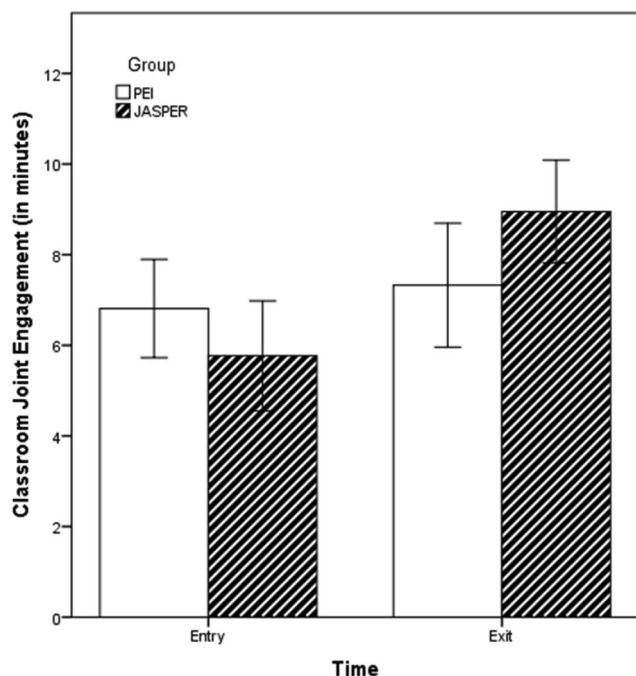


Figure 3. Classroom joint engagement (in minutes). JASPER = joint attention, symbolic play, engagement and regulation; PEI = psychoeducational intervention.

Discussion

The aim of this study was to determine whether parent-mediated interventions would significantly affect parenting stress and child behaviors above and beyond the early intervention services children were receiving. There were four main findings. First, consistent with our hypotheses, a hands-on parent-training program (JASPER) resulted in significantly more treatment gains in dyadic joint engagement than a parent education program (PEI). Maintaining joint engagement requires parent strategies that capture the child's interest and engagement with activities at the child's developmental level, consistent with tenets of JASPER. Children also have to be active participants in treatment since it is not sufficient for parents to simply keep the child's attention on the task at hand. In this study, the measure of joint engagement was coded from an independent assessment of the parent playing with child using a standard set of novel toys not previously used in intervention sessions. Parents coached in specific JASPER strategies were significantly more effective at engaging their children in play at posttreatment and follow-up than parents who received information about specific strategies through the PEI. Effect sizes were moderate to large.

Second, independent observations found that children in the JASPER condition engaged with their teachers more in their early intervention classroom. These findings may be among the first indicating generalization of joint engagement skills from a parent-mediated intervention to new partners and contexts. Teachers and classroom observers were blinded to the child's treatment assignment and had not received any training regarding the contrasting treatment conditions. Other studies using adaptations of JASPER have found similar generalization of engagement. Kasari et al.

(2006) found increased joint engagement between mothers and children from therapist mediated interventions, and Kaale et al. (2012) found generalization from preschool teacher mediated intervention to parent-child interactions. Longer durations of joint engagement over time facilitate greater opportunity to communicate with others and to learn additional skills from them. Thus, these findings lend greater support to joint engagement as an important treatment target for young children with ASD.

Third, mixed results were found for our secondary child outcomes in play and joint attention. Compared with children in the PEI condition, children in the JASPER condition demonstrated significantly greater improvements in functional-play diversity and overall play level at the end of treatment; however, these skills did not maintain at follow-up. The lack of maintenance may indicate the need for continued booster sessions for parents in order to maintain the strategies learned in the intervention. In regard to joint attention, children showed very few initiations of joint attention skills at the start of treatment, with more than half of all children showing no joint attention at all on independent assessments. Given this situation, we used a conservative analytic technique in order to model change in these skills across treatment and follow-up. Few children crossed the "hurdle" onto the measurement scale, and if they were on the scale, they did not show significant gains in joint attention skills over the course of treatment and follow-up. In contrast to findings with preschool-aged children with ASD, we did not find treatment effects on our measure of joint attention initiations, despite targeting initiations of joint attention (Kasari et al., 2006). Initiating joint attention is difficult for children with ASD and children may have needed more time to learn these skills than allotted in the present study. At the same time, we cannot rule out that another approach may have been more effective.

While children demonstrated mixed progress in joint attention and play skills, they did make significant developmental gains in language skills over the study with 17 months gain in receptive language and 10 months gain in expressive language over the 9-month study. These data provide further support for the disassociation between core deficits of children with ASD and general developmental gains. Most children with ASD appear to make significant developmental gains when provided with early intervention, but improvements in core deficits of social communication require targeted and specific interventions (Kasari et al., 2008).

Finally, results indicated reduction in parenting stress for families in the PEI condition. There is no question that raising a child with ASD increases parenting stress related to the disorder (Osborne, McHugh, Saunders, & Reed, 2008; Schieve et al., 2007). In parent-mediated models of intervention, parents must assume an additional role as therapist with their child, causing increased stress for some parents (Osborne et al., 2008). In this study, nearly all parents reported very high levels of parenting stress, with over half of the parents above the ceiling of the measure at the beginning of the study. However, all children were simultaneously enrolled in an intensive EI program where children had access to a variety of professionals. Thus, stress related to trying to obtain services should have been alleviated. Results revealed that parents in the PEI condition, who consulted with an expert about their children and gained greater knowledge about autism, reduced their levels of stress as a result of the treatment. In contrast, parents in

the JASPER condition, who provided direct intervention to their child, maintained their previously elevated levels of parenting stress. There may be several explanations for these findings. One is that parents may have preferred a counseling approach over a hands-on approach because of the high dose of direct services their children were already receiving. Another possibility is that parents' worries increase when they take on an interventionist role with their child and are directly faced with their child's progress, or lack thereof. Additional research is warranted, including the potential of combining JASPER and PEI, or the testing of therapist plus parent interventions for effects on the well-being of parents. Future studies will also want to compare interventions that control for the amount of supervised parent-child play in order to isolate differences related to the type of directed parent support.

The current study is both consistent and inconsistent with previous parent-mediated interventions with young children with ASD. While it is one of the larger parent-mediated interventions for children with autism, a few others are notable. Rogers et al. (2012) compared a parent-mediated version of the Early Start Denver Model to treatment-as-usual for 98 parents and toddlers (15 to 24 months old) with 12 hr of treatment over three months. No differences were observed on parent or child outcomes, but it warrants noting that the children in the Rogers study were 12 months younger, on average, than the children in the current study. However, in a similar age range (16 to 20 months), Wetherby et al. (2014) noted significant improvement in social communication and receptive language scores for children who received parent coaching versus parent education over nine months. Thus, dose and length of intervention may be significant factors in increasing outcomes for children less than two years. However, neither study controlled experimenter contact between conditions or provided follow-up data; thus, differences due to dose or maintenance of gains are unknown.

Green et al. (2010) compared a parent-mediated intervention, Preschool Autism Communication Trial (PACT), to treatment-as-usual for 150 parents and preschoolers with autism who were, on average, 13 months older than the children in the current study. This 1-year-long study, delivering about 18 hr of intervention, resulted in significantly greater parent responsiveness and child initiations of social communication for participants in the PACT group as compared with community controls. The data in the current study are consistent with the PACT trial for parent-child outcomes, as well as with studies demonstrating greater gains from parent coaching models over parent education ones (Kasari et al., 2014; Wetherby et al., 2014). A notable strength of the current study is the comparison between two active evidence-based parent-mediated interventions. JASPER is an empirically validated, targeted, and modular treatment for young children with ASD with significant treatment effects noted when tested against treatment-as-usual control groups using expert therapists (Kasari et al., 2006, 2008), teacher-delivered interventions (Kaale et al., 2012; Kaale et al., 2014; Lawton & Kasari, 2012; Wong, 2013), and parent-mediated interventions (Kasari et al., 2010; Kasari et al., 2014). The current study highlights the effects of JASPER when compared with an active comparator, PEI, that has also been empirically validated (Brereton & Tonge, 2005). Another notable strength of the current study is the ability to isolate the contribution of the experimental treatments against other treatments the participants were receiving. Most studies of parent-implemented inter-

ventions vary on dose of intervention between experimental and comparison conditions. While commonly tracking other services by parent report, it is difficult to control for reporting error and variability in types and dose of services (Rogers et al., 2012; Wetherby et al., 2014). In the current study, all children received the same early intervention program with equivalent dose and type of intervention.

While these data suggest that focusing on core deficits can result in important changes in parent and child outcomes, they also raise questions about individual differences in child and parent outcomes. Overall, clinical effect sizes were large for the primary outcome, and small to moderate on secondary outcomes. Sustainability (i.e., maintenance of treatment gains) was limited to the primary outcome measure of joint engagement. Future studies should strive for achieving a better understanding of the active ingredients of the treatment and profiles of children and parents most likely to benefit from specific early interventions.

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Review

Parent training: A review of methods for children with autism spectrum disorders

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ABSTRACT

Autism Spectrum Disorders (ASD) are common in the general childhood population, and are both serious and lifelong. Tremendous strides have been made in the treatment of these ASD in recent years, particularly with respect to psychological interventions. Given the considerable amount of time and cost involved in providing these interventions, parent training and involvement is a particularly appealing intervention option. This paper is a review and status report on evidence based methods that are available for training parents of children with ASD as therapists. Current trends and future directions are discussed.

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Autism Spectrum Disorders (ASD) constitute one of the most problematic and heavily studied childhood disorders (Chiang, 2008; Matson, 2007a,b; Matson & LoVullo, 2009; Matson & Nebel-Schwalm, 2007a, 2007b). Prevalence rates are high and growing, with the occurrence of ASD in 1 in

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150 children now considered the correct rate (Croen et al., 2002; Fombonne, 1999). Additionally, symptom patterns within and across the five disorders that make up the spectrum can be very heterogeneous (Matson & Boisjoli, 2007; Matson, Fodstad, & Boisjoli, 2008b; Willemsen-Swinkels & Buitelaar, 2002). ASD are generally considered to be neurodevelopmental in origin (Matson et al., 1996), and are characterized by impairments in social skills, communication, and repetitive/restrictive behavior (Matson, 2007a,b; Matson & Boisjoli, 2007; Matson, Carlisle, & Bamburg, 1998a). Furthermore, co-occurring disorders such as intellectual disability, seizures, challenging behaviors and comorbid psychopathology are common (Applegate, Matson, & Cherry, 1999; Hartley, Sikora, & McCoy, 2008; Matson, Dempsey, LoVullo, & Wilkins, 2008a; Matson, Fodstad et al., 2008; Matson & Smirollo, 1997; Paclawskyj, Matson, Rush, Smalls, & Vollmer, 2001; Rojahn, Aman, Matson, & Mayville, 2003; Rojahn, Matson, Naglieri, & Mayville, 2004). These additional disorders bring with them a host of problems as well (Agaliotis & Kalyva, 2008; Farran, 2008; Holden & Gitlesen, 2008; La Malfa, Lassi, Bertelli, Pallanti, & Albertini, 2008; Lifshitz, Merrick, & Morad, 2008; Mitchell & Hauser-Cram, 2008; Myrbakk & von Tetzchner, 2008; O'Reilly et al., 2008). Finally, a lifelong course of ASD can be anticipated (Dawson, Matson, & Cherry, 1998; Matson, Carlisle et al., 1998; Matson, Smirollo, & Bamburg, 1998b; Szatmari, Bryson, Boyle, Streiner, & Duku, 2003).

The picture is not altogether a gloomy one. Early Intensive Behavioral Intervention (E-IBI) can prove to be very important and effective in modifying or eliminating many of the most serious symptoms (Ben Itzchak, Lahat, Burgin, & Zachor, 2008; Ingersoll, Schreibman, & Stahmer, 2001; Matson & Smith, 2008). Issues of social skills, communication, compliance, rituals and stereotypies are routinely targeted (Heiman & Berger, 2008; Hsieh, 2008; Matson, Dixon, & Matson, 2005; Matson, Leblanc, & Weinheimer, 1999; Matson & Wilkins, 2009; Njardvik, Matson, & Cherry, 1999). The implementation of psychologically based methods across time and settings (e.g., school and home) is a primary treatment approach (Coe et al., 1999; Ingersoll et al., 2001; Ringdahl, Call, Mews, Boelter, & Christensen, 2008). More controversial but also used frequently are pharmacological treatments (Advokat, Mayville, & Matson, 2000; Singh, Matson, Cooper, Dixon, & Sturmey, 2005). This latter therapeutic method is particularly common in the treatment of challenging behaviors which occur in high rates for ASD and the often accompanying intellectual disabilities (Matson & Bamburg, 1998; Matson et al., 1997).

1. Overview

The general consensus is that behaviorally oriented parent training procedures used with the general population, and to some extent with developmentally disabled populations, are effective for parents of children with ASD (Brookman-Frazee, Stahmer, Baker-Ericzén, & Tsai, 2006). Having said this, authors also stress that ASD presents with a wide range of symptom patterns and challenging behaviors (Aman, 2005). Thus, the likelihood that parents would need and could benefit from such training is significant.

It is also important to stress that drop out rates from parent training in general are high. Forehand, Middlebrook, Rogers, and Steffe (1983) note that for typically developing children with challenging behaviors the rate was 28%. And, parents who perceived the treatment to be ineffective are more likely to drop out. Thus, training parents using the procedures that have the most evidence to support their efficacy would seem prudent. Along these lines Helm and Kozloff (1986) recommended a training model that focused on functional skills and which employ behavioral methods that enhance generalization and maintenance. The effective methods described which have an evidence base, rely on behavior therapy/applied behavioral analysis. A description of some of these interventions is as follows.

2. Training techniques

The notion that parents of children with ASD should be involved in their treatment, and that this involvement should come at an early age, is not a new one (Lovaas, Koegel, Simmons, & Long, 1973). Typical effective parenting methods are provided by Jocelyn, Casiro, Beattie, Bow, and Kneisz (1998). They describe care givers being trained to provide services to their children in community based day

care centers. Preschoolers ($n = 35$) who met DSM-III-R criteria for autism or Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS) served. Children were randomly assigned to an experimental or control group. Experimentals received 12 weeks of intervention involving lectures and on-site consultation by therapist/trainers. Control received the normal day care program. Experimentals had greater gains in language and parents acquired greater knowledge of autism. They also were satisfied with the training and felt they had achieved greater positive control in the parent/child relationship.

One of the best known and most commonly used training procedures, particularly for young children with ASD, is discrete trial training. Thus, a logical step would seem to be parent training in these procedures. Lafasakis and Sturmey (2007) did just that. They taught three mothers of developmentally disabled children. Furthermore, they reported generalization of these applied behavior analysis principles to novel skills. It should be noted, that while this is the only study devoted exclusively to describing discrete trial training to parents, it has been achieved in other contexts. Numerous large package treatments of 20–40 h per week over a year time and described as early intensive behavioral interventions, employ discrete trial training. In these studies, teaching parents to carry out these methods in addition to trained therapists are commonly reported (Matson & Smith, 2008).

These basic applied behavioral analysis methods have also been included in manuals for parents and in combination with psychotropic drugs (Johnson et al., 2007). However, the more conventional approach with normalized training is to use it alone based on applied behavior analysis principles. Typical of this approach are the efforts of Laugesen, Frankel, Mogil, and Dillon (2008). They taught parents to treat their teens (age 13–17 years) with ASD on a series of social skills. Among the behaviors targeted for treatment were conversational skills, peer entry and exit skills, developing friendships, good sportsmanship, being a good host at get togethers, dealing with arguments, and teasing and bullying. Similarly, Sofronoff, Leslie, and Brown (2004) tailored psychoeducational procedures for psychosocial issues of Asperger's children. Among the targets for interventions were challenging behaviors, dealing with routines and overblown specialized interests, and anxiety problems.

One of the most visible and best empirically supported parent training programs is the Stepping Stones Triple P (Positive Parenting Program). Group training is used for sessions involving teaching the parents treatment strategies. Special adaptations for the ASD population included adding comic strip conversations and social stories. Target areas include developing positive relationships, encouraging desirable behavior, teaching new skills and behaviors (e.g., physical guidance, using incidental teaching, chaining, establishing ground rules, and giving clear calm instructions). Whittingham, Sofronoff, Sheffield, and Sanders (2009) studied 59 families (29 in the treatment group and 30 in the wait list control group). The Triple P Program was effective and parents found the program helpful. Treatment procedures they considered particularly helpful were time-out, physical guidance and blocking.

3. Communication

As noted earlier in this paper, communication is a core symptom of ASD. As a result, it is appropriate that communication would be a target for parenting programs. Elder, Valcante, Yarandi, White, and Elder (2005) obtained frequency counts of skills taught to fathers via play sessions that had been videotaped. In home father training resulted in these parents evincing greater levels of appropriate imitation and responding. Another important gain was increased child vocalizations.

A second example of this approach is provided by Gillett and LeBlanc (2007). They use what they describe as a Natural Language Paradigm (NLP). Participants in their study were three children with autism and their mothers. Parents were trained in NLP for use with their largely nonverbal children. The mother sat on the floor with various toys and books, facing their child. Items were used as a stimulus to initiate vocalizations. The mother would describe the action of the toys and then wait up to 5 s for the child to make the expected vocalization. If no response occurred, the mother continued to model the vocal behavior up to three trials. This method was repeated by the mother using various objects. Parents were trained in these procedures via instructions and observation of a videotape of a

psychologist implementing NLP with a child who had autism. Significant improvements in play were noted for two of the three children. Parents reported that NLP was useful and easy to learn.

Across developmental disabilities in general, and for ASD as well, the most common goal of parent training is challenging behaviors. O'Dell, Blackwell, Larcen, and Hogan (1977), for example, describe such a program with the goal of integrating the children into regular or special education classrooms. Similarly, Butter (2007) used a manualized parent training program of 24 weeks duration targeting irritability, tantrums, aggression and self-injury. Noncompliance and irritability were decreased and daily living skills were increased. Similar results for challenging behaviors of autism have been reported with the philosophy and practice of mindfulness (Singh et al., 2007).

Several elements are common denominators in all these successful programs. Being organized, targeting specific operationally defined behaviors which can be treated, establishing consequences, and maintaining consistency in programming are all important. Osborne, McHugh, Saunders, and Reed (2008) underscore a number of these points in their research on parent effectiveness. They studied 72 children age 5–16 years who had ASD and their parents over a 9–10-month period. They looked specifically at the effects of parenting behaviors on their children's challenging behaviors. These authors noted that early effective limit setting by parents was the best predictor of fewer challenging behaviors. Furthermore, they concluded that equipping parents with behavior management skills early is a very successful strategy. These data then, underscore a large movement in the parenting literature with ASD: the move to early intensive behavioral interventions which include a parent training component.

4. Early intervention

Mahoney and Wiggers (2007) underscore the notion that parents should play an important role in early intervention programs. They stress that these early intervention programs could and should do more to put parents in the central role in treatment, given the substantially greater number of opportunities parents have to effect learning on the part of their offspring. Furthermore, when parents serve as the primary therapist, professionals are able to markedly increase the number of families they can serve. An excellent example of this approach is described by Sheinkopf and Siegel (1998). They trained 11 parents to implement applied behavior analysis for their pervasive developmental disordered preschoolers. Results of treatment were compared to 11 other matched preschoolers with pervasive developmental disorders. The treatment group received an average of 27 h of treatment weekly for 20 months. At post-test, children in the treatment group received higher scores on IQ tests, and displayed far fewer symptoms of autism.

In a similar study, Smith, Buch, and Gamby (2000) trained parents and paraprofessionals they had hired to provide therapy at home. Care providers received 6, 1-day workshops over a 5-month period on the application of applied behavior analysis principles with these children. Five of the six children rapidly acquired communication and self-care skills, but only two children showed marked improvement at follow-up, 2–3 years later. While results were mixed, parents were highly satisfied.

Mudford, Martin, Eikeseth, and Bibby (2001) also describe a parent directed early intensive behavioral intervention program in England. They interviewed 75 parents of children with ASD who were participating in these programs. By 4 years of age 71% of the children had begun the program, with the oldest age at initiation of treatment being 7 years of age. These authors noted improvements in the children's overall behavior profile, but not all at the same magnitude as that observed in studies where professionals were the primary therapy provider. The authors concluded that having parent based implemented programs may require more assistance from consultants and other professionals than previously thought.

Bibby, Eikeseth, Martin, Mudford, and Reeves (2002) also looked at parent management programming, in their case with 66 children receiving services from 25 different professionals. They reported gains in adaptive functioning, but not for IQ, over the course of the 31.6-month treatment program. Age and IQ were also major predictors of outcome. No child over 4 years of age was described as functioning normally at post-test, and an initial IQ over 85 was necessary for mainstreaming in school. Additional data showed that 60 children evinced progress in mental age, adaptive behavior and language (Bibby et al., 2002).

Taking this idea a step further, [Anan, Warner, McGillivray, Chong, and Hines \(2008\)](#) put more emphasis on the parents as the therapist. Designated Group Intensive Family Therapy (GIFT) is described as a 12-week program delivered for 3 h each weekday. Designed for preschoolers with ASD, parents are individually trained in direct applications of applied behavioral analysis. Children improved on cognitive and adaptive functioning.

Taken as a whole, there is a recognition that early intervention can benefit from marked parental involvement. The biggest issue regarding such involvement is pragmatic. For example, do parents have the amount of time needed to carry out such training, particularly if they have young children. Additionally, can they carry out the training program accurately. This latter point of discussion has been emphasized in a number of studies (e.g., [Mudford et al., 2001](#)).

5. Stress and anxiety

Another topic in the general areas of ASD where parent training has been addressed is stress and anxiety. [Baker-Ericzén, Brookman-Frazee, and Stahmer \(2005\)](#) in one such study report that mothers and fathers of children with ASD, as well as the children themselves, report high levels of stress. Additionally, these stress levels are significantly greater than what is observed with typically developing children. Furthermore, social skills, a core feature of ASD, were particularly related to stress levels. Thus, targeting treatments in this core symptom domain would appear to be prudent.

Stress and anxiety in children with ASD can be manifested in two major ways. One is general anxiety, and the other is fears and phobias that result in stress and anxiety. [Love, Matson, and West \(1990\)](#) describe an early study designed to teach mothers to treat specific fears of their children with ASD. There were two boys with ASD, age 4.5 and 6 years, in this study. Fears were particularly important since they were functional behaviors required to enhance independence. For one child, fear of the outdoors was the target behavior, while for the second participant fear of a running bathroom shower was the target for intervention. Children were exposed gradually to fearful stimuli, with the mothers reinforcing adaptation to these stimuli. Dependent variables were number of approach to feared stimuli, appearance of fear, and vocalizations of fear. Children overcame fear of the targeted situations, and gains were maintained at 1 year for one child. [Raven and Hepburn \(2006\)](#) underscore these findings in their review of parenting for anxiety symptoms of children with ASD. They note that the literature supports cognitive behavioral therapy as the treatment of choice for these populations.

6. Conclusions

Parent training has received some research attention in the field of ASD, and what has emerged at this point is promising. Parents are able to develop skills, largely within the domain of applied behavioral analysis, which result in more effective treatment for their children. Obvious advantages of these methods include enhanced generalization, cheaper and less resource intensive interventions, and greater potential for maintenance of treatment gains. Additionally, such interventions position parents to better understand how to effectively treat their child. At the same time, parents are able to gain insights about effective interventions. These factors make the parent a better consumer with respect to treatment efficacy and fidelity.

There is a long tradition of parent training in the ASD literature, but it has not reached the sophistication level of treatment packages seen for typically developing children with compliance problems. Determining the best package methods for given ASD, and ASD severity, as well as modifications to programs based on age, are in order. Early intensive behavioral intervention packages often include a parenting component. This approach is significant and important since getting parents involved in these treatments as early as possible is advisable. However, less cohesive models exist as the child ages out of these early treatment programs. Researchers know that symptoms wax and wane with age in the ASD group. Furthermore, as with all youth, the types of issues encountered as a teenage for example, are vastly different than issues a beginning preschool child faces. These factors have not been adequately addressed in the literature.

A lifelong treatment model of parent training would seem to be prudent, even for the best responders to early intensive behavioral treatments. At this point researchers do not know the

maintenance properties of early intensive behavioral interventions over an extended period of time. However, it would seem advisable that parents periodically (as needed) provide booster sessions to maintain existing skills. Furthermore, programs need to be developed that help the child with ASD cope with new life challenges over time.

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Anexo VIII

Schertz, H. & Odom S. (2007). Promoting joint attention in toddlers with autism: A parent-mediated developmental model. *Journal of Autism and Developmental Disorders*, 37(8), 1562–1575. Índice de impacto: SJR (SCImago Journal Rank) 2014: 1.696.

Promoting Joint Attention in Toddlers with Autism: A Parent-Mediated Developmental Model

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Abstract Joint attention, a foundational nonverbal social-communicative milestone that fails to develop naturally in autism, was promoted for three toddlers with early-identified autism through a parent-mediated, developmentally grounded, researcher-guided intervention model. A multiple baseline design compared child performance across four phases of intervention: focusing on faces, turn-taking, responding to joint attention, and initiating joint attention. All toddlers improved performance and two showed repeated engagement in joint attention, supporting the effectiveness of developmentally appropriate methods that build on the parent–child relationship. A complementary qualitative analysis explored family challenges, parent resilience, and variables that may have influenced outcomes. Intervention models appropriate for toddlers with autism are needed as improved early identification efforts bring younger children into early intervention services.

Keywords Joint attention · Early intervention · Toddlers · Parent mediation · Autism

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Introduction

The research reported here studied an approach to promoting joint attention in toddlers with autism that considers developmental foundations and builds on the existing parent–child relationship (Schertz, 2005a). Models appropriate for younger children with autism are a high priority for the field because with earlier and effective intervention, we can expect superior long-term outcomes (National Research Council, 2001; Volkmar, Lord, Bailey, Schultz, & Klin, 2004). As early identification efforts improve with effective toddler screening programs (e.g., Robins, Fein, Barton, & Green, 2001; Stone, Coonrod, & Ousley, 2000), this need becomes more urgent.

Joint attention is defined as visually coordinating attention with a partner to an external focus, showing social engagement and an awareness of the partner's mutual interest for the purpose of “commenting” rather than “requesting” (Carpenter & Tomasello, 2000; Mundy & Stella, 2000; Schertz, 2005b). Like receptive and expressive verbal language, joint attention appears in both responding and initiating forms and is demonstrated by following another's eye gaze or point, or by showing or pointing to objects (Kasari, Freeman, & Paparella, 2001). This important foundational competency crosses three domains of early development (Schertz & Odom, 2003) by supporting theory of mind or an awareness of others' mental states (Baron-Cohen, 2000), language learning (Carpenter, Nagell, & Tomasello, 1998; Paparella & Kasari, 2004), and social development (Adamson & Russell, 1999). During the first year of life, precursors of joint attention are typically evident in a natural progression through face-to-face engagement in the first months,

involvement with objects by mid-year and, by the last quarter of the year, response to joint attention overtures from caregivers (Adamson & Bakeman, 1991). Typically appearing in the first year as a passive response that relies heavily on caregiver support, joint attention is fully consolidated by about 18 months (Adamson & Russell, 1999).

Disruption in the development of joint attention is unique to autism, providing one of the earliest discernable markers of autism in toddlers. When compared to control groups with typical development, developmental delay, and language delay, groups with autism show difficulties with joint attention that cannot be explained by general cognitive or language differences (McArthur & Adamson, 1996; Mundy, Sigman, Ungerer, & Sherman, 1986). These findings suggest a need to study intervention models that directly target development of joint attention and to compare results with more traditional approaches that focus on symbolic communication.

In a study designed for the exclusive purpose of promoting joint attention in young children with autism, Whalen and Schreibman (2003) used naturalistic behavior modification to elicit joint attention in 4-year-olds with autism. Using physical and verbal prompts, interspersal of mastered tasks, task choice, and contingent reinforcement, their intervention resulted in moderate gains, but limited skill maintenance, which was attributed to the lack of planned parent involvement. Kasari et al. (2001) suggest that generalizability limitations may also result from a reinforcement-based, externally motivated approach to promoting what is a spontaneous, internally generated form of early communication.

Other intervention considerations surround issues of developmentally appropriate practice for toddlers (Bredekamp & Copple, 1997). In a consensus-building effort to guide practices for young children with autism, the National Research Council (2001) identified intensity of services as critical, although its importance is questioned by others (Bono, Daley, & Sigman, 2004; Prizant & Wetherby, 1998). Toddlers may be less adaptive than older children to intensive, highly structured, adult-directed, skill-based approaches and some have called for early intervention models that move beyond promoting isolated skills to considering family systems, child engagement, integrated and authentic intervention, and variable response to intervention (Bryson, Rogers, & Fombonne 2003; Howlin & Moore, 1997; Pretti-Frontczak & Bricker, 2004; Volkmar et al., 2004). Dawson and Osterling (1997) advocated a developmental approach for toddlers with

autism, emphasizing early social skills and child initiation.

Relationship-based approaches (Greenspan & Wieder, 1999; Klein, 2003; Prizant, Wetherby, & Rydell, 2000) can address social-communication needs within a developmental framework. McCollum (1984) transmitted generalizable principles rather than specific skills to help parents adjust their interactive style to match infant characteristics. Cognitive-mediational approaches also use relationships to promote children's internal learning capacity. Theories of "cognitive modifiability", based on Vygotskian thought, emphasize transactional aspects of socially based learning to influence child motivation, self-efficacy, and desire for learning (Feuerstein, 1980; Haywood, Brooks, & Burns, 1992). Butera and Haywood (1992) advocated a cognitive model to help children with autism process the complexities of social communication.

Accommodation to a social world, an emerging challenge for toddlers, is supported by parent-child interaction in joint attention encounters. Typically, parent initiative is prominent in the early stages of joint attention development (Adamson & Bakeman, 1991) and the level of early caregiver scaffolding (i.e., support provided to enable success) relates to the infant's later ability to initiate joint attention (Vaughan et al., 2003). Maternal responsiveness was found to mediate communication development in young children with developmental delays and autism (Kaiser & Hemmeter, 1996; Mahoney & Perales, 2003; Yoder & Warren, 1999) and, if the interaction supports joint attention, parent-mediated intervention could extend through much of the child's waking hours. Ingersoll and Dvortcsak (2006) promoted generalization and maintenance of professionally trained child skills in their group training program for parents of young children with autism. Klein (2001) placed parents in a more central role in a parent-mediated relationship-based intervention that supported early cognitive development. Compared to controls, the experimental group realized superior cognitive outcomes that were sustained in 3-year follow-up measures.

The purpose of the current study was to determine the effectiveness for toddlers with early-identified autism of a model that initiated intervention before age three, promoted joint attention by building on its developmental precursors, and used the parent-child relationship to mediate child learning. A secondary purpose was to study possible transactional influences among family factors, intervention-related variables, and intervention outcomes.

Method

Participants

The participants were three parents of toddlers with autism. Eligibility criteria were child age less than 36 months at entry and strong early markers of autism. The first three eligible families who agreed to commit to the intervention were accepted for participation. To recruit participants, pediatricians in two group practices agreed to administer the Modified Checklist for Autism in Toddlers (M-CHAT; Robins et al., 2001) at all 18- and 24-month well child checks, providing a researcher-generated letter to identified families that invited their participation in the study. Concurrently, Part C-funded early intervention providers in a multi-county area were requested to administer the M-CHAT for children they identified as having disproportionate delays in social and communication development. The researcher re-administered the M-CHAT to identified willing families by interview. Although it is a screening and not a diagnostic instrument, the M-CHAT has shown strong sensitivity (identifies 85–95% of true positives, depending on exclusion criteria) and specificity (correctly excludes 93% of children who will not be diagnosed) in field tests (Dumont-Mathieu & Fein, 2005). M-CHAT results for participants were replicated on the Pervasive Developmental Disorders Screening Test-II (PDD-ST-II; Siegel, 2001) and the researcher-developed Infant Social-Communication Questionnaire (ISQ) (Schertz, unpublished). Diagnostic clinics in the region were reluctant to diagnose autism in children under age 3; however, the researcher

administered the Childhood Autism Rating Scale (CARS; Schopler, Reichler, & Renner, 1988), resulting in scores for all children in the “severely autistic” range. Parent-initiated independent evaluations from research hospital clinics subsequently confirmed diagnoses of autism for all three children.

All parent participants were mothers and the three toddlers were boys. Child A’s mother was age 27 and a high school graduate with self-reported dyslexia and depression. Child A, age 24 months at enrollment was an only child. He received Part C-funded early intervention services limited by parent choice to one hour weekly. Child B’s mother, 32 years of age, was a college graduate with special education work experience. Child B, who entered the study at age 33 months, had a diagnosis of epilepsy. He received 7–8 h weekly of Part C-funded early intervention services and transitioned to Part B preschool services during his participation in the study. Two older siblings, both boys, had also received Part C services. Child C’s mother, age 23, was a high school graduate who reported that she had diagnoses of dyslexia, ADHD, bipolar disorder, and previous addiction to narcotics. Child C, age 22 months at entry, also had two older siblings who had received early intervention services. The family participated in Part C-funded services 2 h weekly and his mother reported that Child C had diagnoses of asthma and epilepsy. All three mothers reported pregnancy complications resulting in extended bed rest. Developmental assessment results were gathered from early intervention providers. Screening and assessment scores are presented in Table 1.

Table 1 Developmental assessment scores in months, autism screening results, and CARS ratings

Domain	Child A CA = 23 mos.: DPIT	Child B CA = 28 mos.: HELP	Child C CA = 20 mos.: HELP
Gross motor	21.5 (20/23)	24 (18/30)	19.5 (18/21)
Fine motor	13.5 (12/15)	20 (18/22)	13 (12/14)
Cognitive	17.5 (16/19)	16.5 (11/22)	15 (9/21)
Communication	7 (6/8)	12 (6/18)	10.5 (9/12)
Adaptive	13.5 (12/15)	15 (14/16)	12.5 (9/16)
Social/emotional	4 (3/5)	21 (15/27) ^a	15 (9/21)
Mean	12.8	18.1	14.2
<i>Autism screening by parent report at enrollment: number/percent of screening items failed</i>			
M-CHAT ^b	16/70% (critical: 6/100%)	14/61% (critical: 3/50%)	16/70% (critical: 5/83%)
PDD-ST-II	14/100%	11/79%	9 / 64%
ISQ	14 of 18/78% (1 blank)	17 of 19/89%	17 of 19/89%
CARS ratings ^c	52	40.5	45

Note: CA = chronological age; DPIT = Developmental Programming for Infants and Toddlers; HELP = Hawaii Early Learning Profile; M-CHAT = Modified Checklist for Autism in Toddlers; PDDST-II = Pervasive Developmental Disorders Screening Test-II; ISQ = Infant Social-Communication Questionnaire; mo = months; CARS = Childhood Autism Rating Scale

^a This reported score was inconsistent with parent report of approximately 9 mos

^b Failure of at least 3 total or 2 “critical” items indicates need for diagnostic evaluation

^c “Severely autistic” range = 37–60 with higher scores representing more severe level of autism

Design

A mixed methods research design can serve purposes not achievable through quantitative or qualitative methodologies carried out alone, including complementarity, defined as enhancement through exploration of overlapping or related data (Johnson & Onwuegbuzie, 2004). In the current study, complementarity of data was achieved through the combination of single subject multiple baseline and qualitative research designs. The single subject design was implemented across targeted outcomes for the purpose of documenting causal relationships between the intervention and child performance in the four levels of social-communicative competency: focusing on faces, turn-taking, responding to joint attention, and initiating joint attention. This design, replicated across the three participants, resulted in a graphic depiction of changes in child performance for each level. The inclusion of multiple participants with staggered movement from baseline into intervention conditions isolated changes attributable to the intervention from those possibly related to external factors such as maturation. A sufficient number of data points demonstrated stable patterns for baseline and intervention conditions.

Although single subject design studies typically report on structured behavioral and skill-based interventions using measures that correspond to elicited skills, this study applies the design to nonverbal social communication outcomes that are not directly “trained” through a structured reinforcement-based approach. Rather, in Heflin and Simpson’s (1998) conceptualization, this model can be classified as “relationship based” in that it fosters parent–child interaction in a planned, but open-ended format within the context of the relationship rather than through a skill-based approach that reinforces specific skills in isolation or as ends in themselves. In the current study, the intervention targeted relationship-based competencies through the open-ended medium of parent–child interaction and did not employ a specific program of reinforcement apart from that derived naturally from the interaction. Similarly, Ingersoll and Dvortcsak (2006) distinguished between “direct” and “indirect” teaching methods with direct methods including naturalistic behavioral approaches that use learning theory techniques (e.g., Kaiser & Hemmeter, 1996; Koegel & Schreibman, 1996) and indirect methods including developmental approaches that focus on parent–child interaction and emphasize parent responsivity. Using this framework, the current study employs indirect methods. In these respects, the approach aligns with those described by

Greenspan and Weider (1999), Klein (2003), McCollum (1984), and Prizant et al. (2000).

To explore underlying family and intervention-related variables that may have influenced child performance and to shed light on parents’ understanding of, progress with, and response to their role in the intervention, a complementary qualitative research design was implemented using data from audiotaped parent–researcher discussions and parent notes. The qualitative analysis explored influences that may have played a role in observed changes. Data from initial parent interviews and weekly parent–researcher conversations included intervention-related concerns and other parent-identified issues. Initial interview questions included the M-CHAT items and questions that explored the children’s development, parents’ desires related to parent–child communication, and parents’ conceptions of the parent–professional role. Parents’ daily notes included descriptions of children’s participation in daily parent–child interaction.

Intervention Procedure

Intervention sessions were conducted in families’ homes. To promote interaction, parents played face-to-face games using toys that were present in the home. The Joint Attention Mediated Learning (JAML) manual (Schertz, 2005c) provided a framework for parent–child interaction. The manual’s content focused on developmental foundations of joint attention and the format was modeled on the Affective Cognitive Enabling: Mediating Learning Strategies curriculum (Kahn & Hosaka, unpublished), a curriculum targeting parent mediation of infant cognitive learning. At the end of the baseline period, the researcher provided parents with an oral and written overview of mediated learning principles (adapted from Klein (2003)) as they relate to development of joint attention and as children progressed, explanations and suggested activities were provided for each of the four intervention phases.

Phases were introduced in sequence, along with descriptions of targeted competencies and their importance. Two levels comprised each phase, the first relying on parent initiative and the second seeking more initiative from the child. Rather than rigid prescriptions, suggested activities were intended to help parents envision ideas of their own to encourage their child’s best response. Suggested activities were linked to earlier-presented mediated learning principles.

Focusing on faces strategies were aimed at increasing child tolerance for looking at faces, the single greatest difference found between 12-month-olds later

identified with and without autism (Osterling & Dawson, 1994) and an avenue for the child to discern social cues. Examples included using interactive face-oriented vocal games with strong rhythms, pairing looks to the face with expressions of affection, making the parent's face hard to avoid, imitating facial gestures, and mirror play. *Turn-taking* activities aimed to promote reciprocity, a component of joint attention, and included imitation of child-initiated gestures, responding to child actions as if they were intended as interactions, embedding parents' actions into the child's isolated repetitive play, following the child's lead, pausing for the child's response after the parent's turn, and playing teasing games. *Responding to joint attention* strategies targeted shared attention to objects through supportive parent initiations. For example, parents were encouraged to introduce a toy after establishing eye contact, hold the toy close to their faces when offering it to the child, and use excitement or suspense to encourage the child to look between a toy and the parent's face. Finally, *initiating joint attention* activities encouraged the child to engage the parent's attention in relation to an object by expressing excitement about the child's play with a toy or introducing "surprise" bags or wrapped packages.

Parents were requested to spend approximately one hour daily in face-to-face parent-child interaction, selecting and implementing activities in routine and planned interactions and to describe child performance in brief daily notes. Weekly sessions with the researcher included a review of parent notes, videotaping of a 10-min parent-child interaction session for data analysis, introduction of new material, joint planning for the upcoming week, and discussion of parent concerns. Dyads A and B were scheduled for once weekly and Dyad C for twice weekly sessions, but actual participation was closer to once weekly for Dyad C. The number and duration of sessions in which the families participated are presented in Table 2. Intervention was discontinued for Children B and C when they had progressed through the four phases of intervention and showed multiple instances of initiating joint attention. Intervention was discontinued for Child A after mutual agreement by his mother and the researcher that his response to the intervention had reached a plateau.

Data Collection and Analysis

Parents were informed of the four targeted outcomes before data collection began, allowing them to elicit their child's best performance during the baseline condition. An experienced early intervention provider was trained on coding criteria to an average Kappa

Table 2 Fidelity of parent-child mediation: percentage of sessions with full, partial, or no fidelity; number of scheduled sessions attended; and duration of participation

Extent of fidelity	Dyad A	Dyad B	Dyad C
Full fidelity: Notes were provided, addressed appropriate phase of intervention, and revealed parent understanding of intervention plans	8%	85%	70%
Partial fidelity: Notes were provided but showed lack of fidelity with correct intervention phase or lack of conceptual understanding	46%	0%	0%
No fidelity: Notes were not provided for the session	46%	15%	30%
Number of intervention sessions attended	14	16	11
Duration of intervention in weeks	16	26	9

Note: Children A and B were scheduled for once weekly and Child C for twice weekly sessions. Parent notes from a full week were considered as a set for calculation

agreement level of .89. Naïve to the baseline or intervention condition, the coder observed each 10-s interval from weekly videotaped 10-min parent-child interaction sessions (60 segments per session) for occurrence of targeted outcomes. *Focusing on faces* was coded if the child looked at any part of his mother's face during the interval. *Turn-taking* required the child to perform one of at least two actions as part of a full turn-taking routine completed within no more than two consecutive intervals. *Responding to joint attention* was credited if the child responded to the parent's attempt to draw his attention to an object by alternating looks between the parent's face and the object for the apparent purpose of sharing interest. *Initiating joint attention* was coded if the child alternated looks between the parent's face and an object for the apparent purpose of drawing the parent's attention to the object (i.e., "showing"). Interobserver agreement (Kappa), calculated on 25% of videotaped sessions, was .86 for focusing on faces (range = .73 to .96), .82 (range = .47 to 1.00) for turn-taking, .80 (range = .66 to .92) for responding to joint attention, and .87 (range = .73 to .92) for initiating joint attention with a mean Kappa agreement of .84.

Qualitative data were collected from initial interviews, weekly sessions, and daily parent notes. Audio-recordings yielded 257 pages of field notes for analysis. These notes were coded, organized into categories, and analyzed for emergent themes that centered on the relationship of the intervention to child progress, parent-voiced challenges, and indicators of resilience.

QSR NVivo[®] software provided a structure for organizing and coding the qualitative data. Triangulation, achieved through convergence within and across the qualitative and quantitative data, strengthened the credibility of conclusions. For example, parent responses to a social validity questionnaire supported qualitative descriptions of child changes and parent reports of child progress converged with videotape data. All parent participants were offered an opportunity to verify and clarify qualitative data and conclusions and the one parent who accepted reported agreement with no recommendations for changes. A second experienced early intervention provider, working from six randomly selected transcripts, identified codable items and found that 97% were addressed in researcher memos, that all quotes were represented accurately, and that all associated interpretations and conclusions in the final report were supported by source data.

In fidelity of intervention measures, a comparison of weekly audio transcriptions to child outcomes confirmed that intervention phases were introduced sequentially in researcher guidance to parents. When a child showed multiple instances of the targeted outcome in a phase in each of at least two sessions, and both the parent and researcher agreed that the child was ready to move on, the phase was reinforced

and a new phase introduced. To establish fidelity of parent–child mediation, daily parent notes were reviewed for indications that parents had demonstrated an understanding of and adherence to the active phase of intervention in their reports of daily parent–child activities. The percentage of notes that showed full, partial, and no fidelity was calculated and is presented in Table 2. Parents B and C showed close fidelity with weekly intervention plans while Parent A showed difficulty with conceptual understanding of turn-taking and joint attention, resulting in less adherence to the appropriate phase of intervention in reported daily activities.

Results

Quantitative

Changes in child performance were reflected as the number of 10-s intervals during weekly 10-min video segments in which the child engaged in focusing on the parent’s face, turn-taking, responding to parents’ joint attention overtures, and initiating joint attention encounters with the parent. These data are shown in Fig. 1 with child progress tracked through the ordered

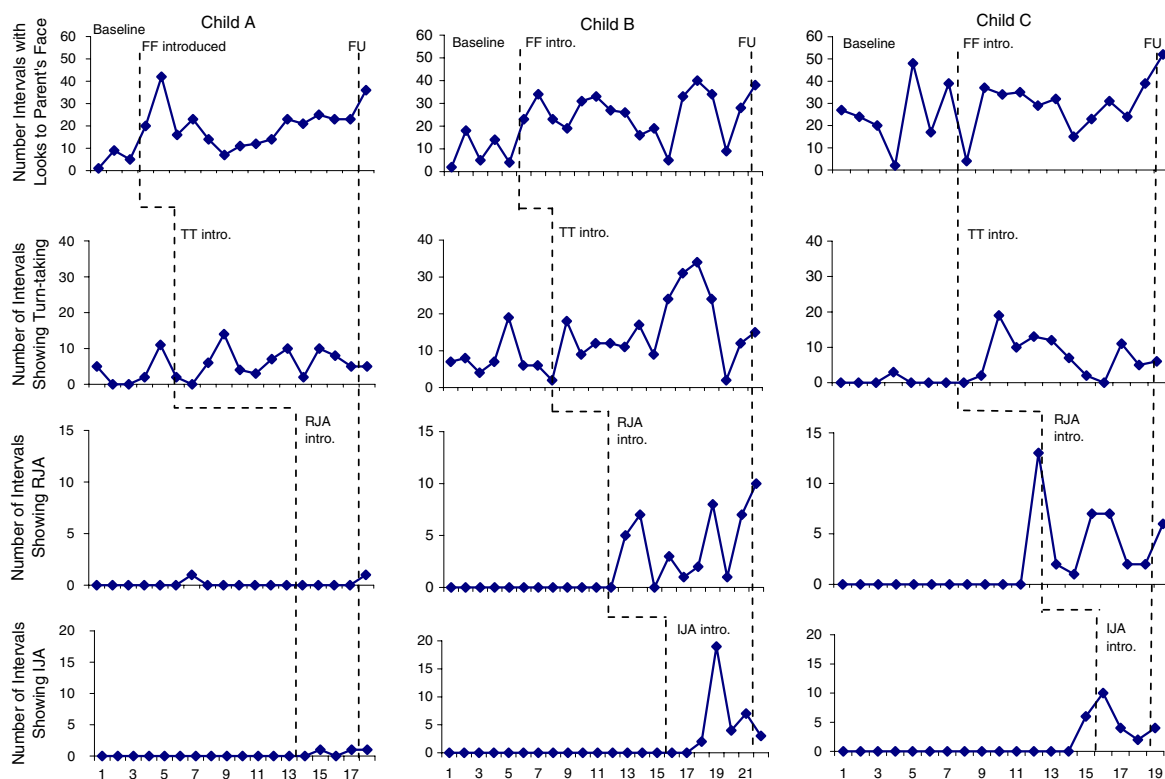


Fig. 1 Individual child progress on targeted outcomes by phase of intervention. *Note:* FF = focusing on faces; TT = turn-taking; RJA = responding to joint attention; IJA = initiating joint attention; FU = follow-up

presentation of phases preceded by baseline conditions of increasing duration. Before the intervention was introduced, the three toddlers showed varying levels of focusing on faces and turn-taking, however none showed responding to or initiating joint attention, the ultimate goal of the intervention. With intervention, Child A's greatest area of improvement was focusing on faces with moderate progress in turn-taking and slight progress with the two joint attention measures. Child B showed steady improvement in all phases with progress closely following the introduction of each new phase. Child C, who engaged in focusing on faces before beginning intervention, progressed rapidly through the remaining three phases and showed instances of joint attention before those phases had been formally introduced. In the intervention condition, each of the three toddlers surpassed baseline performance levels for all four targeted outcomes.

Generalization and Maintenance

In alternative settings (kitchen, back yard, and restaurant), all parents elicited the same range of child performance that had been consistently observed in previous sessions. Although parents were not asked to continue the intervention at the conclusion of the intervention phase, in 5-week post-intervention maintenance measures, each child's performance for every phase was higher than his mean performance during baseline conditions and exceeded mean intervention condition levels for the majority of targeted competencies (see Table 3).

Social validity measures assessed the degree to which goals, techniques, and outcomes of the intervention were acceptable to the three parents. A researcher-developed five-point Likert scale questionnaire allowed for differentiated levels of response as recommended by Schwartz and Baer (1991). This approach to measurement of social validity diverges from that used in other joint attention intervention research which evaluated "normalcy" ratings (Whalen & Schreibman, 2003) but was similar to the approach used in a recent study that provided training to parents of children with autism (Ingersoll & Dvortcsak, 2006). Parent responses, summarized in Table 4, indicated parents' support for the importance and appropriateness of intervention goals, their role in implementation, their participation in weekly sessions, activity suggestions, and level of intrusiveness. All parents predicted better long-term child competence as a result of the intervention and indicated improved confidence in their own ability to support child interaction. Parents

Table 3 Mean performance across conditions

Child	Target	Baseline	Intervention	Follow-up
A	FF	5	20	36
	TT	4	6	5
	RJA	0	0	1
	IJA	0	0	1
B	FF	9	25	28
	TT	8	16	15
	RJA	0	3	10
	IJA	0	5	3
C	FF	25	28	52
	TT	0	7	6
	RJA	1	4	6
	IJA	0	5	4

Note: FF = focusing on faces; TT = turn-taking; RJA = responding to joint attention; IJA = initiating joint attention

B and C expressed satisfaction with the level of child improvement in all intervention phases while Parent A noted her son's limited progress in joint attention phases. Another indicator of parents' commitment to and acceptance of the intervention, participation in weekly sessions, varied across participants; however, all participated in most scheduled sessions.

Qualitative

Parents' views of child progress, expressed in weekly discussions with the researcher and in their daily notes, mirrored trends in the quantitative data. These qualitative data coalesced into five themes, providing insight into variables possibly associated with child progress and suggesting implications for intervention and future research: (a) parent fidelity with planned intervention mediated child progress, (b) child progress in social-communication development facilitated reduced aggression, (c) physical activity motivated children to interact, (d) simplifying the presentation of the parent's face facilitated focusing on faces, and (e) turn-taking activities based on face-to-face play promoted joint attention better than play with toys.

The researcher provided planned and sequential, but informal guidance on the four phases of intervention. To promote focusing on faces, the researcher provided explanations, possible activities, and affirmation of parent competence.

He's learning about social skills [and] communication.... You can think of success in terms of how long he can sustain that eye contact..., keeping him engaged with you as long as he will tolerate it; moving your head toward or away from him

Table 4 Parent assessment of research participation

Items	M (range)
The purpose of the research study was to help your child share interest with you about objects and events as a stepping stone to language and social development. This goal was important to me	5 (5–5)
I think that providing parent–child interaction activities throughout the day is important	5 (5–5)
I liked making my own decisions about which materials or toys to use in daily activities. <i>Comments</i> (Parent B): I liked this part, but when things are most difficult, having ideas given to me	4 (4–4)
Making daily notes and discussing them with the researcher was important to help her understand what we did during the week. <i>Comments</i> : (Parent B): It was important, but I think it helped me understand how the process worked each week and gave me ideas for the next week	4 (4–4)
The amount of time spent with the researcher was about right (about one hour once weekly)	4.7 (4–5)
Activity suggestions for focus-on-faces, turn-taking, responding to joint attention, and initiating joint attention were helpful	4.7 (4–5)
Weekly discussions with the researcher were helpful (e.g., explanations, guidance for the next week’s activities, etc.)	4.7 (4–5)
Reviewing and discussing videotapes of me interacting with my child (i.e., a current or previous session) was helpful. <i>Comments</i> (Parent B): This was very helpful to see progress	4.7 (4–5)
I am satisfied with my child’s progress in focusing on faces	5 (5–5)
I am satisfied with my child’s progress in turn-taking	4.3 (4–5)
I am satisfied with my child’s progress in responding to joint attention	3.7 (3–4)
I am satisfied with my child’s progress in initiating joint attention. <i>Comment</i> : (Parent B): Getting there	3.7 (3–4)
I believe the approach used with this study was no more intrusive than necessary and fit well with my family’s needs	4.7 (4–5)
I feel I am more competent in helping my child to interact as a result of the intervention	4.7 (4–5)
I believe that my child will have better long-term social and communication skills because of this intervention	5 (5–5)

Note: 1 = strongly disagree; 2 = disagree; 3 = undecided; 4 = agree; 5 = strongly agree

into his line of vision..., helping him to succeed by making your face hard to avoid.... Your affective involvement [gives] meaning to looking at faces.

Parents’ internal debates and observations helped them work through issues and gain conceptual understanding and buy-in as they progressed through the phases. In the initial phase of focusing on faces, Parent B reported, “I just feel so bad for him, because it seems like I have to calm him just to get him to [look at me].... There are days when I think... he needs to have his own world for whatever reason.” Later she observed, “He will look straight at you if he is wearing sunglasses and I think in his mind it’s ‘You can’t see my eyes.... I’m getting not just more eye contact and interaction when he’s really happy, but also when he’s really mad’”. Parent C described how she and her husband had encouraged looks to their faces. “When we were talking to him, we noticed that his eyes would drift downwards, and... we’d kind-of touch him right there and his eyes would go toward our eyes.” All three parents were observed to easily conceptualize the focusing on faces phase of intervention and to integrate it into parent–child interactions. This factor likely contributed to the rapid child progress observed during this phase (*Note*: Child C showed competency with focusing on faces during the baseline phase).

In the turn-taking phase, the researcher provided explanations and examples. “We want him to get into that reciprocal back-and-forth thinking..., to involve you in his activity [so] it’s not just about him, but it’s [also] about another person.”. Parents showed creativity in building on their children’s interests. “I found that if I keep it very light and very simple, and I don’t demand too much of him, it becomes a pleasant experience” (Parent B). “I counted his toes, then I patted the bottom of his foot, and when I did, he’d like that, so every couple of seconds, he’d stick his foot back up and I’d pat it again.” Parent C reported on an activity of stacking baby formula cans. “I had my hand sitting right there and he... let me know [when it was my turn] by giving me that little look”. Children B and C both showed strong progress in response to turn-taking intervention as seen in Fig. 1. Dialogue with Parent A showed that she had some difficulty conceptualizing and eliciting reciprocity in turn-taking, relying on a limited number of rote activities such as manipulating a busy box. It is not clear whether this factor or the severity of her child’s autism contributed to his uneven response to the intervention.

In the third and fourth phases of intervention, the researcher described the relationship of joint attention to language and clarified parameters. In one example, Parent A struggled to translate the concept of joint

attention into daily interactions when she described her child nonverbally asking for help putting beads into a can. “He needs me to do it; he needs help.” The researcher clarified to distinguish this from joint attention, “Yes, he’s *requesting* because he can’t do it himself.” Recognizing the sharing aspect of joint attention, Parent A offered, “His books are joint attention because sometimes he’ll bring it and come over and let us sit with him and look at it.” The researcher again clarified that, “[We want] him to show you that he’s interested by looking at the book and then looking at your face.” Parent B revealed her initial skepticism that her son could engage in joint attention. “I would be surprised if he saw a novel thing and... looked at me as if to say ‘look, this is really neat’”. Later however, she reported the first observed instance of initiating joint attention. Her son brought his portable video player to her and suddenly he “looked at the video... and then at my eyes and smiled... I’m sure he was trying to show me his cartoon—for a couple of seconds, we enjoyed something together”. As illustrated in Fig. 1, Children B and C showed a strong response to the intervention in phases 3 and 4 while Child A showed only isolated instances of joint attention.

The emergence of receptive and expressive verbal language at the end of the intervention, although not included in quantitative measures because it was not a directly planned outcome, was voluntarily reported by parents and observed by the researcher. This development was notable with Children B and C, both of whom had engaged in joint attention in multiple sessions. Child A achieved a level of competency with Picture Exchange Communication System (PECS) for requesting. Parent C described the beginnings of receptive and expressive language. “[His grandmother] said, ‘See ya’ and he goes ‘Ee ya’. We asked if he wanted [a soda] and he goes [shakes head “yes”].... So I think he’s starting to comprehend what we’re asking.”

Although not assessed quantitatively, parents volunteered background information on the larger family experience that may have impacted intervention effectiveness. They also described their own challenges and resilience relative to their children’s needs. Emergent themes reflecting challenges included searching for a diagnosis, limited child response to traditional services, co-occurrence of familial disabilities, and broader family stressors. Themes of parent resilience included coming to terms with the child’s diagnosis and evolving views of the child’s potential and of their own competence and self-efficacy.

Parents related difficulties, most prominently behavioral challenges, that were associated with their children’s autism. Parent A connected her son’s tantrums to his restricted interests. “He’s so zombie into the movie lately. I don’t know how to get out of it. I turned off the TV..., then he just went into more of a fit, and he punched and hit and went all out.” Early in the intervention period, Parent B also wearied of her son’s constant demands. “In the morning I can be pretty good about it, but by [evening]..., I’m like, ‘You have to take him. I don’t want to be touched; I don’t even want to be looked at.’” She also worried about empathy. “If one of the other boys gets hurt..., [he] may be interested in looking at the tears to try to figure out where they came from, but he doesn’t seem to understand that means that someone’s hurt.” Parent C expressed concern with her son’s aggression, noting that he began to engage in frequent head butting and biting beginning at approximately 18 months of age. Parent B’s initial concerns about her son’s aggressiveness abated as he progressed through the intervention. By parent report, Child C’s aggressive behaviors continued throughout the intervention period with some reduction by follow-up; however, larger family concerns may have helped to maintain his aggression. By observation and parent report, Child A’s aggressive behavior showed no signs of abatement during the intervention or follow-up phases.

During the intervention period, all participants struggled with the initial tentative nature of their child’s diagnosis (a factor that compromised the process of coming to terms) and the struggles they experienced obtaining a definitive diagnosis. Parent A reported that her doctor did not give her direct answers when she expressed initial concerns. When diagnosticians reported preferring to wait until age three to give a diagnosis of autism, she reported responding, “I’m stuck because there are a lot of things I need the diagnosis for [eligibility for services; helping her husband come to terms with their son’s difficulties].” Parent B also reported experiencing initial uncertainty about the source of developmental concerns and sought out initial and later confirming diagnoses. Parent C expressed relief at her son’s tentative early diagnosis. Although she questioned the diagnosis after seeing intervention-related improvement, the original results were confirmed. All mothers reported that their husbands followed a more difficult path in coming to terms with the diagnosis. Over the course of the intervention, two of the husbands left their families, a move that both mothers attributed to the stress of having a child with autism.

Before the research intervention began, Parent B reported that in spite of the high level of services received, “I don’t think we’re helping him [with traditional services]”. She referred to the continual need to “lower the bar” of expectations and noted a lack of progress over the two years her child had received services. This pattern was repeated with the other two dyads. All participants reported co-occurrence of learning disabilities or other developmental concerns among members of their immediate families. Parents A and C reported on their own learning disabilities and mental health concerns. Parents B and C noted developmental and medical concerns with siblings, including seizure disorders. Paternal aggression was reported by Parent C and income limitations contributed additional stressors for this family. Limited support from extended family was cited to varying degrees by all participants.

All participants were motivated to counteract these challenges. They showed an interest in learning about autism and progressed from focusing primarily on their children’s limitations toward increasing acceptance and recognition of child potential. Parent B observed, “I am getting more awareness that I am here. It’s not just because he needs something... and I feel like that is huge progress”. Parent A recognized progress with focusing on faces and Parent C expressed excitement with her child’s use of receptive and expressive language. Parents also invested in their own personal development, Parent A by teaching herself to read and participating in an autism support group; Parent B by creating a support group for families, sharing her intervention experiences at a national conference, and pursuing employment in a related field; and Parent C by learning about her children’s complicated medical issues and initiating licensed practical nurse training. All parents took firm control of their children’s services.

Discussion

This study provides evidence that in response to a parent mediated, developmentally oriented, and interaction based intervention model, two of three toddlers with early identified autism demonstrated joint attention, a typical milestone that failed to develop naturally. The third demonstrated progress with focusing on faces and turn-taking, hypothesized precursors of joint attention. Results complement Whalen and Schreibman’s (2003) study which used behavior modification to promote joint attention in older preschoolers with autism. Achievement of child outcomes in the current study may be attributable to a family centered

approach that built on developmental foundations of joint attention and used the parent–child relationship as the medium for intervention, harnessing parents’ expertise and strong investment in their children’s developmental outcomes. Parents infused intervention through play and in natural family routines, an approach that had secondary benefits for parents by helping them to envision both the child’s potential and their own abilities as ongoing mediators of their children’s learning.

Results point to the possible importance of providing a developmental foundation to support both symbolic communication and its precursor, joint attention. Joint attention research indicates that face-to-face engagement, social interaction, child initiation, and responding to joint attention may provide a developmental foundation for the child to freely initiate joint attention social overtures to a partner (Adamson & Bakeman, 1991). These developmental precursors to initiating joint attention were operationalized in the current study as focusing on faces, turn-taking, and responding to joint attention. Joint attention, in turn, appears to provide a developmental foundation for verbal language (e.g., Carpenter et al. 1998; Paparella & Kasari, 2004). Attention to others’ faces, an ability that is compromised for infants later diagnosed with autism, is a necessary component of joint attention because it allows the child to ascertain the partner’s interest in their mutual focus of attention. Turn-taking, also a component of joint attention and a form of reciprocity, further supports the interactional aspects of joint attention. Turn-taking may lead most directly to joint attention if it is initially based on dyadic play rather than play with toys because it is engagement with the parent that is a greater need for children with autism than attention to objects. Initiating joint attention is typically built on a base of responding to joint attention and this appears to have occurred with the toddlers with autism in this study. Eliciting initiation of joint attention required from the parent only a receptive demeanor once this foundation had been laid.

Because of social difficulties in autism, the current study was designed to build on the already established parent–child relationship. The intervention did not train parents in specific techniques; rather, parents created activities that they believed would best encourage their child’s social participation across contexts and over time in the child’s natural environment. This encouraged parents’ leadership in the intervention while capitalizing on their expertise, intimate knowledge of the child, and strong investment in child outcomes. The interventionist assumed a supporting role, highlighting the purpose and goals of each phase,

providing examples of activities that parents could adapt, and tracking changes.

The intervention addressed other difficulties inherent in more structured skill-based interventions. One concern is that joint attention is an abstract ability that is not easily “trained” (Kasari et al., 2001). The mediated learning approach addresses this concern as well as related problems of generalization and maintenance often reported in behaviorally oriented approaches. The aim of mediated learning approaches is to affect the child’s desire to learn and interact rather than to train specific skills through a system of external rewards (Klein, 2003). Parents in this study appeared to have an instinctive grasp of how to mediate learning for their children but needed guidance on the meaning and importance of joint attention for future language and social development. Parents with varying abilities were able to create opportunities to promote interactional competencies when armed with general theoretical knowledge and suggested strategies. Benefits were also observed for parents themselves, who expressed greater confidence in their child’s potential and in their role in effecting child changes. Importantly, these changes were evident irrespective of their socioeconomic and educational experiences.

The interventionist’s role is more complex in this model than in more traditional professionally implemented approaches. Interventionists must master theory and make it accessible to adult learners, provide situational coaching based on ongoing assessment of parent understanding, serve as a sounding board and source of support relative to a wide range of parent concerns, bolster parents’ confidence in the possibility of change, and recognize and affirm parents’ competence. This role relies on sharing theoretical knowledge and posing questions that can include parents in the discovery process in ways that build on existing child and parent competencies (i.e., beginning at a skill level where both parent and child can experience success). To address these needs, personnel training should focus on theory related to joint attention, family systems, and adult learning theory. The use of family case studies (e.g., McWilliam, 2000) can support understanding of complex family needs in times of crisis, parents’ potential to promote early social communication development even in the face of serious child and parent challenges, and the individualization of parent education, coaching, and support strategies.

Findings in the current study are limited by the small number of participants and by the fact that the intervention was implemented and reported by a single researcher. Also, confidence in follow-up measures is qualified by the limitation of nonrepeated measures

(i.e., a single data point). A limitation with the intervention is that while many parents may prefer the flexibility and freedom of selecting or creating their own activities based on a sample of suggested activities, others (e.g., those challenged to conceptualize intervention goals) may benefit from more targeted guidance and structure relative to activity selection. Future studies are therefore needed to replicate and extend this research. Qualitative findings also suggest questions for further study: Can simplifying the presentation of the parent’s face facilitate focusing on faces? How can turn-taking activities best be designed to lead to joint attention? What is the impact of joint attention development on child aggression?

Research findings suggest implications for practitioners. First, recommended family-centered and family-guided practices (Sandall, McLean, & Smith, 2000) for young children with disabilities should take a more prominent role in early autism intervention as these findings demonstrated the potential efficacy of such approaches. Second, building intervention from the parent–child relationship is a priority as children are identified at toddler ages during which the relationship with the caregiver naturally serves as the primary medium for social-communicative learning. Third, recommendations that services for young children with autism be intense should be examined in light of current findings that joint attention can be effectively promoted for some toddlers with autism using once weekly intervention that supports developmentally grounded parent–child interaction in natural family settings. This contrasts with models that call for intensive investment of intervention resources that directly target specific skills, that are implemented by specialists, and that must be supplemented by additional resources to promote generalization to natural environments. One factor that may have influenced response to the low intensity approach in the current study is the early age at which this intervention was initiated. Fourth, developmental precursors of joint attention (e.g., focusing on faces, turn-taking, etc.) and symbolic language (e.g., joint attention) should be incorporated into intervention for children with autism to lay the groundwork for more natural development of higher level competencies. Fifth, because of the high levels of stress experienced by families who are in the initial stages of autism diagnosis, attention to larger family concerns may play an important role in a parent-implemented intervention and warrant further study. For example, future research could explore whether fathers being more actively in the intervention might facilitate their process of “coming to terms”, with

resultant positive outcomes for families. Finally, relying on less formal and definitive diagnostic protocols to identify high risk for autism during the toddler years may be important to permit initiation of services before nonproductive patterns of interaction are established.

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Appendix A

Joint Attention Mediated Learning (JAML) Parent Manual (excerpt)

The following pages have ideas for helping your child make progress in focusing on faces, turn-taking, and joint attention—all important to help your child communicate and interact socially with others. Each idea or learning strategy is just that—an idea. Working with the researcher, you will have other ideas that can help reach similar goals. Each strategy is connected with one or more learning principles, identified in bold after each strategy.

These learning principles show five ways to help children learn. The five learning principles are:

1. **Focusing**: Helping your child to focus helps her look at or listen to something that can help her learn, to share attention with you by looking at what you want her to see, or by showing you what she wants you to see.
2. **Giving meaning**: You can help your child understand the meaning of things by expressing your feelings (such as excitement) when you are sharing attention with him about an object or a happening. Giving meaning helps him to understand what parts are important to pay attention to because they are special in some way.
3. **Expanding**: When you and your child are paying attention to something, you can help your child to expand his understanding of an object or event. You do this by providing labels, by helping him see something about an object that he had not noticed

before, or by seeing how something relates to other things he knows about.

4. **Encouraging**: Toddlers learn best when they feel successful. You can help your child experience success by making activities challenging enough but not too hard, by pointing out what he did that caused his success, by expressing affection when he is successful, and by showing him that you are confident that he can succeed.
5. **Organizing and planning**: Helping your child experience order can boost his learning by helping him see how what he is doing relates to the larger world. If activities are structured, he can better predict what comes next. He may be more willing to do something that he does not like (but that is important for his learning) if he knows a preferred activity will come later. Also, if activities happen in a logical sequence, your child can better see the connections between things. Structure is especially helpful to promote learning for toddlers with social and communication difficulties. You can help to structure activities by
 - a. showing your child only the part he needs to know for what you want him to learn,
 - b. helping him to keep his attention on one thing at a time,
 - c. reducing sights and sounds that may draw his attention away from the activity,
 - d. helping him to understand “first ____, then ____” (to know what comes next),
 - e. moving gradually from simple tasks to ones that are more complicated,
 - f. helping him to see how things are organized—the relationships between things
 - g. keeping objects in the same location; putting toys in order at the end of play
 - h. helping him to understand the value of rules.

During play sessions, all of the time is not spent working on new and more difficult learning strategies. It is important that your child enjoy interacting with you and experience success most of the time. The targeted strategies will help him to learn new things, and these new activities should be mixed in with comfortable activities he already knows, enjoys, and is successful with. However, the purpose of the parent-child play sessions is for him to interact, so you *should* expect your child to interact with you during all play activities—he can be left to play with toys on his own at other times.

Children learn best when they choose their activities. You can help this to happen by *following your child's lead*. You do this by joining into his play rather than asking him to switch from something he is doing to an activity you want to do. However, you can guide him toward new activities when he loses interest with an activity. The most important thing to remember is to keep him engaged in interaction with you as long as possible.

Suggested strategies for developing your child's social-communication skills are divided into four areas: (1) focusing-on-faces, (2) turn-taking, (3) responding to joint attention, and (4) initiating joint attention. Each of these four areas is divided into two levels. With the first level, you are doing most of the work by showing your child how to do things. In the second level of each area, your child is expected to do more of the work by practicing the skills you have taught him.

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Anexo IX

Wallace, K. S., & Rogers, S. J. (2010). Intervening in Infancy: Implications for Autism Spectrum Disorders. *Journal of Child Psychology and Psychiatry*, 51 (1), 1300–1320. Índice de impacto: ISI Journal Citation 2014: 6.459.

Intervening in infancy: implications for autism spectrum disorders

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There is a scarcity of empirically validated treatments for infants and toddlers under age 3 years with autism spectrum disorders (ASD), as well as a scarcity of empirical investigation into successful intervention characteristics for this population. Yet early screening efforts are focused on identifying autism risk in children under age 3 years. In order to build ASD interventions for infants and toddlers upon a foundation of evidence-based characteristics, the current paper presents the results of a systematic literature search and effect size analysis of efficacious interventions for infants and toddlers with other developmental disorders: those who were born prematurely, have developmental impairments, or are at high risk for developmental impairments due to the presence of a biological or familial condition associated with developmental impairments. A review of 32 controlled, high-quality experimental studies revealed that the most efficacious interventions routinely used a combination of four specific intervention procedures, including (1) parent involvement in intervention, including ongoing parent coaching that focused both on parental responsiveness and sensitivity to child cues and on teaching families to provide the infant interventions, (2) individualization to each infant's developmental profile, (3) focusing on a broad rather than a narrow range of learning targets, and (4) temporal characteristics involving beginning as early as the risk is detected and providing greater intensity and duration of the intervention. These four characteristics of efficacious interventions for infants and toddlers with other developmental challenges likely represent a solid foundation from which researchers and clinicians can build efficacious interventions for infants and toddlers at risk for or affected by ASD. **Keywords:** Early intervention, autism, ASD, parent coaching, infant, toddler, evidence-based intervention.

The primary purpose of early detection of autism spectrum disorders (ASD) is to prevent or mitigate the symptoms and severity of disability associated with ASD. Early detection science requires that early treatment science develop in parallel, so that tested treatments are ready for infants and toddlers identified by early detection. However, while there is considerable progress being made in early detection of ASD, thanks to the productive infant sibling studies and early screening studies under way, there is currently a scarcity of empirically validated treatments for infants and toddlers under age 3 years with ASD, and a scarcity of treatment studies for those under 18 months. While well-structured, data-based, long-term early intervention involving many hours per week of intervention (from staff and/or parents) is currently the most effective strategy for improving functioning for 2–5-year-olds with ASD (Lovaas, 1987; McEachin, Smith, & Lovaas, 1993; Rogers & Dawson, 2009), these models have been developed for preschoolers, and do not fit the lifestyle or learning patterns of infants and toddlers in the first and second years of life (Rogers & Vismara, 2008).

Given the importance of designing interventions for infants and toddlers with ASD on a foundation of evidence-based characteristics, we turned to rigor-

ously designed intervention studies for infants and toddlers with other developmental disorders or developmental risks (i.e., those who were born prematurely, those with developmental delays including Down syndrome, and those at risk for intellectual disabilities due to parental poverty and intellectual impairment) to determine intervention characteristics that are associated with improved developmental functioning. The current paper provides the results of a systematic review of infant and toddler intervention research from these three clinical groups, including methodological investigation, effect size analyses, and extraction of key ingredients of the most efficacious interventions.

Method

Search criteria and study selection

Inclusion criteria for papers were as follows: (1) the article was published in a peer-reviewed journal, (2) the article described a well-designed, controlled intervention efficacy study involving infants or toddlers with developmental impairments or significant risk of such impairments; (3) study participants were in the age range of birth through 3 years, and (4) the paper reported sufficient data to calculate effect sizes (e.g., group sizes, means and standard deviations of core measure performance for each group; this inclusion criterion excluded papers such as Piper et al., 1986). We identified three clinical conditions: prematurity,

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developmental delay including Down syndrome, and risk of intellectual disability. We then conducted an internet search using PsycINFO and Pubmed, using a variety of groupings of keywords. For each condition, we searched condition name and early intervention, condition name and method and intervention, and condition name and intervention.

Following the internet search, we hand-searched through six texts focused on efficacy of early intervention, listed below.

- *From Neurons to Neighborhoods: The Science of Early Childhood Development* (Shonkoff & Phillips, 2000)
- *Handbook of Infant Mental Health* (Zeanah, 2005)
- *Handbook of Developmental Disabilities* (Odom, Horner, Snell, & Blacher, 2007)
- *The Effectiveness of Early Intervention for At-Risk and Handicapped Children* (Guralnick & Bennett, 1987)
- *Handbook of Early Childhood Intervention* (Meisels & Shonkoff, 1990)
- *Handbook of Early Childhood Intervention*, Second Edition (Shonkoff & Meisels, 2000)

Within each, we searched the Table of Contents and Index for keywords related to the topic areas, located all the papers referenced for the target conditions, and applied the inclusion criteria to them. Our search criteria may not have yielded every published intervention study for these topic areas, but our findings represent all those found by the search procedure described above. Given our interest in general interventions aimed to improve children's overall development, we excluded papers that focused on very specific intervention aims, such as improvement in language or motor functioning only.

Methodological investigation

These papers were then classified according to the criteria for establishing empirical support outlined by Nathan and Gorman (2002), which are as follows:

- **Type 1 Studies** are randomized, prospectively designed clinical trials which use randomly assigned comparison groups. They also utilize blind assessments, clear inclusion/exclusion criteria, treatment fidelity measures, treatment manuals (including use of structured curriculum), and state-of-the-art diagnosis. They have adequate sample sizes to power the analyses and clearly described statistical methods.
- **Type 2 Studies** are clinical trials using a comparison group to test an intervention. These have some significant flaws but not critical design flaws that would prevent one from using the data to answer a study question. This category also includes single-subject designs.
- **Type 3 Studies** have significant methodological flaws. These include uncontrolled studies using pre-post designs and studies using retrospective designs.
- **Type 4 and Type 5 Studies** are secondary analysis papers.
- **Type 6 Studies** are case reports.

Two independent raters evaluated each paper and inter-rater agreement regarding this classification was assessed via the examination of 20% of papers. Reliability for classifying randomization, inclusion and

exclusion criteria, and use of standardized diagnostic batteries, comparison group, blind assessors, and treatment fidelity was 100%, and reliability for classifying use of a treatment manual was 87.5%. Any classification differences were resolved by discussion among the raters.

It is important to note that classification of a study as lacking a methodological characteristic refers to the published description of the method: it may not always indicate a true lack of the characteristic within that study. Authors may not have described methods they were using, such as use of blind assessors or treatment fidelity checks within their manuscripts.

Only papers classified as Type 1 or Type 2 using the Nathan and Gorman (2002) criteria were included in analyses. The efficacy of the interventions described within these papers was investigated as described below, and the methods used were examined in detail to determine key intervention features. All papers are presented in Table 1, including details regarding study sample, outcome measures, treatment procedures, findings, effect sizes, and Type classification.

Results

The literature search yielded 32 Type 1 or Type 2 papers across the three groups. Across all disability groups, 6 papers attained the highest classification (18.75%), while the remaining 26 were classified as Type 2 (81.25%). It is important to note that Type 2 criteria are quite strict—a study missing only one of randomization, use of blind assessors, inclusion and exclusion criteria, a standardized diagnostic battery, treatment fidelity, or a treatment manual would qualify that paper as a Type 2 as opposed to a Type 1.

There was great disparity in the range of studies for each disability group. Out of the 24 papers reporting early intervention for premature infants and toddlers, 6 papers were Type 1 (25%), while the remaining 18 were Type 2 (75%). Out of the 5 papers reporting early intervention for infants and toddlers with developmental delays including Down syndrome, all were classified as Type 2 (100%). Similarly, all 3 papers reporting early intervention for infants and toddlers at risk for or affected by intellectual disability were Type 2 (100%). We documented in Table 1 the presence or absence of seven methodological procedures involving scientific rigor as specified by the Nathan and Gorman (2002) criteria: randomization, assessments by raters blind to intervention group, use of inclusion/exclusion criteria, a standardized diagnostic battery, presence of a well-matched, nonrandomized comparison group, treatment fidelity procedures, and a treatment manual. Across all 32 studies, 23 randomized subjects (72%) and 6 did not (19%). Three studies utilized partial randomization procedures (9%). For example, in an early intervention study for premature infants, Zahr (2000) randomly assigned some participants to treatment or control groups,

Table 1 Type 1 and Type 2 intervention studies for children ages 0–3 with a variety of disabilities (gray highlighting represents a successful intervention study)

Author(s) and year	Sample	Outcome measures	Treatment procedures	Findings	Nathan and Gorman (2002) criteria
EARLY INTERVENTIONS FOR INFANTS AND TODDLERS WITH DEVELOPMENTAL DELAYS:					
Connolly, Morgan, Russell, & Richardson (1980)	20 ss, 53 control	Stanford-Binet Intelligence Scale or Cattell Infant Intelligence Scale; Vineland Social Maturity Scale	Early Intervention Program at the Child Development Center of the University of Tennessee Center for the Health Sciences; parent-child relationship and maximization of overall development of each child; 10 1-hr sessions during which professionals taught parents developmental interventions for individualized home use stimulation programs, 1-hr parent group, and .5-hr feeding skill development; 10 wks of individualized programs	At 3–6 yrs., ES = .48 (corrected, .49) for Stanford-Binet and .28 for social quotient	Type 2 study: -RCT, -Blind assessments, +Incl/excl criteria, +Standardized dx battery, +Comparison group, -Tx fidelity, -Tx manual
Connolly, Morgan, Russell, & Fulliton (1993) (Follow-up of Connolly, Morgan, Russell, & Richardson (1980))	10 ss, 10 controls	Stanford-Binet Intelligence Scale; Vineland Social Maturity Scale; Bruininks-Oseretsky Test of Motor Proficiency	See Connolly, Morgan, Russell, & Richardson (1980)	At about 16 yrs., ES = .97 (corrected, .93) for IQ and 1.63 for social quotient	Type 2 study: -RCT, -Blind assessments, +Incl/excl criteria, +Standardized dx battery, +Comparison group, -Tx fidelity, -Tx manual
Piper & Pless (1980)	21 ss, 16 controls	Griffiths Mental Developmental Scales; HOME	Center-based twice weekly, 1-hr sessions; activities designed to encourage normal development were demonstrated to parent, and written instructions sent home	At 15 mon., ES = -.11 (corrected, -.11) for total Griffiths score	Type 2 study: -RCT, +Blind assessments, -Incl/excl criteria, +Standardized dx battery, +Comparison group, -Tx fidelity, -Tx manual
Seifer, Clark, & Sameroff (1991)	23 ss, 17 controls	Coding of videos of mother-child interaction; BSID; Uzgiris and Hunt Ordinal Scales of Development	6 sessions of interaction coaching; taught mothers about overstimulation	At 18 mon., ES = .70 (corrected, .69) for mental age	Type 2 study: -RCT, +/- (partial) Blind assessments, -Incl/excl criteria, +Standardized dx battery, +Comparison group, -Tx fidelity, -Tx manual

Table 1 (Continued)

Author(s) and year	Sample	Outcome measures	Treatment procedures	Findings	Nathan and Gorman (2002) criteria
Sloper, Glenn, & Cunningham (1986)	12 ss, 12 controls	Scales of object permanence, attention span, and imitation every 3 wks; BSID; Stanford-Binet Intelligence Scale	Parents in tx group given exercises to carry out daily to development object permanence, attention span, imitation (parents were to practice 5 times per day and record data); parents in control group given general guidance on stimulation, discussed these and other areas of concern, and parent and clinician developed stimulation activities	At 4.5 yrs., ES = .19 (corrected, .18) for mental age, but sig. differences on later items of the checklists (example: ES = .87 for imitation of crayon stroke)	Type 2 study: -RCT, +/- (partial) Blind assessments, +Incl/excl criteria, +Standardized dx battery, +Comparison group, -Tx fidelity, -Tx manual
EARLY INTERVENTIONS FOR INFANTS AND TODDLERS AT RISK FOR INTELLECTUAL DISABILITY:					
Breitmayer & Ramey (1986)	For optimal Apgar: 22 ss, 27 controls; For nonoptimal Apgar: 19 ss, 12 controls	McCarthy Scales of Children's Abilities; BSID; Stanford-Binet Intelligence Scale	Direct educational programming through the provision of systematic, developmental day-care; particular emphasis on language; began attending b/w 6 wks and 3 mon. of age; ran 7:45-5:30 each weekday for 50 weeks per yr.; up to 3rd birthday: Carolina Infant; up to school entry: systematic exposure to areas such as math, science, & music	At 54 mon., for optimal Apgar participants, ES = .24 for McCarthy Scales; At 54 mon., for nonoptimal Apgar participants, ES = 1.04 (corrected, 1.03) for McCarthy Scales	Type 2 study: +RCT, +/- (partial) Blind assessments, +Incl/excl criteria, +Standardized dx battery, +Comparison group, -Tx fidelity, +Tx manual
Ramey & Campbell (1984)	54 ss, 53 controls	BSID, Stanford-Binet Intelligence Scale, or McCarthy Scales of Children's Abilities at 6, 12, 18, 24, 30, 42, 48, & 54 mon.	Carolina Abecedarian Project; child-centered, prevention-oriented tx program delivered in a daycare setting; infancy-5 yrs.; ran 7:45-5:30 each weekday for 50 weeks per yr.; infant curriculum: language, motor, social, and cognitive items; after age 3: standard preschool curricula; particular emphasis on language	At 54 mon., ES = 1.22 (corrected, 1.21) for Stanford-Binet	Type 2 study: +RCT, -Blind assessments, +Incl/excl criteria, +Standardized dx battery, +Comparison group, -Tx fidelity, +Tx manual
Ramey & Smith (1976)	25 ss, 22 controls	Two-choice visual discrimination task; BSID	Daycare program designed to prevent developmental retardation; 8 hrs per day, 5 days per wk; began attending b/w 6 & 12 wks of age; curriculum individualized and focuses on perception and cognition, language, and social and motor development	At 18 mon., ES = 1.40 (corrected, 1.38) for Bayley	Type 2 study: +RCT, +/- (partial) Blind assessments, +Incl/excl criteria, +Standardized dx battery, +Comparison group, -Tx fidelity, +Tx manual

Table 1 (Continued)

Author(s) and year	Sample	Outcome measures	Treatment procedures	Findings	Nathan and Gorman (2002) criteria
EARLY INTERVENTIONS FOR PREMATURE INFANTS AND TODDLERS:					
Avon Premature Infant Project (1998)	116 ss in developmental education group, 106 ss in parent advisor group, 106 controls	Griffiths Mental Development Scales	The Avon Premature Infant Project; ss randomized to developmental education group (using Portage, consisting of activities to introduce the parent to aspects of child's development; nurses served as interventionists), parent advisor group (seminars and individual and group work focused on parent support), or control; interventions delivered weekly from hospital discharge for a few months, 2-4 weekly for the next yr., and monthly until 2 yrs. of age	At 2 yrs., ES = .59 (corrected, .59) for Portage group and .27 (corrected, .27) for parent advisor group for children under 1250 grams at birth	Type 2 study: +RCT, +Blind assessments, +Incl/excl criteria, +Standardized dx battery, +Comparison group, -Tx fidelity, +Tx manual
Johnson, Ring, Anderson, & Marlow (2005) (Follow-up of Avon Premature Infant Project (1998))	63 ss in developmental education group, 61 ss in parent advisor group, 63 controls	British Ability Scales II; Movement ABC; CBCL	See Avon Premature Infant Project (1988)	At 5 yrs., ES = -.12 (corrected, -.12) for Portage group and -.05 (corrected, -.05) for parent advisor group	Type 2 study: +RCT, +Blind assessments, +Incl/excl criteria, +Standardized dx battery, +Comparison group, -Tx fidelity, +Tx manual
Bao, Sun, & Wei (1999)	52 ss, 51 preterm controls, 53 full-term controls	Child Development Center of China scale at 1.5 and 2 yrs.	Parent training of exercises to stimulate motor, cognitive, speech, and social behavior; monthly instruction for the first year and instruction every other month for the second year; at least half-hour meetings; occasional small parent classes, organized in didactic manner to teach about development and early intervention	At 2 yrs., ES = .58 for MDI in favor of intervention group over normal control group, and ES = 1.28 for MDI in favor of intervention group over premature control group	Type 2 study: +RCT, +Blind assessments, -Incl/excl criteria, +Standardized dx battery, +Comparison group, -Tx fidelity, -Tx manual

Table 1 (Continued)

Author(s) and year	Sample	Outcome measures	Treatment procedures	Findings	Nathan and Gorman (2002) criteria
Barrera, Doucet, & Kitching (1990)	22 ss in parent-infant tx, 16 ss in developmental programming tx, 21 preterm controls, 24 full-term controls	Vineland Social Maturity Scale; Flint Infant Maturity Scale; BSID	12-28 1-2-hr home visits; DPI: specific activities designed to encourage infants' development in cognition, communication, fine and gross motor, socio-emotional & self-help; PII: improve parent-infant interaction, followed child's and parents' leads	For Vineland Social Maturity Scale, ES = .21 for DPI versus preterm controls and .06 for PII versus preterm controls	Type 2 study: +RCT, +Blind assessments, +Incl/excl criteria, +Standardized dx battery, +Comparison group, -Tx fidelity, +Tx manual
Bustan & Sagi (1984)	8 ss, 8 controls	At about 3 mon. of age: Broussard Scale; Infant Characteristic Questionnaire; interaction observations; Maternal Questionnaire	3 sessions of discussion with ICU staff regarding mother's feelings and provision of information about prematurity; provision of Prematurity Manual which elaborates on prematurity	No positive effect of intervention on maternal personal attitudes and feelings (ES = .24 for attitudes regarding maternal role), but some positive effects for mother-infant interactions (e.g., ES = .87 for close body contact)	Type 2 study: -RCT, +/- (partial)Blind assessments, +Incl/excl criteria, +Standardized dx battery, +Comparison group, -Tx fidelity, +Tx manual
Gianni et al. (2006)	18 ss, 18 controls	Griffiths Mental Development Scale	An early post-discharge developmental mother-child tx program; 3-12 mon of age, mother-infant pairs attended 1.5-hr, twice monthly group sessions, focused on mother grief/guilt and infant's observation and promotion of perceptual and social-cognitive skills in mother-infant interaction	At 36 mon, ES = .79 for personal social, .32 for hearing and speech, .78 for hand and eye coordination, .58 for performance, and 1.00 for practical reasoning (corrected effect size of .67)	Type 2 study: +RCT, +Blind assessments, +Incl/excl criteria, +Standardized dx battery, +Comparison group, -Tx fidelity, -Tx manual
IHDP (1990)	377 ss, 608 controls	BSID; Stanford-Binet Intelligence Scale; PPVT; Beery Test of Visual Motor Integration	Home visits across 3 yrs, educational daycare beginning in yr 2, monthly parent group meetings, and case management; cognitive stimulation curriculum for low birth weight infants (Early Partners) and a cognitive stimulation curriculum for infancy and early childhood (Partners for Learning)	At 36 mon., ES = .83 for Stanford-Binet for the heavier participants, and .41 for the lighter participants (average corrected effect size of .62)	Type 2 study: +RCT, +Blind assessments, +Incl/excl criteria, +Standardized dx battery, +Comparison group, -Tx fidelity, +Tx manual

Table 1 (Continued)

Author(s) and year	Sample	Outcome measures	Treatment procedures	Findings	Nathan and Gorman (2002) criteria
Brooks-Gunn, Liaw, & Klebanov (1992) (Expansion of IHDP (1990))	377 ss, 608 controls	BSID; Stanford-Binet Intelligence Scale; PPVT; Beery Test of Visual Motor Integration	See IHDP (1990)	At 24 mon., ES = .46 for vocabulary, .49 for receptive language, 1.01 for visual-motor and spatial factors; at 36 mon., ES = .46 for vocabulary, .49 for receptive language, .55 for visual-motor and spatial factors, .42 for reasoning ES = .22 (corrected, .22) for MDI	Type 2 study: +RCT, +Blind assessments, +Incl/excl criteria, +Standardized dx battery, +Comparison group, -Tx fidelity, +Tx manual
Kaarensen et al. (2008)	69 ss, 67 controls	At 2 yrs.: BSID; CBCL; PSI	Modified version of The Mother-Infant Transaction Program; emphasizes the transactional nature of development and seeks to enable parents to appreciate their infant's unique characteristics and respond appropriately to infant's cues; 1-hr daily sessions for a week, then four home visit follow-ups 3, 14, 30, and 90 days after hospital discharge		Type 1 study: +RCT, +Blind assessments, +Incl/excl criteria, +Standardized dx battery, +Comparison group, +Tx fidelity, +Tx manual
Kang et al. (1995)	64 ss in hospital experimental, 77 ss in home visit experimental, 70 ss in hospital control, 116 ss in home control	NCAPS; NCATS	Hospital experimental: State Modulation (program designed to promote infant behavioral responsiveness and interaction with mothers; 1-hr program); home visit experimental: Nursing Systems Toward Effective Parenting-Preterm (designed to promote parent adaptation to preterm infants; 9 visits across 5 mon.); hospital control: car seat instructional program (1-hr program); home control: standard public health nursing	For NCAPS, ES = .32 for hospital intervention and ES = -.20 for home intervention; For NCATS, ES = .61 for hospital intervention and ES = .41 for home intervention	Type 2 study: +/- (partial)RCT, -Blind assessments, +Incl/excl criteria, +Standardized dx battery, +Comparison group, -Tx fidelity, +Tx manual

Table 1 (Continued)

Author(s) and year	Sample	Outcome measures	Treatment procedures	Findings	Nathan and Gorman (2002) criteria
Kleberg, Westrup, Stjernqvist, & Lagercrantz (2002)	11 ss, 9 controls	BSID at 1 yr. corrected age	Newborn Individualized Developmental Care and Assessment Program (NIDCAP); involves sequential, formalized, naturalistic observations of the infant prior to, during, and after care-giving procedures; observer assesses the infant's current ability to organize and modulate the 5 highly interactive subsystems categorized in the synactive theory – the autonomic physiological, motor, state organizational, attention interactive and self-regulatory systems – then recommendations for individualized care and changes in the environment are formulated	At 12 mon. corrected age, ES = 1.45 (corrected, 1.39) for MDI and .50 for PDI	Type 2 study: +RCT, +Blind assessments, +Incl/excl criteria, +Standardized dx battery, +Comparison group, -Tx fidelity, +Tx manual
Melnyk et al. (2001)	20 ss, 22 controls	BSID; State-Trait Anxiety Inventory; Profile of Mood States; Parental Stressor Scale: Neonatal Intensive Care; Maternal-Infant Interaction Scale; NCAFS; HOME; Parental Belief Scale: NICU	COPE – a parent-focused tx; four-phase educational-behavioral program that began 2–4 days postbirth and continued through 1 week following discharge from the NICU; provided infant information and parent activities	At 6 mon., ES = .72 (corrected, .71) for MDI	Type 1 study: +RCT, +Blind assessments, +Incl/excl criteria, +Standardized dx battery, +Comparison group, +Tx fidelity, +Tx manual
Newnham, Milgrom, & Skouteris (2009)	35 ss, 33 controls	Edinburgh Postnatal Depression Scale; collection of birth, medical, and SES information; Neonatal Medical Index; Short Temperament Scale for Infants; Synchrony Scale; PSI; Ages and Stages Questionnaire	Mother-Infant Transaction Program, focused on teaching parents to recognize infant disorganization and stress and responding to cues; 9 sessions across 3 mon.	At 6 mon., ES = 2.00 for mutual attention on Synchrony Scale	Type 2 study: +RCT, +/- (partial)Blind assessments, +Incl/excl criteria, +Standardized dx battery, +Comparison group, -Tx fidelity, +Tx manual

Table 1 (Continued)

Author(s) and year	Sample	Outcome measures	Treatment procedures	Findings	Nathan and Gorman (2002) criteria
Olafsen et al. (2006)	71 ss, 69 preterm controls, 75 full-term controls	Early Social Communication Scales	A modified version of the Vermont Intervention Program for Low Birthweight Infants; aims were to (1) enable the parents to appreciate their baby's specific behavioral and temperamental characteristics, (2) sensitize parents to the infant's cues, and (3) teach parents to respond appropriately to those cues in order to facilitate mutually satisfying interactions; daily 1-hr sessions for 7 days, and 4 1-hr home visits	At 12 mon., ES = .49 for initiating joint attention	Type 1 study: +RCT, Blind assessments, +Incl/excl criteria, +Standardized dx battery, +Comparison group, +Tx fidelity, +Tx manual
Rauh et al. (1988)	25 ss, 29 LBW controls, & 28 NBW controls	Quality of Mothering and Degree of Receptivity to the Program; Seashore Self-Confidence Rating Paired Comparison Questionnaire; Taylor Manifest Anxiety Scale; Carey Infant Temperament Questionnaire; Satisfaction Scale; BSID; McCarthy Scales of Children's Abilities	Implemented by a NICU nurse; 11 1-hr sessions over 3 mon. (7 in hospital, 4 in home); followed mothers' leads; aimed to facilitate maternal adjustment to care of infant, and indirectly affect infant development; various topic areas such as maternal sensitivity and infant distress	ES = .80 (corrected, .79); cognitive diff. at age 4 yrs., maintained until age 9 yrs	Type 1 study: +RCT, +Blind assessments, +Incl/excl criteria, +Standardized dx battery, +Comparison group, +Tx fidelity, +Tx manual
Achenbach, Phares, Howell, Rauh, & Nurcombe (1990) (Follow-up of Rauh et al. (1988))	24 ss, 32 LBW controls, & 37 NBW controls	At 7 yrs: Kaufman Assessment Battery for Children; PPVT	See Rauh et al., 1988	ES = .70 for total Kaufman score for LBW tx over LBW control	Type 1 study: +RCT, +Blind assessments, +Incl/excl criteria, +Standardized dx battery, +Comparison group, +Tx fidelity, +Tx manual
Achenbach, Howell, Aoki, & Rauh (1993) (Follow-up of Rauh et al. (1988) and Achenbach et al. (1990))	24 ss, 31 LBW, & 36 NBW controls	At 9 yrs.: Kaufman Assessment Battery for Children; PPVT; CBCL for Ages 4-18; Teacher's Report Form of CBCL	See Rauh et al., 1988	ES = .65 for Kaufman total achievement (LBW treatment versus LBW control)	Type 1 study: +RCT, +Blind assessments, +Incl/excl criteria, +Standardized dx battery, +Comparison group, +Tx fidelity, +Tx manual

Table 1 (Continued)

Author(s) and year	Sample	Outcome measures	Treatment procedures	Findings	Nathan and Gorman (2002) criteria
Resnick, Eyster, Nelson, Eitzman, & Bucciarelli (1987)	124 ss, 131 controls	BSI	Developmental interventions in the hospital and at home for first 2 yrs of life as well as counseling and parent education, water beds, visual stim, developmental exercises; individualized and updated frequently	At 24 mon., ES = .66 (corrected, .66) for MDI and .54 for PDI	Type 2 study: +RCT, +Blind assessments, +Incl/excl criteria, +Standardized dx battery, +Comparison group, -Tx fidelity, +Tx manual
Sajaniemi et al. (2001)	49 ss, 51 controls	BSID at 2 yrs.; Wechsler Preschool and Primary Scale of Intelligence at 4 yrs.; Preschool Assessment of Attachment	Weekly 60-min. OT sessions at home from 6-12 mon. of age; goals: to promote normal sensorimotor development, development of play, and social-emotional development by promoting parent-infant relationship	ES = .42 (corrected, .42) for full-scale IQ at 4 yrs.	Type 2 study: +RCT, +Blind assessments, +Incl/excl criteria, +Standardized dx battery, +Comparison group, -Tx fidelity, -Tx manual
Scarr-Salapatek & Williams (1973)	15 ss, 15 controls	Brazelton Cambridge Newborn Scales; Cattell Infant Intelligence Scale; ratings of maternal care	Visual, tactile, & kinesthetic stimulation during 6 wks in NICU; weekly home visits until 12 mon. of age	At 12 mon., ES = .71 for IQ	Type 2 study: +RCT, +Blind assessments, +Incl/excl criteria, +Standardized dx battery, +Comparison group, -Tx fidelity, +Tx manual
Teti et al. (2009)	84 ss, 89 controls	At 3-4 mon. corrected age: Maternal Self-Efficacy Scale; Maternal Behavioral Q-Set; BSID; PSI-Short Form; Life Events Survey	Psychoeducational video about NICU environment, infants' development, and parent-child relationship; serial administration of Brazelton Neonatal Behavioral Assessment Scale; maternally-administered infant massage; 8 sessions over 20 wks	At 3 mon., ES = .72 (corrected, .72) for Bayley MDI for extremely low birthweight infants	Type 2 study: +RCT, +Blind assessments, +Incl/excl criteria, +Standardized dx battery, +Comparison group, -Tx fidelity, +Tx manual
van der Pal et al. (2008)	84 ss, 84 controls	Infant Behavior Questionnaire-Revised (at 9 mon.); Infant-Toddler Social and Emotional Assessment & Nijmegen Parenting Stress Index-Short Version (at 1 yr)	NIDCAP (behavior observations and guidance by a trained developmental specialist)	No sig. effects (e.g., ES = .36 for social relatedness)	Type 2 study: +RCT, -Blind assessments, +Incl/excl criteria, +Standardized dx battery, +Comparison group, -Tx fidelity, +Tx manual
Zahr (2000)	43 ss in extended-visitation group, 40 ss in short-visitation group, 40 controls (all Latino and low SES)	At 1, 4, 8, 12, 18, & 24 mon.: BSID; NCAFS; NCATS; Maternal Confidence Questionnaire; PSI; HOME; Arizona Social Support Interview Schedule	Home visits by public health nurses; extended-visitation received 19 visits across 12 mon. and short-visitation received 11 visits across 4 mon.; mothers were taught to identify cues of infants and about general caretaking skills; provision of support for mothers; goals: to enhance infant development and mother-infant interaction	ES = -.66 (corrected, -.65) for mental scores at 24 mon. in extended-visitation group, and -.43 (corrected, -.43) in short-visitation group	Type 2 study: +/- (partial)RCT, +Blind assessments, +Incl/excl criteria, +Standardized dx battery, +Comparison group, +Tx fidelity, -Tx manual

Table 1 (Continued)

Author(s) and year	Sample	Outcome measures	Treatment procedures	Findings	Nathan and Gorman (2002) criteria
Zahr, Parker, & Cole (1992)	26 ss, 15 controls	Assessed weekly on Assessment of Preterm Infant Behavioral or neurobehavioral observation; BSID; Infant Characteristics Questionnaire; Mother-Infant Interaction; Maternal Confidence Questionnaire: HOME	Teaching sessions aimed to teach mothers about infants' behavioral cues; average 3.6 sessions, 60-90 min. each; individualized	At 8 mon., ES = 1.22 (corrected, 1.20) for MDI for infants <1500 grams at birth and .10 for infants >1500 grams at birth	Type 2 study: +/- (partial)RCT, +Blind assessments, +Incl/excl criteria, +Standardized dx battery, +Comparison group, -Tx fidelity, -Tx manual

Abbreviations used: ss = subjects; tx = treatment; sig. = significant; LBW = low birthweight; NBW = normal birthweight; DS = Down Syndrome; OT = occupational therapy; PT = physical therapy; BDI = Battelle Developmental Inventory; PSI = Parenting Stress Index; PPVT = Peabody Picture Vocabulary Test; CBCL = Child Behavior Checklist; BSID = Bayley Scales of Infant Development; NCAFS = Nursing Child Assessment Feeding Scale; NCATS = Nursing Child Assessment Teaching Scale; HOME = Home Observation for Measurement of the Environment.

while others were assigned by default to a specific group based on geographical factors.

Effect size calculations

As noted above, all papers included in the analyses reported sufficient statistics to calculate effect sizes. Effect sizes were calculated for primary outcome measures for each paper, and ranged from effect sizes representing changes in IQ scores to effect sizes representing changes in children's vocabulary. Effect sizes were calculated by subtracting comparison group mean outcome scores from treatment group mean outcome scores, and dividing that result by the average of standard deviations of scores for both groups. These are presented in Table 1.

We then identified those studies that used psychometrically sound, standardized measures of overall developmental ability: the Bayley Scales of Infant Development, the Stanford-Binet Intelligence Scale, the Griffiths Mental Development Scales, the McCarthy Scales of Children's Abilities, the Kaufman Assessment Battery for Children (one study), the Cattell Infant Intelligence Scale (one study), and the British Ability Scales II (all outcome measures are described in Table 1). This involved all but 11 of the total number of studies. Effect sizes generated from these instruments were then corrected for small sample size, following the methods reported in Reichow and Wolery (2009). Once these corrections were made, the standard error of the corrected effect size and the 95% confidence intervals were calculated, following Reichow and Wolery (2009). These corrected effect sizes are also included in Table 1, under the heading Findings. Papers reporting moderate to large effect sizes (.50 and above) are highlighted in gray. The corrected effect sizes and confidence intervals for studies using these instruments are plotted for each of the three diagnostic groups in Figures 1 and 2, with the Type 1 studies and the Type 2 studies grouped by type. Ages of the sample at the time of follow-up are noted in each entry. For studies in which there are multiple follow-up periods, the age of follow-up closest to age 29 months was selected, since that represented the mean age at first outcome study across all the studies.

Extraction of key ingredients

We identified the studies for each diagnostic group that were the most effective at changing child developmental outcomes based upon effect size analysis and we then examined the methodology of these intervention studies for similarities that might reflect the most powerful elements resulting in child change. In the following section, we describe these results.

Effective interventions for premature infants. A remarkable intervention study for premature infants

was carried out by the Infant Health and Development Program (IHDP; 1990), a consortium of eight sites that conducted randomized controlled trials involving 1000 infants who were followed up at age 3 years. Participants' mothers were primarily African American and Caucasian, and had attended some high school or had earned a high school diploma. Six of the seven methodological elements were described in the paper; the lack of a description of fidelity measures resulted in the Type 2 classification.

The program consisted of parent training in home visits across the first three years of life, with weekly visits for the first year and biweekly visits thereafter. Interventionists taught parents to use two cognitive stimulation curricula for low birthweight infants and toddlers, one emphasizing cognitive, linguistic, and social development via a program of games and activities, and the other involving a systematic approach to help parents manage self-identified problems. In the second year of life, infants began attending an educational daycare five days per week, in which teachers continued to utilize the stimulation curriculum, and this continued until 36 months of age. Children received 20+ hours in intervention per week, and bimonthly parent group meetings began when the infants were 12 months of age. Infants were assessed at 40 weeks and 4, 8, 12, 18, 24, 30, and 36 months of age. At age 36 months, the effect sizes for Stanford-Binet scores were .83 for heavier

participants and .41 for lighter participants (resulting in an average corrected effect size of .62).

In terms of intervention characteristics, this intervention was both long-lasting and intensive. The intervention began in the home during infancy and transferred to a center-based program during the toddler period. It involved parent training in infancy during weekly home visits and through parent groups during toddlerhood. The intervention was individualized for each child. Parents were provided additional supports in terms of parent groups, case management, and transportation if needed.

Another remarkably effective intervention was reported by Rauh, Achenbach, Nurcombe, Howell, and Teti (1988), in a Type 1 study involving 25 premature infants (with an average maternal education of 14.1 years), 29 randomized comparisons, and 28 normal birthweight comparison infants followed up at age 7 years by Achenbach, Phares, Howell, Rauh, and Nurcombe (1990) and again at age 9 years by Achenbach, Howell, Aoki, and Rauh (1993). The intervention, focused on supporting maternal care, was implemented by an NICU nurse and consisted of 11 one-hour sessions over a 3-month period. Intervention began during the final week of infant hospitalization and extended into the home. Seven sessions occurred in the hospital, and four occurred in the families' homes. Nurses targeted topics related to maternal sensitivity and infant distress and fol-

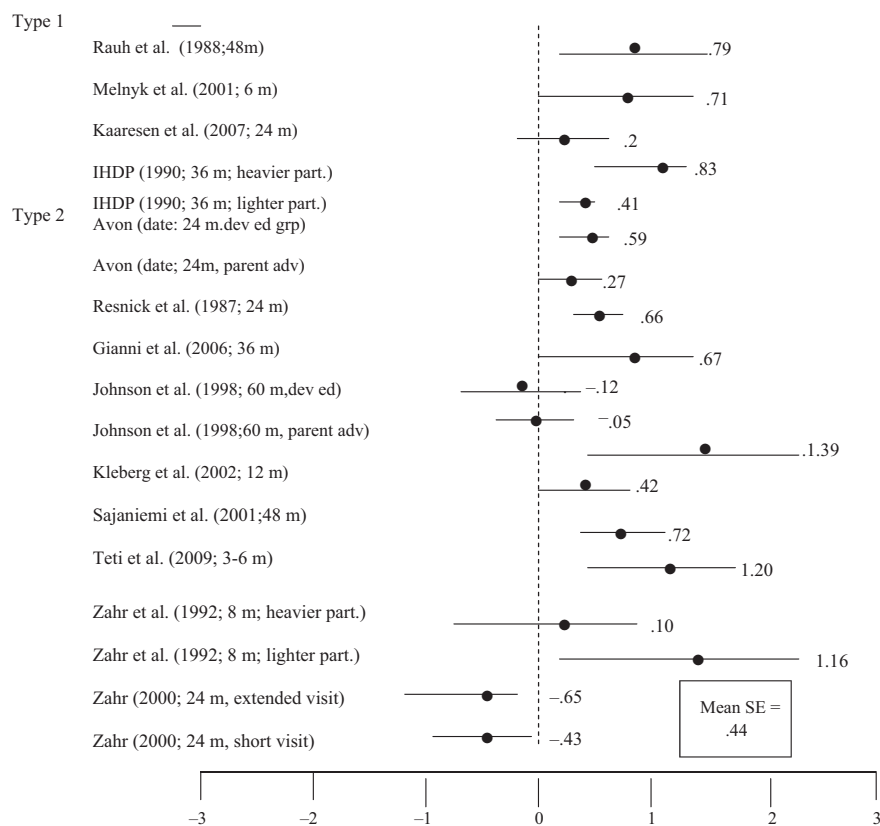


Figure 1 Corrected effect sizes, ages in months at outcome, and 95% confidence intervals of Type 1 and Type 2 interventions for premature infants

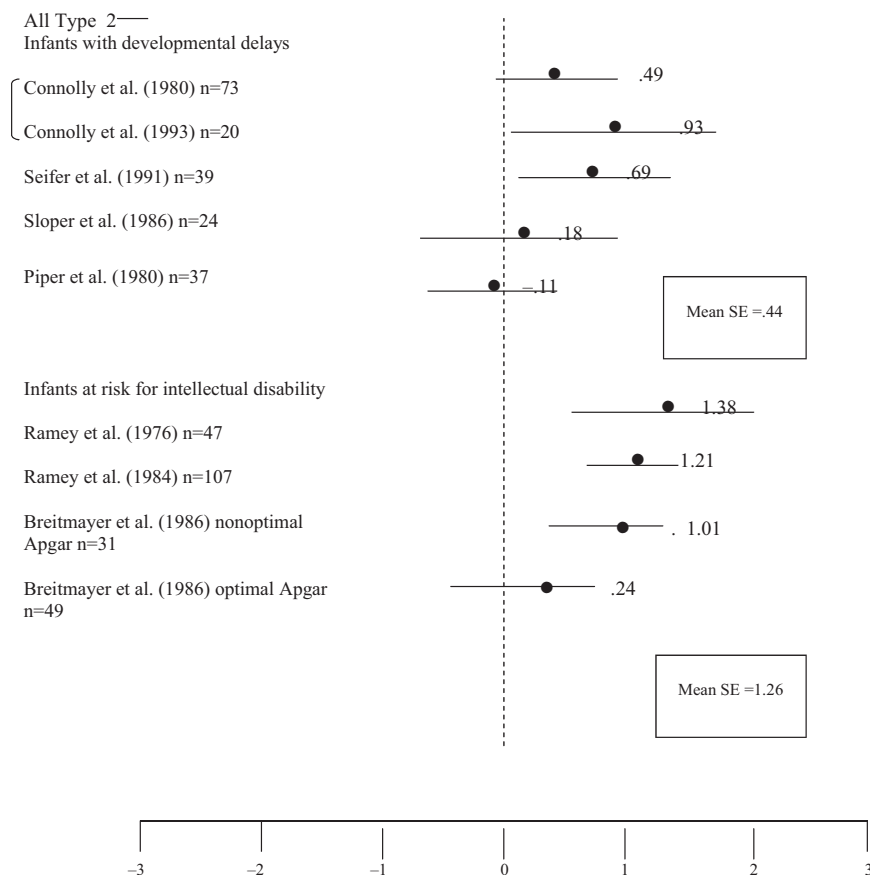


Figure 2 Corrected effect sizes, ages in months at outcome, and 95% confidence intervals of Type 1 and Type 2 interventions for infants with developmental delays and those at risk for intellectual disability

lowed the mothers' leads in terms of emphasis and pace.

Intervention outcomes were assessed with a multitude of measures administered to infants and to the mother–infant dyads every 6 months across a 4-year period. Mothers in the treatment group reported significantly higher self-confidence and satisfaction with mothering, as well as more favorable views of infant temperament than did the comparison group. Beginning at age 3 years, children in the treatment group progressively caught up to the normal birthweight comparison group on cognitive scores (Rauh et al., 1988). Further follow-up at age 7 years (Achenbach et al., 1990) and at age 9 years (Achenbach et al., 1993) continued to find the treatment groups' cognitive scores similar to those of normal birthweight children and significantly higher than the premature control group. Effect sizes for cognitive scores at age 4 years was .79 (corrected effect size), at age 7 years was .70, and at age 9 years was .65.

This intervention occurred over a short period of 3 months and involved contacts both in the community and at home. Parents were coached in techniques aimed to bolster the development of their infants. The intervention was broad-based, individualized, and provided one-on-one in homes by parents. Parents were not provided with additional support beyond the intervention.

These two randomized controlled studies demonstrate the largest effect sizes in this sample that were sustained well into early childhood and beyond. They stand out for two reasons: the IDHP (1990) study because of the enormous sample size and lengthy follow-up period, and the Rauh et al. (1988) study because of the sustained effects over a very long follow-up period. However, the interventions are quite different, with the former a very long-lasting and intensive intervention carried out for 36 months and the second a very brief intervention lasting only 3 months and carried out by a visiting nurse. Common elements include an individualized developmental curriculum for children, a strong focus on parent training and parent delivery of the intervention, and emphasis on supporting parents.

There was also a study that did not find any positive change due to intervention (Zahr, 2000). This study focused on low-income infants from minority families and involved a low-intensity intervention focused on general caretaking skills and sensitivity to infant cues. The intervention was delivered either for 19 visits across 12 months, or 11 visits across 4 months. Corrected effect sizes were $-.65$ for the extended period group and $-.43$ for the shorter period group.

In reviewing these studies as a group, and as demonstrated in Figure 1, there are overall moderate effects of these intervention strategies for premature

infants, though there is much variability. The mean effect size of this group of studies is .44, demonstrating that these intervention strategies, focused on parent coaching, are effective in improving developmental outcomes of the infants receiving the experimental treatments, at least within the time period assessed.

Infants with developmental delays. Connolly, Morgan, Russell, and Richardson (1980) examined the effects of treatment on children diagnosed with Down syndrome who had participated in the Early Intervention Program at the Child Development Center of the University of Tennessee Center for the Health Sciences when under the age of 3 years. This program's goals involved improving the parent-child relationship and maximizing the overall development of each child. For 10 weeks, families participated in weekly, 2.5-hour group sessions at the Center. During the first hour of each session, parents and children participated together while professionals taught and demonstrated to parents various developmental interventions. During the second hour, parents participated in a group therapy session, discussing their feelings and concerns, while the children were treated individually. Finally, a half-hour was spent dealing with feeding-skill development. In the winter and summer following this 10-week program, parents continued individualized home programs, and had occasional visits by staff of physical therapy and nursing departments.

At age 3-6 years, 20 children who completed this intervention were compared to 53 children who had not received it. There was a significant group difference on the Stanford-Binet favoring the children who received the intervention, with a corrected effect size of .49. At age 16 years, ten children who had received the intervention were again compared on the Stanford-Binet to ten who had not, with a corrected effect size of .93 favoring the intervention group. However, this study had a variety of methodological weaknesses, including lack of randomized assignment, lack of raters blind to intervention status, and lack of treatment manuals or fidelity measures. There was also considerable attrition in both groups at the age 16 assessment.

In terms of intervention characteristics, density and duration were moderate and mixed across participants. The intervention was delivered in the community and at home and involved parents heavily in terms of coaching and relying on them to practice developmental activities with their children. It was broad-based and individualized, and provided in a mixed one-to-one and group setting. Families were provided with additional support in the form of parent groups and therapy.

In reviewing these studies as a group, and as demonstrated in Figure 2, there are overall moderate effects of these intervention strategies for infants with a variety of significant developmental disorders,

though, as above, there is much variability. The mean effect size of this group of studies is .44, demonstrating that these intervention strategies, most of them focused on parent coaching, are effective in improving developmental outcomes of the infants receiving the experimental treatments, at least within the time period assessed.

Children at risk for intellectual disability. The Carolina Abecedarian Project (Ramey & Campbell, 1984; Ramey & Smith, 1976) was one of several well-publicized studies that attempted to prevent intellectual disability in infants at risk due to poverty and intellectual impairments of their mothers. Fifty infants were randomized into intervention and comparison groups. The full-day intervention was delivered in specialized daycare centers beginning when the infants were 6-12 weeks of age and continued until age 5 years. The infant curriculum consisted of activities designed to stimulate language, motor, social, and cognitive skills and was delivered by the daycare staff. After the third birthday, the intervention became an excellent preschool curriculum with a particular emphasis on language development. Families were provided with additional support in the form of case management, nutrition, medical assistance, and transportation if needed.

Ramey and Campbell (1984) compared the scores of these children to 53 control children on the Bayley Scales of Infant Development, the Stanford-Binet Intelligence Scale, and/or the McCarthy Scales at 6, 12, 18, 24, 30, 42, 48, and 54 months of age. Beginning at 18 months and on every test thereafter, those in the treatment group outscored control children. The corrected effect size for Bayley scores at 18 months was 1.38, and for Stanford-Binet scores at 54 months of age was 1.21.

In terms of intervention characteristics, both density and duration were high, with 40 hours per week of intervention for a period of 60 months. Ratios were those of excellent daycare centers. The curriculum was broad-based and individualized, with special emphasis on language development. Methodological weaknesses included absence of blind assessors and treatment fidelity checks.

In reviewing these studies as a group, and as demonstrated in Figure 2, there are overall large effects of these intervention strategies for infants at risk for intellectual disability due to parental lower IQs and poverty, though there is much variability. The mean effect size of this group of studies is 1.26, demonstrating that these intervention strategies, most of them delivered in high-quality child care settings combined with parent coaching and support, are effective in markedly improving developmental outcomes of the infants receiving the experimental treatments, at least within the time period assessed.

For the purposes of comparison, we have also included a similar figure from Reichow and Wolery

(Figure 3; 2009), demonstrating effect sizes for young children with autism receiving intensive applied behavior analysis following Lovaas's (1981, 1987, 2003) model. For the children in these studies, interventions were carried out for 30–40 hours per week, in 1:1 ratios, mostly at home but a few in special group settings, using discrete trial teaching. While these studies are delivering more intensive intervention than most of the other studies cited in this paper, the mean corrected effect sizes reported are moderate, similar to those achieved by intervention studies for other infants with delays.

Taken as a group, the mean effect sizes across all these studies suggests a high degree of plasticity in developmental outcomes in infants and toddlers with known developmental impairments and a marked capacity to respond to carefully delivered infant interventions with developmental acceleration. The autism outcome data from the most intensive and carefully completed intervention studies is quite similar to the effect sizes achieved by the intensive interventions delivered of infants at risk of developmental impairment carried out for long periods of time at high intensity. To what extent the very large effect sizes gained in these two groups are due to the intense and long-lasting interventions, and to what extent they are due to child-specific characteristics in these two groups, is unknown and presents a very interesting question for future research.

Discussion

In all, 32 Type 1 or Type 2 Studies were identified that focused on infants and toddlers in the birth to 3-year chronological age range. In the previous sections, a sampling of the most efficacious studies was provided, focusing on their intervention characteristics and methodological rigor. The effect size

analysis conducted on all 32 studies allows us to extract key intervention ingredients that appear to contribute to successful outcome. Four characteristics appear repeatedly in the efficacious interventions: (1) parent involvement in intervention, including ongoing parent coaching that focused both on parental responsiveness and sensitivity to child cues and on teaching families to provide developmentally based, individualized infant interventions, (2) individualization of curriculum to each infant's developmental profile, (3) focusing on a broad range of learning targets, and (4) temporal characteristics involving beginning as early as the risk is detected and providing greater intensity and duration of the intervention. It is interesting that a large majority of the interventions were carried out in individual homes in regular home visits, coaching families. The only center-based interventions among these Type 1 and Type 2 papers were those for low-income infants, and these involved full time daycare in a language-rich, excellent setting, but group care began after the infants were 1 year old. Before that, the home visit and parent coaching methods involving parental sensitivity and infant development activities were also used. We did not find studies that compared efficacy of center-based to home-based intervention in this literature, but a multitude of carefully controlled studies of typically developing infants find very few meaningful differences between these two child-rearing environments on developmental profiles of preschoolers (e.g., National Institute of Child Health and Human Development Early Child Care Research Network, 2000).

Given these common ingredients among the most efficacious intervention studies, it is interesting to examine the non-efficacious interventions to determine which of these key ingredients were present. The intervention described by Zahr, Parker, and Cole (2000) compared home visitation for two lengths of

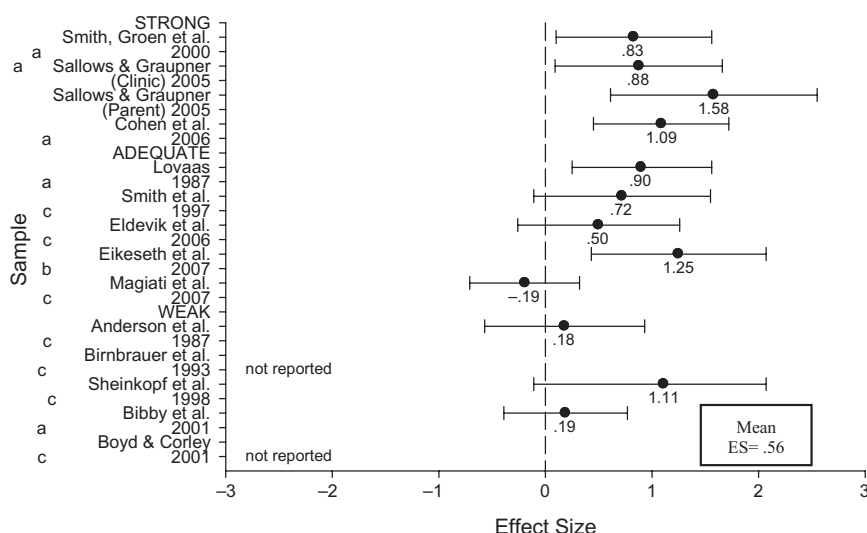


Figure 3 Corrected effect sizes, ages in months at outcome, and 95% confidence intervals of interventions for young children with ASD toddlers. Printed with permission of Springer

time – 4 months versus 12 months after hospital discharge – for impoverished Latino mothers and their premature infants. There were no gains in child developmental rates related to this intervention, though previous studies of the same intervention model by the same authors with other participant groups demonstrated positive intervention effects. The authors note that the caretaking environment in these families, as a group, differed from previous study groups, and that cultural differences in infant rearing patterns, combined with already existing social supports in these Latino communities, may support infant development in these families more strongly than other groups studied, resulting in less ‘room’ for improvements due to the intervention. The studies by Zahr and colleagues are good examples of the program of studies that are needed on a specific intervention approach in order to determine who will benefit and what intensity of intervention is needed. The common elements listed above are excellent candidates for manipulation within experimental designs in future studies to determine moderators and mediators of improved outcomes for children with developmental risks.

However, two words of caution are necessary. First, the results of the Avon Premature Infant Project (1998) point out the crucial importance of long-term follow-up. This very well done, randomized study delivered a developmental curriculum to a large group of parents and infants via nurse visits ($n = 116$) or via parent groups ($n = 106$). At age 2 years, children receiving the regular home visits and developmental curriculum showed much larger effects of the intervention ($ES = .59$) than did the parent group intervention ($ES = .27$). However, follow-up of two-thirds of the sample by Johnson, Ring, Anderson, and Marlow (2005) at age 5 years revealed no group differences (home visit group $ES = -.12$; parent group $ES = -.05$) compared to the controls.

Second, it is important to note that there are some exceptions to key ingredients pulled from the literature review (e.g., that those interventions which provide long-term, intensive, and comprehensive intervention are more efficacious than time-limited, focal interventions). For example, Teti et al. (2009) discuss a short-term focal intervention with impressive results. Nevertheless, the largest trials (e.g., IHDP, 1990; Resnick, Eyler, Nelson, Eitzman, & Bucciarelli, 1987) support the conclusion that long-term, intensive, and comprehensive interventions are highly efficacious. Future research may help to further parcel out the importance of intervention intensity, duration, and comprehensiveness.

To what extent infants and toddlers receiving these early interventions show long-lasting benefit is a seldom studied question. However, the question underscores a critically needed feature of future intervention studies for all groups of infants and toddlers: long-term follow-up. Documentation of long-term effects of early intervention will assist the

public in making important decisions regarding funding for these services and in assessing the costs and benefits to individuals and to communities that come from high-quality infant intervention programs.

Implications for research in infant/toddler interventions for ASD

The age of early recognition of ASD or ASD risk is fast approaching 12 months and research groups are working hard to identify risk signs even earlier, for the express purpose of enabling treatment to begin as soon as possible in order to reduce or reverse signs and symptoms of autism. The large body of research in infant intervention for other clinical infant groups and their families suggests starting points for research on infant interventions for ASD. Given the amount of science that already exists in early intervention for ASD, it would be extremely helpful for ASD researchers to design comparative studies that allow for isolation of the ‘active ingredients’ for best outcomes for infants with ASD. Specific intervention variables to be examined when considering intervention for infants at risk for ASD include the following.

ASD-specific versus general developmental intervention. Some approaches to early ASD intervention, both from applied behavior analysis and from developmental approaches, target a broad range of learning targets (Maurice, Green, & Luce, 1996; Rogers & Dawson, 2009), similar to what has been described above in the infant literature from other groups. However, in the literature on ASD there has also been the focus on primary deficits, or core features that are impaired in ASD and that appear to prevent other areas of development from flourishing, resulting in secondary deficits. Core deficits suggested early in ASD have included joint attention (Whalen, Schreibman, & Ingersoll, 2006), imitation (Rogers & Williams, 2006), language, and symbolic play (Young, Brewer, & Pattison, 2003). While there is currently considerable controversy about whether there are such ‘primary deficits’ (Happé & Ronald, 2008), there is repeated evidence that targeting one or more of these core features does result in positive changes in other areas – ‘collateral effects’ is the term most often used. Furthermore, these collateral effects typically occur among the various core features of ASD listed above, suggesting that they are not independent of each other (Whalen et al., 2006). Intervention approaches for preschoolers with ASD that have focused on core skills rather than a broad array of skills include Pivotal Response Training, focused on communication (e.g., Koegel, Koegel, Harrower, & Carter, 1999), the work by Kasari and colleagues focused on joint attention and symbolic play (e.g., Kasari, Freeman, & Paparella, 2006; Kasari, Paparella, Freeman, & Jahromi, 2008),

imitation (e.g., Whalen et al., 2006), and social development (Odom & McConnell, 1996). The idea that targeting core developmental features results in downstream gains in other important developmental areas is an important tenet of developmental psychology.

Targeting intervention on core features may be a more economical approach to intervention, in terms of time, family involvement, and cost, than delivering global teaching based on every aspects of a child's development. Determining whether a targeted approach to a limited set of skills is as efficacious as a global approach to development in intervention is a critical research need, given the number of children who need intervention and the limited resources that communities have to provide it. A study design that would help to answer this question would involve assigning infants and toddlers with ASD randomly to either a comprehensive or a targeted set of treatment objectives within a given teaching approach, holding all other variables constant, and following the infants along with careful and frequent assessment of all developmental areas. This type of study would help us learn whether the approach that has been so effective in the other infant interventions – use of a broad developmental curriculum – is also optimal for ASD.

Intensity and delivery system for intervention. The examination of effect sizes reviewed in this paper suggest that treatment intensity, including beginning treatment as early as possible and providing that treatment for long durations, contributes to more efficacious interventions. Thus, a second question that arises in discussing autism early intervention is the intensity of treatment. The current national standard suggests 25 hours per week of intervention for young children with ASD (National Research Council, 2001). However, the only infant treatments for other clinical conditions delivering this many hours of intervention per week are the center-based approaches that focused on infants at socio-cultural risk for intellectual disability (e.g., Ramey & Campbell, 1984). Given the success of home visit formats for infants with other conditions and given the expense of all-day specialty center-based care for children, the use of a home visitation model with ongoing parent training and support is likely a viable model for infant and toddler ASD intervention. When parents incorporate specific techniques into their ongoing interactions with their children, and when they maintain a high rate of interactions with their children throughout the day, then child social learning is occurring throughout the infant's waking hours.

However, we have little information about the extent to which parents actually infuse their newly learned skills into their ongoing caretaking with their children from any of the infant intervention studies. Furthermore, few of the autism treatment manuals

that could be used for toddlers and parents provide tested methods for examining parent implementation of intervention techniques during dressing, feeding, bathing, and other household routines (although see Prizant, Wetherby, Rubin, Laurent, & Rydell, 2006 and Wetherby & Woods, 2006 for a model for others in this area). Research needs for home-based autism intervention delivered by parents include: (1) developing interventions that are meant to be delivered by parents to infants during caretaking and play activities, (2) development of low-cost methods for measuring parental fidelity of implementation in ways that are acceptable to parents and unobtrusive, and (3) developing measurement approaches for yielding reliable data concerning parental intensity of implementation. Can new technologies that are becoming available, like LENA (LENA Foundation, 2010), assist researchers to examine fidelity and intensity of parent-delivered interventions? Until these methods are worked out, we lack good ways of measuring the independent variable. These issues are crucial for designing efficacious autism intervention for infants in the 6–18-month age range.

Transferring intervention skills from therapists to parents. A third question arises when parents are the sources of intervention. What are the best ways of transferring intervention skills from therapists to parents? Several different models for teaching parents to carry out interventions exist. Some models use didactic parent instruction and training (e.g., Nefdt, Koegel, Singer, & Gerber, 2010); others argue for the importance of a coaching versus a didactic relationship (e.g., Vismara & Rogers, 2008). Some approaches teach parents in groups (Coulter & Gallagher, 2001) and others teach parents individually (Hanft, Rush, & Shelden, 2004). Some rely extensively on therapist modeling (e.g., Chandler, Christie, Newson, & Prevezer, 2002); however, therapist modeling raises concerns about contributing to parents' feelings of inadequacy. There is a whole literature on adult versus child learning styles and on individual differences among adults in learning styles. Just as we need comparative studies of the effects of different intervention approaches on children and families who differ from each other (treatment-by-aptitude interactions), we also need such studies to determine the best ways to help and support parents to provide learning opportunities for their children with appropriate frequency and high fidelity.

However, like parents of infants with other developmental disorders, parents of infants and toddlers with ASD are not community intervention providers; they are parents of an infant or toddler just diagnosed with a serious chronic developmental disorder. They are experiencing a tragic and life-altering event, one with long-term effects on everyone in the family. They need information, support, and services

for their child. How do we support them in this part of their lives, and also pass on intervention skills? Mental health professionals must be part of intervention teams, and research projects that examine parents as therapists need to examine this dimension of parenting of an infant or toddler with ASD, as the intervention studies of other infants have demonstrated. Acceptability of a specific intervention for families, and its ability to provide needed support for the family as a whole, is an important aspect to be measured in infant-toddler intervention studies. Furthermore, no one intervention approach will meet the needs of all families. How to individualize, and what to individualize, for each family, within the structure of a manualized, empirically supported treatment, is a crucial research question, in order to meet the needs of diverse families and children. Whether intervention approaches that provide the most adequate family support also result in families which provide high-quality intervention at home is an empirical question, and it is an important one to study as we design and carry out interventions for infants and toddlers with ASD.

Conclusion

The goal of this paper was to provide researchers with a starting point for designing interventions for infants and toddlers with ASD, as well as to determine whether researchers designing intervention studies for infants and toddlers with ASD are on the right track. While intervention research typically follows a pyramid of designs, beginning with case studies, then moving to single-subject designs, then group designs with treatment as usual, and finally comparative designs (Lord et al., 2006; Smith et al., 2007; Uzgiris, 1973), this approach takes many years, as we clearly see in the general infant intervention literature reviewed above. ASD researchers can shorten the period of treatment development by building from this existing body of work instead of starting anew, by designing comparative studies to manipulate the key elements identified here, as well as others, and by testing specific features, rather than comprehensive interventions, so that efficacious interventions for infants at risk of ASD can be tested and ready for the infants identified by the early detection research that is moving so quickly.

Finally, determining the content of what is taught to parents needs to come from a research agenda. The evidence is mounting that assisting parents to learn to read and respond sensitively to their children's communications is helpful for child communication development, for infants and toddlers with typical development as well as those with clinical conditions, including ASD (Siller & Sigman, 2002, 2008). It may be that there are a few other general interaction skills in addition to responsivity and sensitivity that are crucial 'active ingredients' in

beneficial parent-delivered interventions for infants and toddlers at risk of ASD. If studies can use careful empirical methods to isolate, test, and identify those core parent-child interaction skills that lead to maximal child progress, then we may be able to move quickly to develop, package, and transmit effective ASD curricula to parents.

However, it is quite likely that children with different patterns of development and behavior, and parents with different child-rearing styles, beliefs, and values, will benefit from different approaches. This touches on the need to identify mediators and moderators of outcome, involving both child and family characteristics. Designing studies with sufficient group sizes to allow for such analyses, and designing comparative studies that would allow for such analyses, will move us ahead farther than small controlled studies focused on one intervention and looking only for main effects. Identifying and disseminating effective interventions for infants and ever-younger toddlers with ASD depends on our ability to identify active ingredients and mediators and moderators of treatment effects. However, the infant intervention research already accomplished suggests that the appropriate starting place is at home, with families, focused on the child's developmental needs, sensitive, responsive parent-child interaction styles, and family support. For families who need center-based daycare, studies from other infants suggests that high-quality daycare can support development very well. We also have a few studies of children with autism as young as 2 years thriving in both inclusive day programs modeled on high-quality daycare centers (McGee, Morrier, & Daly, 1999; Stahmer & Ingersoll, 2004), and specialty groups providing intensive autism intervention (Owens, Granader, Humphrey, & Baron-Cohen, 2008). We need to understand the active ingredients and mediators and moderators of outcomes of infants and toddlers with ASD in center-based programs as well as those at home, from culturally diverse families, in order to have a group of effective ASD intervention models that can be fit to the huge variation in characteristics and needs of these children and of their families across the globe.

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Key points

- Early screening efforts are focused on identifying ASD risk in children under age 3 years, but there is a scarcity of empirical investigation into successful intervention characteristics for this population.
- With the aim of extracting successful intervention characteristics for infants and toddlers with developmental delays, the current paper presents a literature search and effect size analysis of early intervention studies for infants and toddlers with a variety of non-autism developmental delays or those at risk for such delays.
- Effect size analyses indicate that there are four key intervention characteristics used repeatedly in successful interventions: (1) parent involvement, (2) individualization, (3) focusing on a broad range of learning targets, and (4) providing early, intense interventions for a long duration.
- These characteristics represent a solid foundation from which researchers and clinicians can build efficacious interventions for infants and toddlers with ASD.

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