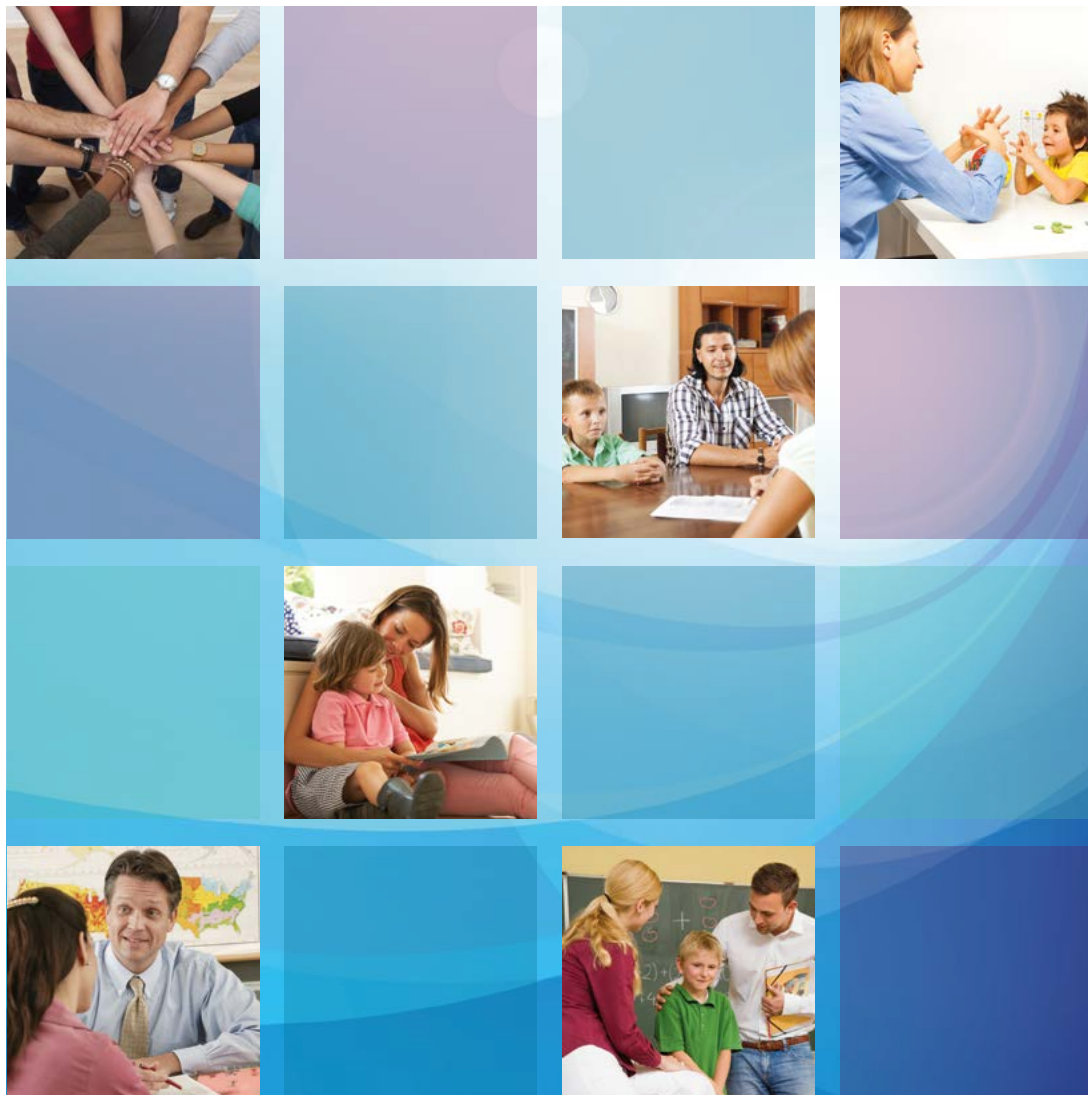




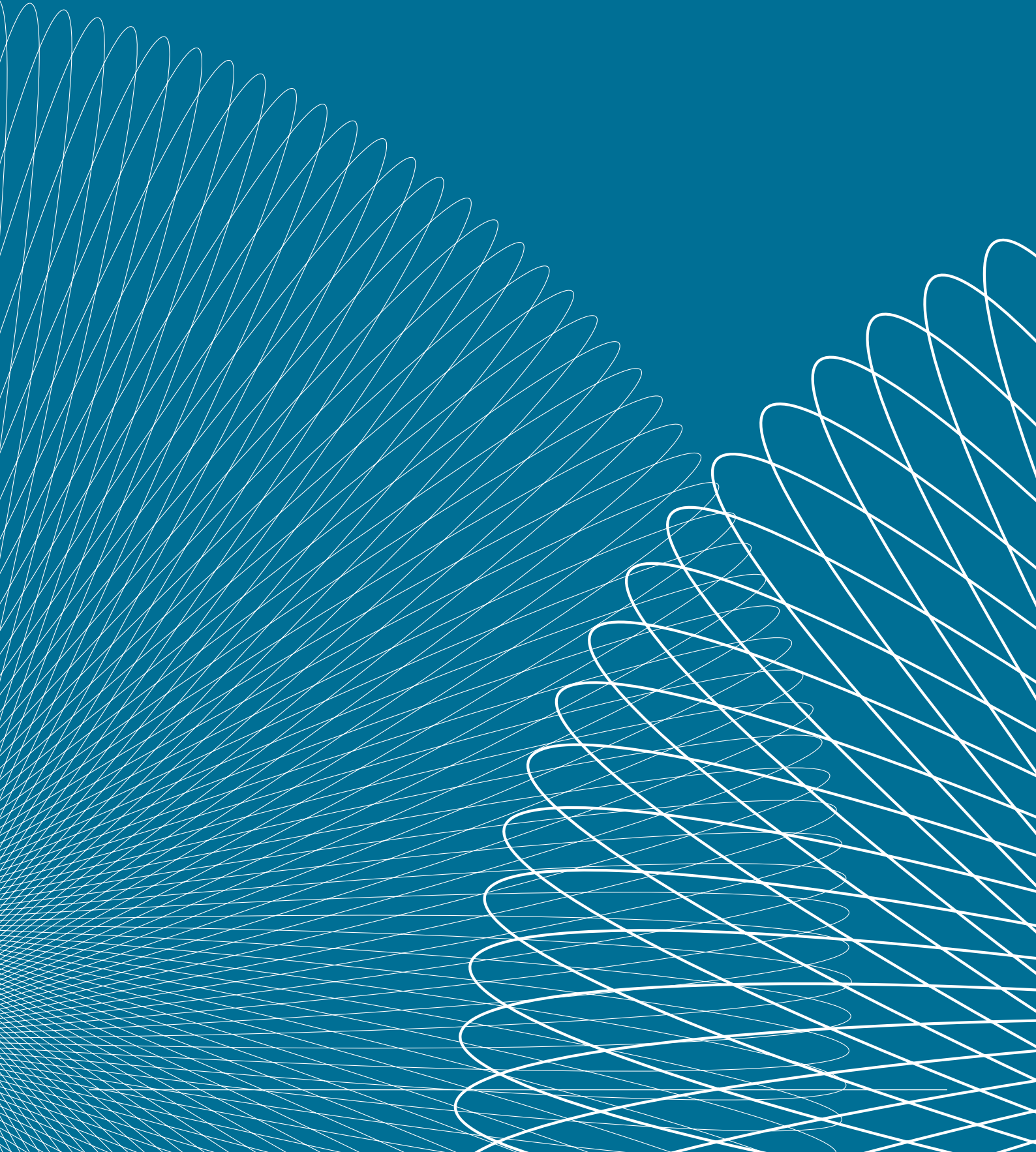
CENTRE FOR AUTISM
MIDDLETOWN

Parent and Professional Partnerships



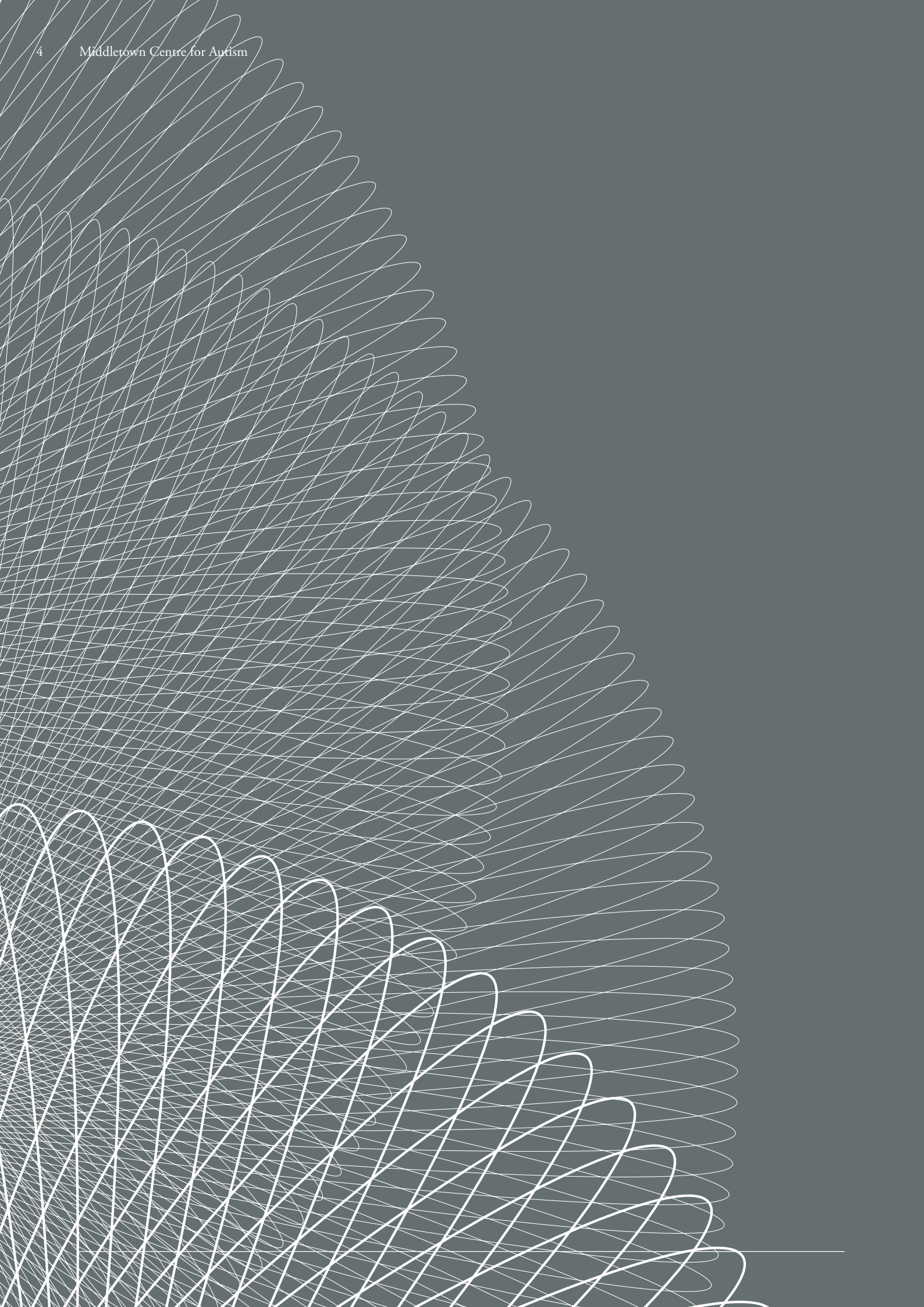
Research Bulletin Issue No. 18

Enhancing the lives of children and young people with autism and their families,
through the delivery of specialist educational services



CONTENTS

Introduction	5
Interview with Dr Wenn Lawson	7
Research Articles Summarised	
1. An Evaluation of School Involvement and Satisfaction of Parents of Children with Autism Spectrum Disorders	10
2. Interdisciplinary Co-Facilitation of Support Groups for Parents of Children with Autism: An Opportunity for Professional Preparation	12
3. Parents' and Professionals' Perceptions of Family-Centered Care for Children with Autism Spectrum Disorder across Service Sectors	15
4. Parents' Perspectives of Collaboration with School Professionals: Barriers and Facilitators to Successful Partnerships in Planning for Students with ASD	18
5. Addressing Parental Concerns at the Initial Diagnosis of an Autism Spectrum Disorder	22
6. Factors Associated with Parental Stress and Satisfaction during the Process of Diagnosis of Children with Autism Spectrum Disorders	24
7. Knowledge is Power: Empowering the Autism Community Through Parent-Professional Training	26
8. Coaching Mothers of Children with Autism: A Qualitative Study for Occupational Therapy Practice	30
9. A Study of Parent-Professional Partnerships Supporting Children with Autism: What do Parents and Professionals value?	32
Conclusion	34



INTRODUCTION

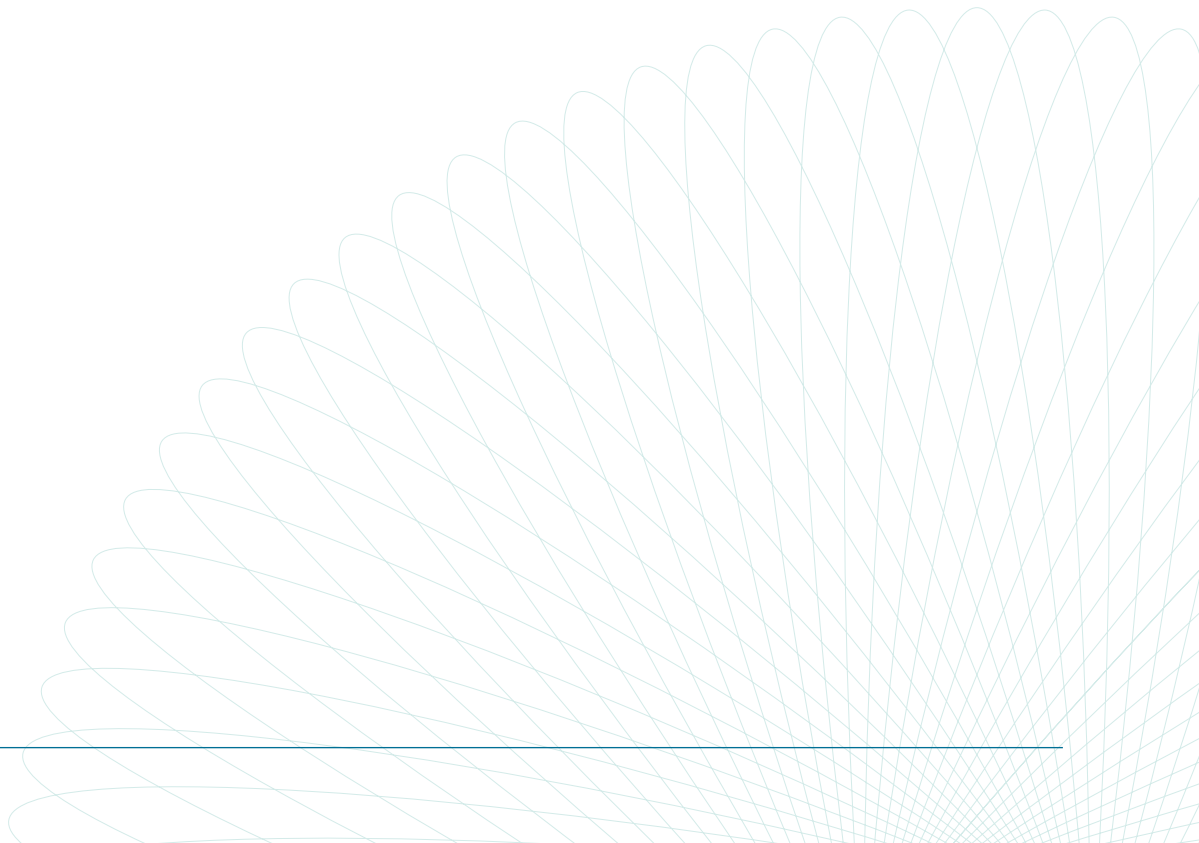
This is the eighteenth Research Bulletin produced by Middletown Centre for Autism. The aim of the Research Bulletin Series is to provide accessible summaries of peer reviewed research for parents and professionals. The current issue provides summaries of nine articles ranging in date from 2011 – 2013.

The Bulletin commences with an interview from Psychologist, lecturer and author Dr Wenn Lawson.

Wenn is passionate about the rights of those who may not speak for themselves. Being autistic and the parent/grand-parent of children on the autism spectrum, Wenn knows the value of family.

Having written numerous papers and books on the topic of autism in a variety of guises e.g., autism and school; autism and sexuality; autism and girls; autism and attention, autism and aging; autism and technology. Wenn says, “There has never been a better time to be autistic; today’s technology is helping us connect to the world we all share.”

Please note that the views represented in this document do not necessarily reflect the views of Middletown Centre for Autism. Reviewers have, where possible, used the original language of the article, which may differ from UK and Ireland usage and the usage of a range of terminologies for autism.





INTERVIEW WITH DR WENN LAWSON

1. How can professionals engage in better collaborative work with parents of children with autism?

Professionals need to skill themselves up on understanding Autism Spectrum (AS) individuals and make the time to get to know their clients individually. They also need to value the voice of parents and AS individuals. This means they need to listen, hear and take notice of what parents and individuals are telling them. This is one way to take on board the concerns of families and then begin to look at how they can help. For guidelines on collaboration and co-production visit: <http://www.autismcrc.com.au/> and download the pdf on file. If talking and communication are difficult find an alternative that enables you to join the interest of the AS individual. Map out ideas on Butcher's paper and "brain storm" to problem solve. Role play, story and video are all useful mediums to collaborate with parents in mutual learning activities that are accessible and constructive.

2. What can parents do to promote collaborative working with professionals?

Parents can gather evidence based materials on what works in AS and use these to back their requests for appropriate support for their children. If professionals aren't forthcoming and the parent feels frustrated they might like to use an advocate or mediator to help build a collaborative relationship. All collaboration should be guided by mutual respect and value equal input by all parties.

3. Where can things go wrong with parental and professional relationships?

Parental and professional relationships can break down when each fails to "listen" to the other. At times some professionals may think they "know best" and not consider the parents' views. Families

work very hard to "keep their heads above water" and sometimes professionals lack the consideration of this point and can be glib and callous in their communication. Sometimes professionals can hint that parents should be doing more; or that they are over dramatising their child's problems, or somehow imply the parents are responsible for the child's inappropriate behaviour. Whilst, at other times, parents may expect too much from the professionals and become disillusioned. Good communication depends upon hearing one another and providing the right feedback.

4. Are there any particular strategies that agencies can use in order to promote a culture of parental partnerships?

I think agencies need to welcome parental participation and actively encourage their shared input into their child's welfare. This might be through news-letters, support group meetings, personal invitation and so on. Parents and other family members are a valued resource and need to be treated as such.

5. What can adults with autism do to promote collaborative relationships with professionals?

Autistic adults can take a number of steps towards promoting collaborative relationships with professionals. Firstly, by sharing their own story and inviting professionals to engage with them. Secondly, for some, it's appropriate to study and learn the "language" that professionals use so there can be a mutual conversation. Social media can be a useful way to post information, as well as individuals "joining" with professionals in co-production. Nothing about us without us!

6. Have you any tips on how to improve teacher education to ensure that teachers understand the complexities of the home environment?

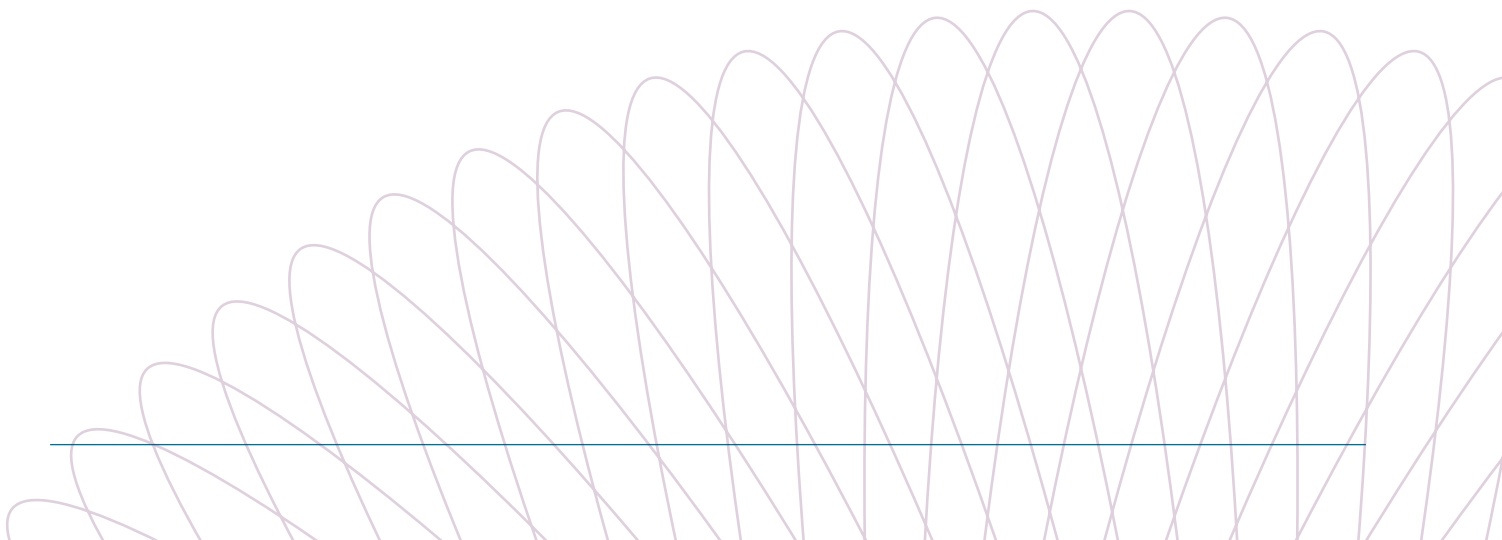
I think it should be mandatory in teacher training that inclusive education practices are taught to student teachers. Courses should also be offered as on-going professional development. Children come to school from a variety of home environments and families where autism is resident, have more than double the demand of that experienced in typical homes. Autism will mean single focused interests, sensory dysphoria (for some), possible motor coordination issues, epilepsy and other co-morbidities (such as ADHD, learning difficulties and possible eating/digestive issues). Teachers need to appreciate that families are living with these types of pressures and autistic children are often very tired, socially exhausted and easily worn out through social and cognitive demand. It's imperative that teachers listen to families, don't judge them and maintain good communication across the board. There are many "teacher toolkits" both on and off-line. Schools have a responsibility to offer autism education to all their staff. But, even if they don't there is plenty of information and useful resources teachers can avail themselves of.

7. Could working as a paraprofessional as part of teacher training help improve the home/school relationship?

Potentially, working as a paraprofessional, as part of teacher training, could improve the home/school relationship. It's potentially easier to relate to individuals who are skilled enough to understand but not so far removed from ordinary folk that families don't feel comfortable to share themselves and their issues with. In other words, it might be less threatening. Paraprofessionals can be highly skilled and bridge the gap in the communication chain, as long as they are appropriately trained and understand autism, school demands and family dynamics.

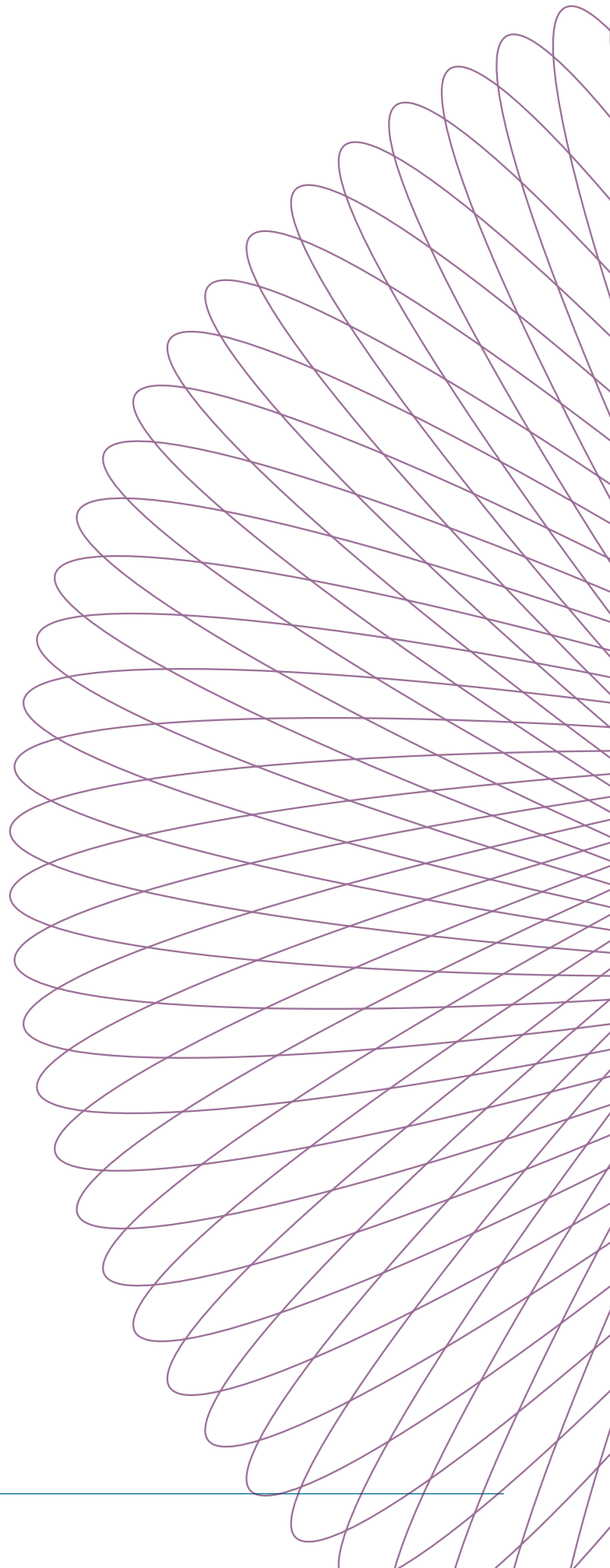
8. In practice, can an "open-door" policy be effectively managed? Are there drawbacks to this concept?

Having an "open-door" policy which means parents are always welcome at school sends a clear message that they are valued. If the school has a policy of mutual respect and appropriate ground rules I believe this "open-door" policy can be very effective. However, there is potential, if not managed right, for autistic children to find it difficult to separate home life from school life and for some to experience some confusion rather than clarity. This implies that appropriate management means training and interventions that build concepts for the children, so they can accept Mum's presence at school without trauma or confusion. This requires expertise, funding and time.



9. How can we encourage male teachers to have a greater involvement with young boys and teenagers with autism to help them understand differing social expectations?

Boys need male role models, especially as they near puberty and adolescence. Female teachers cannot teach “male toilets” etiquette, for example. Male socialisation requires the presence and direct intervention from other males. Dad knows his role only too well. But, Dad might not be at school where boys spend most of their day. Valuing male teachers for their skills as teachers is one thing but, when it comes to boys and understanding differing social expectations, then it’s the male teachers who truly know the best way to impart social information to other males. I would hope that as this is explained male teachers will appreciate the importance of such a role and gladly take it up. I don’t know of any research that has explored phenomena of this nature, but, it would be useful to have evidence based data to support this idea. However, we certainly have anecdotal support for this concept. If male teachers read auto-biographies of older male autistic adults who tell us of their growing up experiences, it might encourage them to take on the challenge of assisting autistic boys to develop appropriate social understanding and learn to practice this in their daily lives. It might also help to listen to “the lived experience” of autistic males.



AN EVALUATION OF SCHOOL INVOLVEMENT AND SATISFACTION OF PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDERS

RESEARCH AIMS

In the United States, the amendment of the Individuals with Disabilities Act in 1997 meant that parents, for the first time, were entitled to the equivalent input as professionals, in the educational process of their children with disabilities. In spite of such legislation, minimal research exists on the relationships developed between parents of children with Autism Spectrum Disorder (ASD) and the associated professionals, while interacting in the educational process. In addition, there has been very little investigation into whether parental involvement level, in a child's educational process, impacts upon parents' satisfaction with the school in question. This study aimed to fulfil these important gaps in the ASD literature.

RESEARCH METHOD

The sample for the present study was derived from the Parent and Family Involvement in Education Survey. This survey was distributed to 10,681 families, in Colombia District, who had children ranging from kindergarten to twelfth grade. The present study required children to be in public school attendance, hence the final sample consisted of 8,978 families. Within this sample, 142 children had a diagnosis placing them on the Autism Spectrum.

The measures utilised are outlined below, beneath the category headings 'Dependent School Variables' and 'Child-level Predictors'.

1. Dependent School Variables

- Parental school involvement was determined by the survey questions relating to how often parents had engaged with school events in the past school year.
- Parental school satisfaction was measured using a four point Likert scale where parents rated their satisfaction from 'very dissatisfied' to 'very satisfied'.
- Parental perception of school communication incorporated a four point Likert scale ranging from 'very well' to 'doesn't do it at all'.
- Parental homework involvement was measured by four questions addressing parents' daily level of involvement in their child's homework.
- Parental satisfaction with IEP (Individualised Education Program) was assessed via a four point Likert scale ranging from 'very dissatisfied' to 'very satisfied'.

2. Child-level Predictors

- ASD diagnosis was determined by a question asking parents whether a health professional had told them that their child has pervasive developmental disorder or autism.
- Other disability was based on whether parents had been told that their child had any comorbid disabilities.
- Demographics were ascertained by questions requesting the child's age, gender and ethnicity.

RESEARCH FINDINGS

A series of regression analyses led to the following findings. Parents of children with ASD were more likely to attend parent-teacher meetings than parents of typically developing children or parents of children with other disabilities. In addition, parents of those with ASD were more likely to approach the school guidance counsellor and to support their children with homework completion. Despite this high level of contact with the school, parents of those with ASD were less satisfied with school communication. It is noteworthy that as the number of comorbidities experienced alongside ASD increased, parental involvement with the school decreased. This is of particular importance as around 86% of the sampled children with ASD had at least one comorbidity.

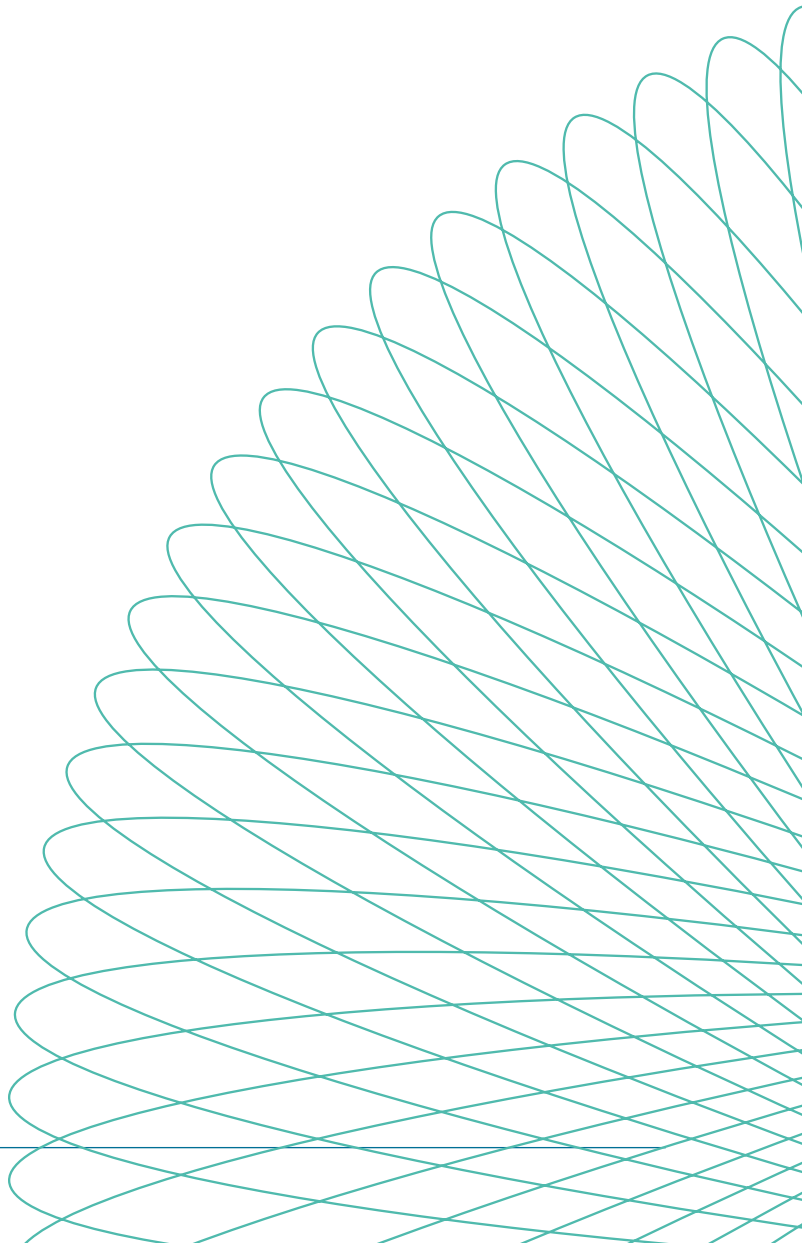
IMPLICATIONS FOR PRACTICE

(by the authors)

- Research has shown that students have better outcomes when parents are engaged with the school. As a result, schools should be proactively sourcing ways to get parents involved, with a particular focus on the engagement of parents who have children with complex disabilities, such as ASD.
- Schools should receive training that will, firstly, allow them to assess the importance of parental engagement on student outcomes within their particular institution. Secondly, training would allow schools the opportunity to collate ideas so that parents are highly motivated to become engaged with the school.
- Schools should develop collaborative partnerships with external ASD support services; this would result in the school having a greater capacity to support children with ASD. Moreover, the school will have an in-depth knowledge of the services available, and thus will be able to link parents to such services. This should improve parent satisfaction with the school and thereby increase the outcomes for children with ASD.
- The authors recommend future research in this area should look at multiple points in time or use a longitudinal approach, to determine when communication with the school has the most critical impact on the learning outcomes of children with ASD.

Full Reference

Zablotsky, B., Boswell, K. and Smith, C. (2012). An Evaluation of School Involvement and Satisfaction of Parents of Children with Autism Spectrum Disorders. *American Journal on Intellectual and Developmental Disabilities*, 117(4), p. 316-330.



INTERDISCIPLINARY CO-FACILITATION OF SUPPORT GROUPS FOR PARENTS OF CHILDREN WITH AUTISM: AN OPPORTUNITY FOR PROFESSIONAL PREPARATION

BACKGROUND

Support groups for parents of newly diagnosed persons with Autism Spectrum Disorder (ASD) are key in assisting the transition into post diagnosis. Parents not only require an outlet to divulge information regarding their child's difficulties, but also a place where they can feel empowered and can help others feel the same way through the sharing of experiences. In addition, support groups also help professionals to establish clearer ideas of the needs of each individual, whilst at the same time upskilling their knowledge of ASD.

RESEARCH AIM

Parents experience a roller-coaster of emotions when they receive a diagnosis of ASD for their child. The research goal was to investigate the benefits of an interdisciplinary co-facilitation model to support parents of children with ASD.

RESEARCH METHOD

The authors introduced two support groups of parents of newly diagnosed children with ASD which were facilitated by different professional disciplines, a Social Worker and an Early Childhood Special Educator. Research took place in the north-eastern United States.

The framework that was used was a six week programme which supported the realisation that parents, due to external reasons, may not be able to commit to longer or more regular meetings. In order for parents to successfully partake in the groups, the authors understood the importance of ensuring that the groups were accessible for all, through location and free participation.

The focus of implementing the support groups followed these key aspects:

1. Pre group planning which took place to ensure that the groups facilitated the needs of the parents and established what role each professional played. The co-facilitators each brought their own expertise which moulded well for the delivery of the support group.
2. Pre session planning was conducted with the facilitators and supervisors. During this time they discussed any last minute changes, established the agenda and agreed responsibilities.
3. Post session debriefing happened after each support group session. During this time the co-facilitators discussed what went well and what did not go so well during the group sessions. It also provided an opportunity for the co-facilitators to discuss how working as part of a team was going and to also pre plan for the next session.
4. Post group debriefing occurred at the end of each week. During this time progress was discussed and any key issues that arose were addressed by the corresponding professional.

In the initial sessions families were given a copy of the First 100 Days Kit and were supported in developing skills, strategies and techniques in relation to ASD. In addition, they were provided with the opportunity to write a social story. In session four parents familiarised themselves with the IEP process and discussed advocacy skills. In session five parents were introduced to other parents and agencies who were more experienced in the post diagnosis process. Finally in session six parents placed themselves where they believed they were after receiving the diagnosis and there was a discussion about future planning.

Data was accumulated from the audio tapes of the twelve post session discussions and the audio tapes of the focus group. These were read independently by the authors and then compared to ensure information which was collated was relevant to the findings.

RESEARCH FINDINGS

Research showed that parents developed their advocacy skills whilst the co-facilitators progressed professionally in developing their skills. Whilst each co-facilitator was bringing their own style to the support groups, they soon began to learn from each other. The Early Childhood Special Educator thrived on pre planning whereas the Social Worker understood the importance of allowing the group to progress on its own and building on what was spontaneously addressed during the sessions. Both facilitators came to the conclusion, that no matter how much pre planning for the sessions took place, parents were still the leaders of the groups.

It was soon clear that the six session model helped parents to acquire the skills to progress their child's development. However, during session five parents seemed more apprehensive in their conversations. Yet, the co-facilitators were able to use their prior knowledge of questions, which were once posed by the parents, to assist them in communicating with the more experienced ASD parents and agencies.

Communication was key in establishing the support groups. Not only did it help with the planning process, through debriefing, but it also helped to establish trusting relationships amongst the co-facilitators. Therefore, it was ensured that the needs of the parents were at the forefront of the support groups.

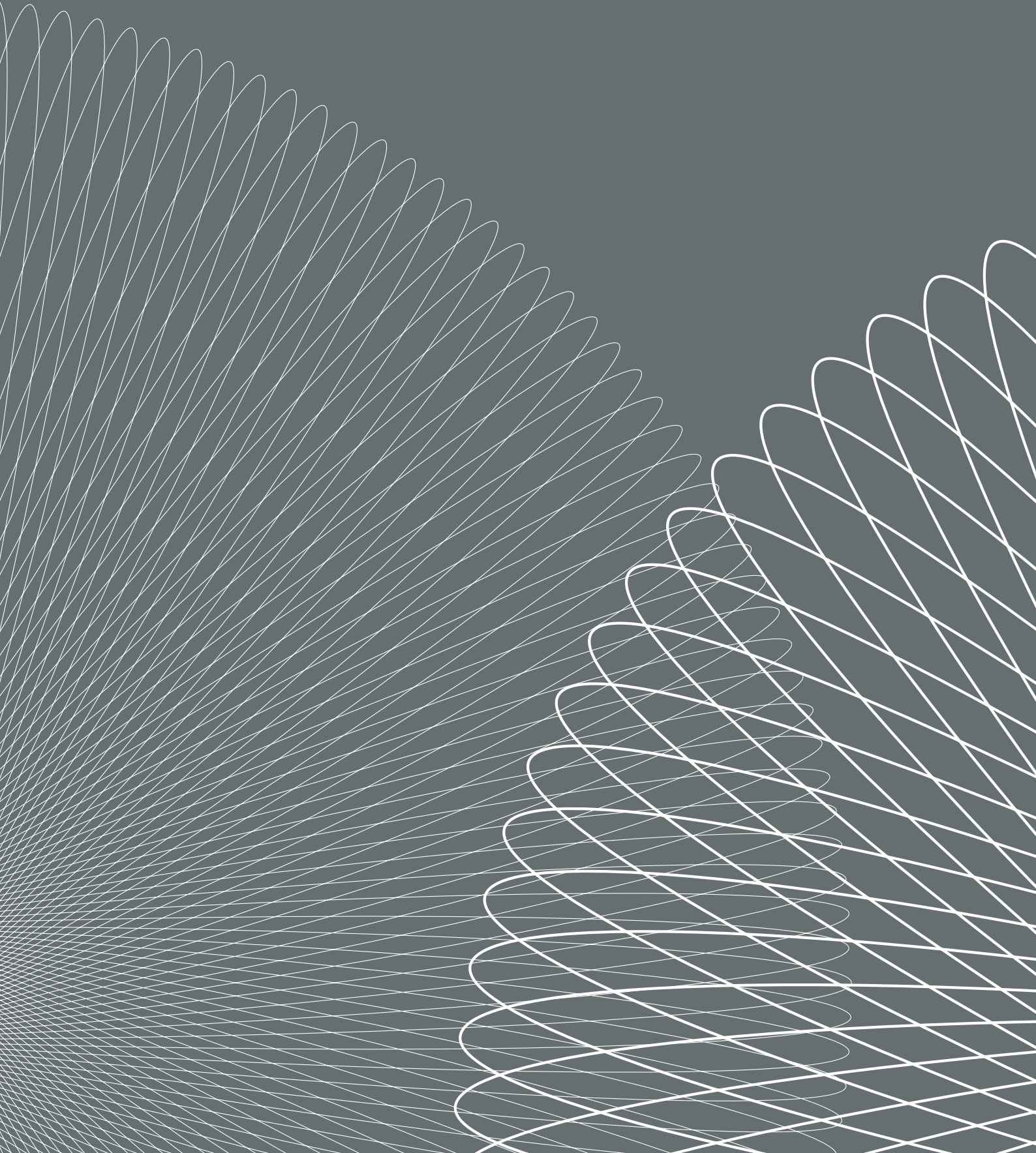
IMPLICATIONS FOR PRACTICE

(by the authors)

- Social Workers and Early Childhood Special Educators are a good combination for co-facilitating parent support groups. However, additional research needs to take place regarding the success of other professionals co-facilitating support groups.
- Following a structured model for implementing a parent support group aids the success of the group. Parents feel more empowered from the information they receive.
- Evaluating support groups after each session lends itself to pre planning for future sessions but also allows each co-facilitator the chance to implement their own professional knowledge, based on any uncertainty addressed by parents during the sessions.
- Although both co-facilitators were complementary of each other's performance and supporting role, the results may have been impaired due to not wanting to offend the other person. Further research would need to be completed to understand if this would have an impact on the findings.
- The study reflects the success of implementing a co-facilitated support group for parents of children recently diagnosed with ASD, however a further study would need to be developed to establish the effectiveness of co-facilitated support groups for parents at different stages of their child's ASD development.

Full Reference

Banach, M. and Couse, L. J. (2012). Interdisciplinary Co-Facilitation of Support Groups for Parents of Children with Autism: An Opportunity for Professional Preparation. *Social Work with Groups*, 35, p. 313 – 329.



PARENTS' AND PROFESSIONALS' PERCEPTIONS OF FAMILY-CENTERED CARE FOR CHILDREN WITH AUTISM SPECTRUM DISORDER ACROSS SERVICE SECTORS

BACKGROUND

Due to the complexity and volume of difficulties and differences associated with autism, the changing needs and priorities of the individual and the family, the need for resources, supports and services for those with autism and their families does not simply stop with impending adulthood; these services are needed throughout the individual's life. In Alberta, Canada, family-centred care (FCC) means that parents and service providers work in partnership, where the family is recognised as the constant in the child's life and thus best suited to determine needs. FCC has been linked with improved parent and child outcomes, yet its implementation can be challenging due to family, professional, organisational and systemic factors and policies.

RESEARCH AIMS

This research aims to ascertain the effectiveness of the FCC, by:

1. Evaluating perspectives of families of children with autism in receiving FCC across service sectors.
2. Evaluating perspectives of professionals across sectors in providing FCC to families of children with autism.
3. Comparing parent versus professional perceptions of FCC for children with autism.

RESEARCH METHOD

The researchers recruited 152 parents with children up to the age of 18 years, with 86 completing surveys through random sampling and 66 from snowball sampling. Of this 152, 98 parents agreed to be interviewed and 19 were selected. The data was collected using the 20-item Measure of Processes of Care (MPOC-20), and parents used a 7-point scale to rate "to what extent do the people who work with your child" demonstrate various family-centred behaviours

"in the past year". Five domain scores were calculated, including: (1) enabling and partnership, (2) providing general information, (3) providing specific information, (4) coordinated and comprehensive care, and (5) respectful and supportive care.

In respect of the professionals, 146 were recruited from a variety of disciplines; occupational, physical, speech and language, behaviour therapies, teachers, social workers, medics and aides. These professionals used the Measure of Processes of Care for Service Providers (MPOC-SP). Service providers used the same 7-point scale as the MPOC-20 to rate "the extent to which" they demonstrated various family-centred behaviours "in the past year". Four domain scores were calculated: (1) showing interpersonal sensitivity, (2) providing general information, (3) communicating specific information, and (4) treating people respectfully.

RESEARCH FINDINGS

Families with preschool-aged children perceived that they received higher levels of FCC than families of older children, yet professionals working in all of the sectors reported providing equivalent levels of FCC.

Parents and professionals both recounted similar areas of FCC strength and weakness, with respectful care, understanding the constraints on and respecting the issues being faced by each other, having the highest rating and the provision of information the lowest, with accessing the relevant information quickly being difficult. However, there were significant differences in parents' and professionals' ratings of the degree to which services were family-centred. Parents reported receiving levels of respectful care that exceeded professionals' self-ratings on this domain, thus professionals are making an impact, when sometimes they do not feel that they are.

Parents reported receiving less general information than professionals' perceived providing. At times, information can be overwhelming whilst in times of stress the information may not have felt as immediate as needed.

There was no significant difference in perceptions for specific information between parents and professionals.

Most parents reported positive experiences with FCC related to professionals who were directly working with their child, especially related to targeting goals that were meaningful to the family and being treated as a valued team member.

Parents generally felt that access to services diminished as their child with autism got older, yet reported that the care system was not easily navigated at any stage.

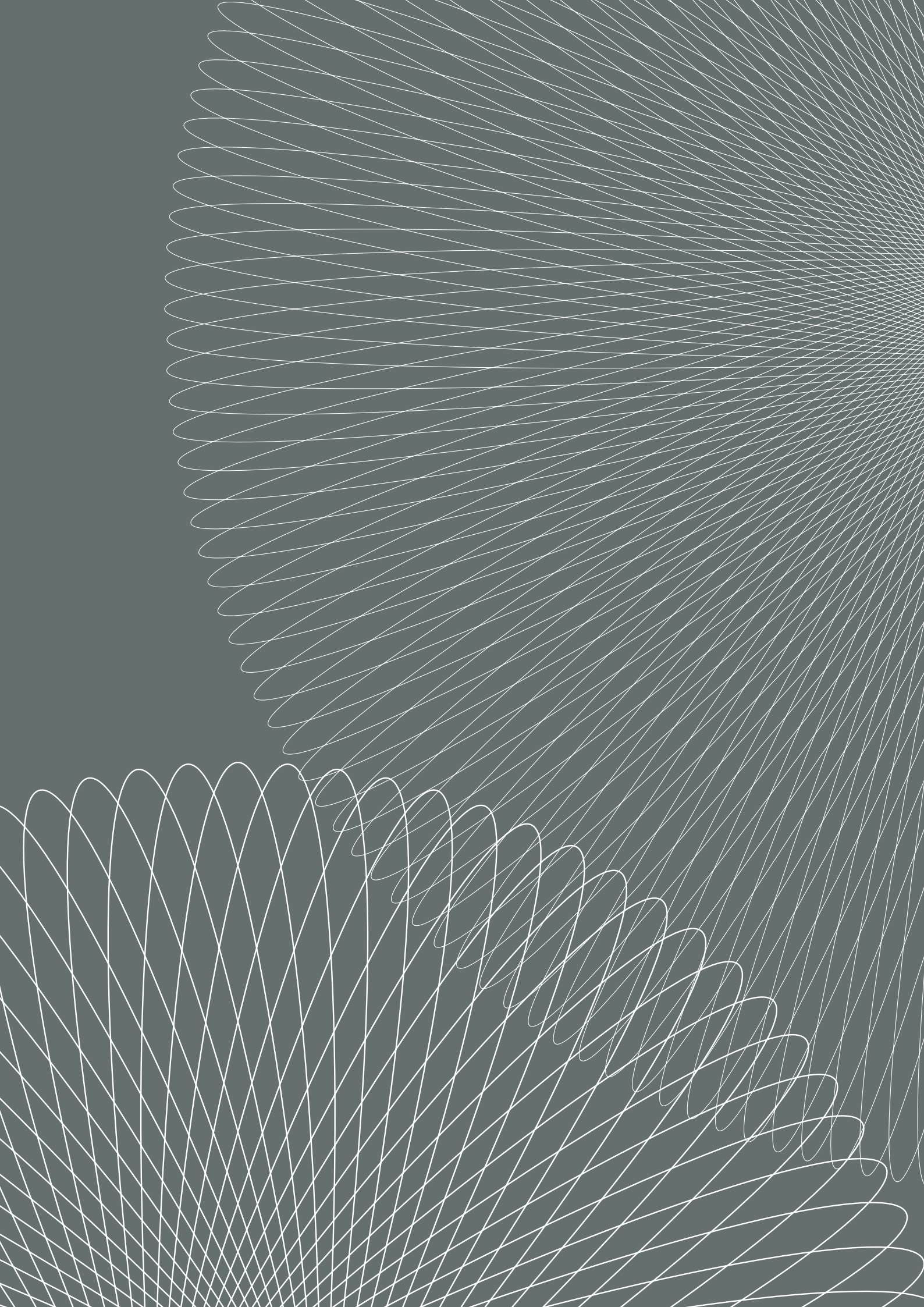
IMPLICATIONS FOR PRACTICE

(by the authors and reviewer)

- To ensure success for families as their child moves to adulthood, the integrated family care approach, encompassing education, health and other services, must begin when the child is young, yet provision must be made for the changing circumstances as the child develops. Parents see their role as supporting not replacing the multidisciplinary team.
- Parents do not feel that they need to be fully included in goal setting where they would have no input. Some goals are school based and thus the parents do not always feel that they need to be informed of each step – simply, that the goal was set, the strategies implemented and once evaluated whether the child had been successful.
- Continuity of care/education must be addressed: parents felt it was beneficial to them and to their children when they knew whom to ask for support and what to ask.
- Parents feel that as their child grows, the issues and areas where support is needed change yet they need the same level of support, not less. Parents feel that they continue to learn about autism and thus need continual training to ensure successful maturation for their child.
- Any system must be transparent for ease of access for all involved and interested. A single point of contact may make things easier for the parents even if the issue is in respect to a different discipline.
- For parents from rural areas or those who are new to the FCC or care/education provision, extra support may need to be in place to ensure the needs of the parents and ultimately the children are recognised and facilitated.
- Understanding and mutual respect for the differing roles, parents and professionals, allowed for greater development for the child with autism.
- Parents note the remarkable nature of the support they receive from the professionals, the team approach is beneficial.
- Heavy caseloads, diversity and complexity of needs of families and children with autism can make the development of the Home/Sector partnership difficult and at times, prohibitive.
- Professionals can only deal with the issues within their realm of expertise and sometimes family expectations are unrealistic.
- Continual professional development in all areas is essential particularly with the complexity and variability of autism. Professionals need to be supported so that they can in turn support parents.

Full Reference

Hodgetts, S., Nicholas, D., Zwaigenbaum, L. and McConnell, D. (2013). Parents' and Professionals' Perceptions of Family-Centered Care for Children with Autism Spectrum Disorder across Service Sectors. *Social Science and Medicine*, 96, p. 138-146.



PARENTS' PERSPECTIVES OF COLLABORATION WITH SCHOOL PROFESSIONALS: BARRIERS AND FACILITATORS TO SUCCESSFUL PARTNERSHIPS IN PLANNING FOR STUDENTS WITH ASD

RESEARCH AIMS

The aim was to examine results from an international based survey regarding perceptions of collaboration and conflict between parents of children with autism and school professionals. The following two questions were addressed:

1. What do parents of children with ASD identify as issues related to collaboration and conflict in the Individualised Education Program (IEP) process?
2. What factors facilitate parents' satisfaction with the educational planning process involving special needs students?

RESEARCH METHOD

An online survey was utilised so that a larger population could be sampled, which would include those geographically dispersed. Five sections in the survey included (a) collaboration, (b) supportive practices and professional behaviour, (c) conflict and resolution, (d) service needs, and (e) educational and outcome priorities. There were 36 questions in total and time for completion took approximately 30 minutes.

135 parents (defined as legal parent, grandparent as primary caregiver, stepparent or foster parent of a child with autism between the ages of 3-25) completed the survey, with a higher percentage of female respondents (95%).

RESEARCH FINDINGS

Data provided insight into parents' perceptions of collaboration with their children's school professionals, as well as sources of potential conflict.

Collaboration

A key component of creating successful collaboration is ensuring involvement by all members in the educational process. Respondents were asked about their level of involvement in the IEP process. This was rated as "High" (71%), "Moderate" (23%), "Very little" (3%), and "None" (3%).

Respondents were also asked to identify the top three ways they were included by the school team in the IEP process. The top three methods as reported by parents included that school teams acted to involve them by "Asking for my input into the IEP draft" (60%), "Providing regular communication about my child's progress" (46%), and "Planning and writing goals and objectives with me" (30%). Separately, respondents rated the methods of collaboration by the IEP team. These included "Maintain regular contact with me" (34%), "Include my suggestions for goals and objectives for the IEP" (31%), and "Include my suggestions for curriculum or instructional approaches" (13%).

Communication with school teams was identified by parents during the survey development process as a priority area for data collection. Data indicated that parents overwhelmingly rated frequent communication as "Very important" (91%), while a small group endorsed "Somewhat important" (19%). The desired frequency of communication with school staff was identified as "As needed" (33%), "Weekly" (20%), and "Several days per week" (16%).

Professional Practices and Behaviours

Respondents were asked about their perceptions of school professionals within the context of their experiences within the IEP process. These questions dealt with what school professionals do, or their actions, as well as parents' perceptions of their level of knowledge and confidence in their ability to lead their child's school team. Parents were probed regarding their perceptions of helpful school professional actions. "Attends IEP and other meetings" was rated most frequently (51%) followed by "Quick response to phone calls and emails" (42%) and "Assists the staff in my child's program to access resources and training" (39%).

Parents indicated that they highly valued certain professional qualities or behaviours such as "Open and honest with me and others" (41%), "Provides leadership to handle problems in my child's program" (41%), and "Takes my suggestions into account regarding my child's IEP" (40%).

Respondents were asked to indicate their perceptions regarding the level of knowledge of staff about their child's disability. Ratings varied from "Very high" to "None" on a 4-point Likert scale. The most frequently endorsed perception of knowledge was "Somewhat" (31%), followed by "Very high" (24%), "Not very" (22%), and "High" (21%). This survey probed parents' reported level of confidence in their leaders, specifically in the school professional's ability to handle problems. The most frequently endorsed area was "Not Confident" (29%) followed by "Somewhat confident" (26%) and "Confident" (24%).

Service Needs

Parents in this survey indicated professional behaviours and actions that assisted with collaboration. Parents' responses indicated their desire for more capacity in teaching skills in both communication and social skills. A large number endorsed "Teaching social skills" (62%), followed by "Creating inclusive opportunities for my child" (43%) and "Teaching communication skills" (42%). A related question asked respondents to identify service areas they felt would be helpful for themselves and their families. The most commonly chosen response was "Training for staff on my child's disability" (52%) followed by "More staff to support the program" (42%) and "More services (e.g. speech, occupational therapy)" (40%).

Conflict

When asked specifically about whether they had experienced conflict with school teams, parents overwhelmingly reported "Yes" (83%) compared to "No" (17%). Parents identified "Disagreement over IEP content (services, goals and objectives)" as the top area of conflict (66%) followed by "Disagreement over placement decisions" (56%) and "Disagreement over curriculum or instructional approach" (52%).

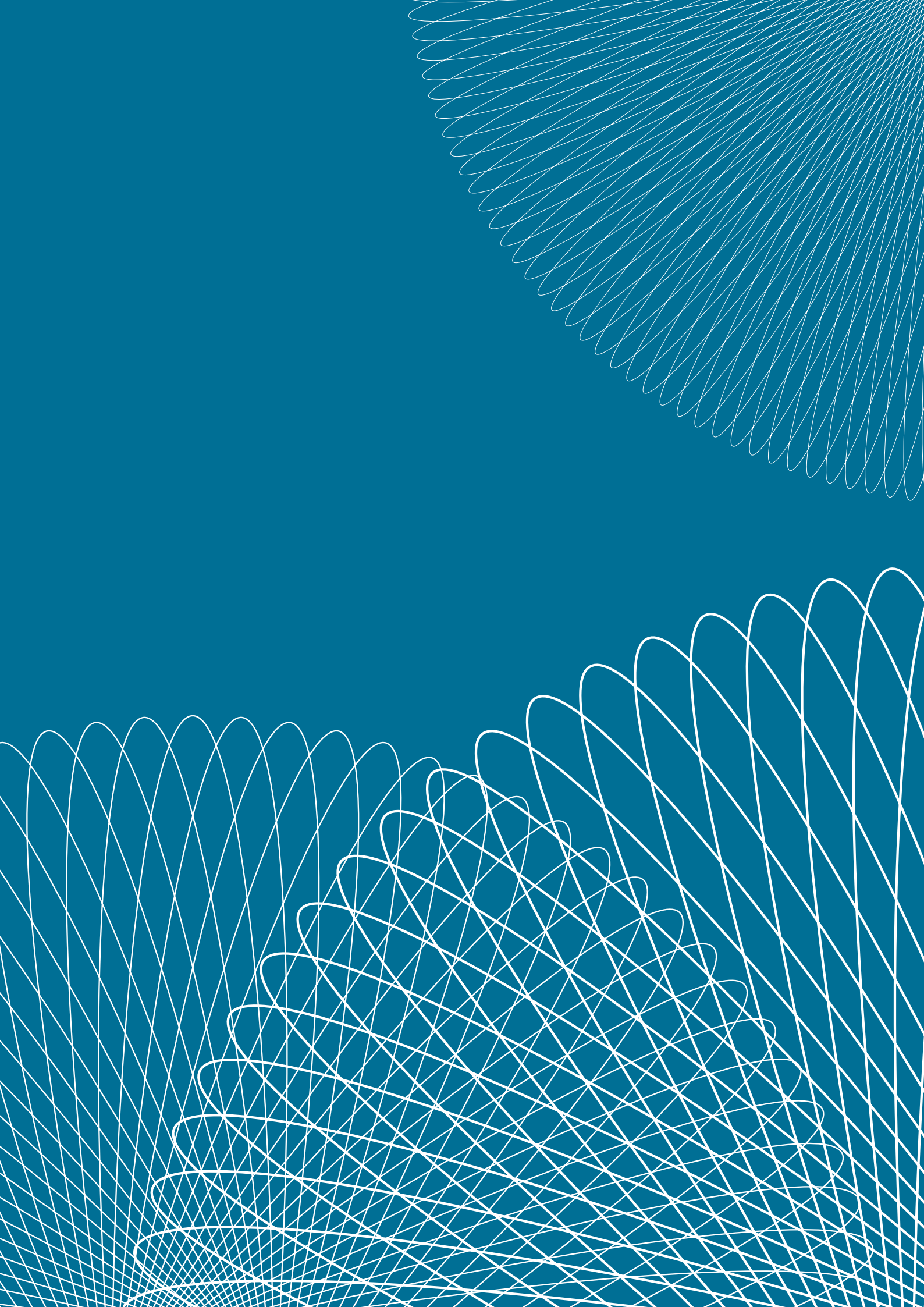
IMPLICATIONS FOR PRACTICE

(by the authors)

- Parents provided information focused on the type and frequency of communication, accessing information to be better prepared, and having their input valued as a member of the IEP team. Parental input in the IEP process appears to be a critical component in creating a collaborative partnership.
- When conflict arose, one reported reason was the lack of parents' perceived ability to give input and participate fully. When parents push to include their input during times of conflict, they may find themselves even farther on the periphery of their child's team. The education field must still make changes to the way it trains teams for collaboration.
- A logical approach to address these issues is to build awareness of the importance and overall benefit of working with families in an ongoing and collaborative manner. Starting at the pre-service level for teachers, related service providers and administrators is recommended.
- Teams should recognise that certain practices denigrate parents' abilities to be a fully informed member of the IEP team. When parents are presented with paperwork they have never seen and are not given time to review, it places the parent in a position of automatically being underprepared and undervalued.
- If teams find themselves in conflict or on a path to disagreement, parents' preferences need to be considered when planning a resolution. Parents identified meeting in person, bringing an advocate, and talking over the phone as viable strategies to resolve disputed issues.

Full Reference

Tucker, V. and Schwartz, I. (2013). Parents' Perspectives of Collaboration with School Professionals: Barriers and Facilitators to Successful Partnerships in Planning for Students with ASD. *School Mental Health*, 5(3), p. 3-14.



ADDRESSING PARENTAL CONCERNS AT THE INITIAL DIAGNOSIS OF AN AUTISM SPECTRUM DISORDER

BACKGROUND

This study was aimed at considering the presentation of the core issues associated with autism and how parents deal with these at the time of diagnosis. In addition, there was a focus on the possibility of additional developmental delays, intellectual disabilities, medical issues and co-morbid disorders and how each child's parents individually cope with the diagnostic process.

RESEARCH AIMS

The object of the study was to assess what issues and problems were of foremost importance to parents at the time of their child's autism diagnosis, and to determine how well they felt these concerns were addressed during the diagnostic process.

RESEARCH METHOD

A sample of four hundred and thirty eight parents of children, with a confirmed diagnosis, completed a web-based survey. This was developed and distributed to members of the Autism Registry in North Carolina, a database that lists individuals with Autism Spectrum Disorder (ASD) who have consented to be notified about research studies.

The study and all other information were provided to participants through the Autism Registry, with no identifiable information available to the researcher. All survey data were entered and maintained via SurveyMonkey.com, Portland. Electronic consent was obtained via an informed consent document under approval of the University of North Carolina, Institutional Review Board.

RESEARCH FINDINGS

The results of the parental survey showed that at the time of diagnosis, the majority of parents were most concerned about those areas that would be considered as their child's "core symptoms" of ASD, to include:

- Language delay.
- Poor social skills.
- Unwanted pattern of behaviours.

The following were reported to be of lesser concern at the stage of diagnosis:

- Sleep problems.
- Gastrointestinal symptoms.
- Poor eating habits.

When the "core features" were the main concern, only half of the respondents felt that these were addressed well.

When the main concerns were factors other than the "core features", only one third of parents felt their concerns were well addressed, with 40% stating that they didn't feel their concerns were addressed at all, suggesting that as many as half of parents are leaving the diagnostic process with concerns about their child's "core issues".

Secondary concerns that parents felt needed to be addressed were follow up services and subsequent treatment options for children following autism diagnosis, educational placements, expectations for their children's future and support networks in the community setting for the family as a whole. The need to discuss either the "core features" and / or secondary concerns appeared to be determined by gender and age of diagnosis. Parents of boys were more concerned with social communication skills than parents of girls. The older the child received a diagnosis, the more concerned parents tended to be about sleep, behavioural issues and verbal communication.

Parents, who appeared unsurprised by their child's diagnosis, were more concerned with the cause of their child's autism and the risk of a sibling having autism. Parents who were more "surprised" by the diagnosis tended to be increasingly concerned about appropriate educational placements for their child.

There were no reported differences on who made the diagnosis (psychologist, physician, other) and the information received.

In conclusion, based on the survey findings, it would appear that clinicians and professionals who are involved in the diagnostic process with children and their families, should focus primarily on addressing a child's core "ASD" symptoms and the appropriate therapeutic interventions to address these and their educational needs.

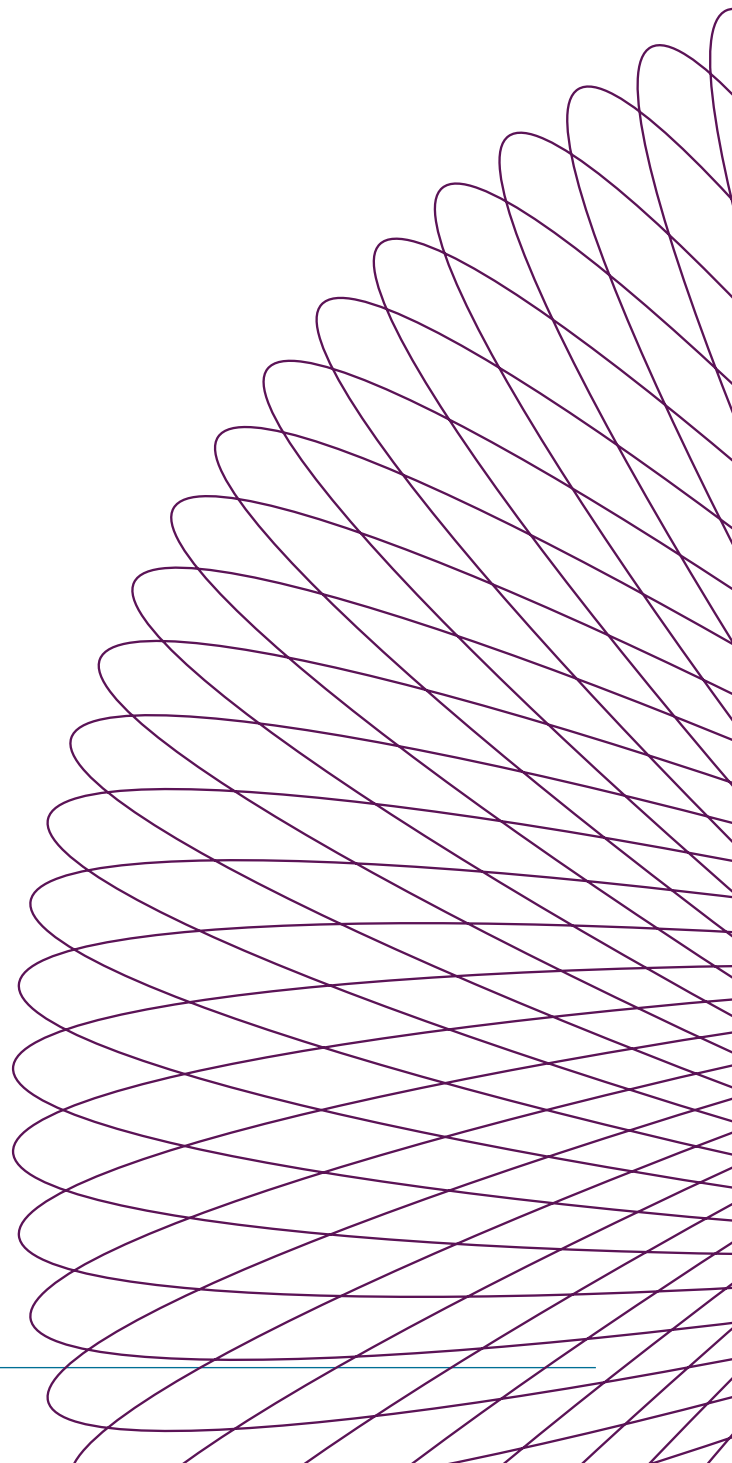
IMPLICATIONS FOR PRACTICE

(by the authors and reviewer)

- Post diagnostic home visit, by a member of the diagnostic team, to discuss in detail the recent diagnosis and answer any specific questions and discuss options for intervention.
- Post diagnostic parental training to address the "core features" of autism.
- Additional follow up sessions to address the development of parental skills, under the topics of: communication, visual structure and sensory regulation.
- Diagnostic team members, following post diagnostic work, should link with their educational colleagues in the advisory teams to offer support and advice to parents regarding educational options.
- Follow up paediatric visit to address concerns in relation to genetic factors that may influence additional siblings.

Full Reference

Gaspar de Alba, M. J. and Bodfish, J. W. (2011). Addressing Parental Concerns at the Initial Diagnosis of an Autism Spectrum Disorder. *Research in Autism Spectrum Disorders*, 5, p. 633-639.



FACTORS ASSOCIATED WITH PARENTAL STRESS AND SATISFACTION DURING THE PROCESS OF DIAGNOSIS OF CHILDREN WITH AUTISM SPECTRUM DISORDERS

BACKGROUND

Due to the nature and complexity of the diagnosis of autism, it is recognised that this process may be one that could potentially cause frustration for parents.

The study examined the duration of the diagnostic period, the number of professionals consulted, the relationship with the professionals and the perceived helpfulness of information provided in relation to how they impact on parental satisfaction and stress during the diagnostic process.

RESEARCH AIMS

The study aimed to obtain both parental and professional perspectives regarding current diagnostic practices and to understand the aspects of the process which may be helpful in increasing professional confidence in diagnosing Autism Spectrum Disorder (ASD).

RESEARCH METHOD

One hundred and two parents of 2-17 year olds with autism, accessed via special schools, intervention centres and hospitals, completed a survey, which incorporated various aspects of the diagnostic process and measures of autism severity, parental stress and satisfaction.

Parents were asked to provide information about the age at which their child was first recognised as having possible ASD signs, assessed and diagnosed, as well as the type and number of professionals consulted. Seventeen professionals completed a similar survey. Ethics approval was obtained from the National University of Singapore Institutional Review Board. All data collected were anonymous and confidential.

RESEARCH FINDINGS

- Higher parental stress was associated with more professionals consulted and lower perceived collaboration with professionals.
 - Higher parental satisfaction was associated with higher perceived collaboration with professionals.
 - Higher satisfaction was associated with higher perceived helpfulness of received information, lower severity of child ASD symptoms and lower levels of stress.
 - One consistent negative experience reported by caregivers is the length of time waiting for the clinical diagnosis.
 - Parents were often more satisfied with the diagnostic process when opportunities to ask questions were given.
 - Higher ASD symptom severity is positively associated with increased levels of parenting stress.
 - Parents of ASD children with more severe communication deficits, reported lower stress in relation to the process of diagnosis.
 - Upon receiving a formal diagnosis, most parents were provided with information on early intervention programmes, speech and language therapy and explanations for their child's difficulties from professionals.
 - Parents were moderately satisfied with their relationship with professionals, with most appreciating professionals who took their concerns seriously and who gave specific information on their child's ASD.
 - Parents with higher education qualifications and higher income noticed problems in the development of their children earlier than those parents with lower education qualifications and income.
-

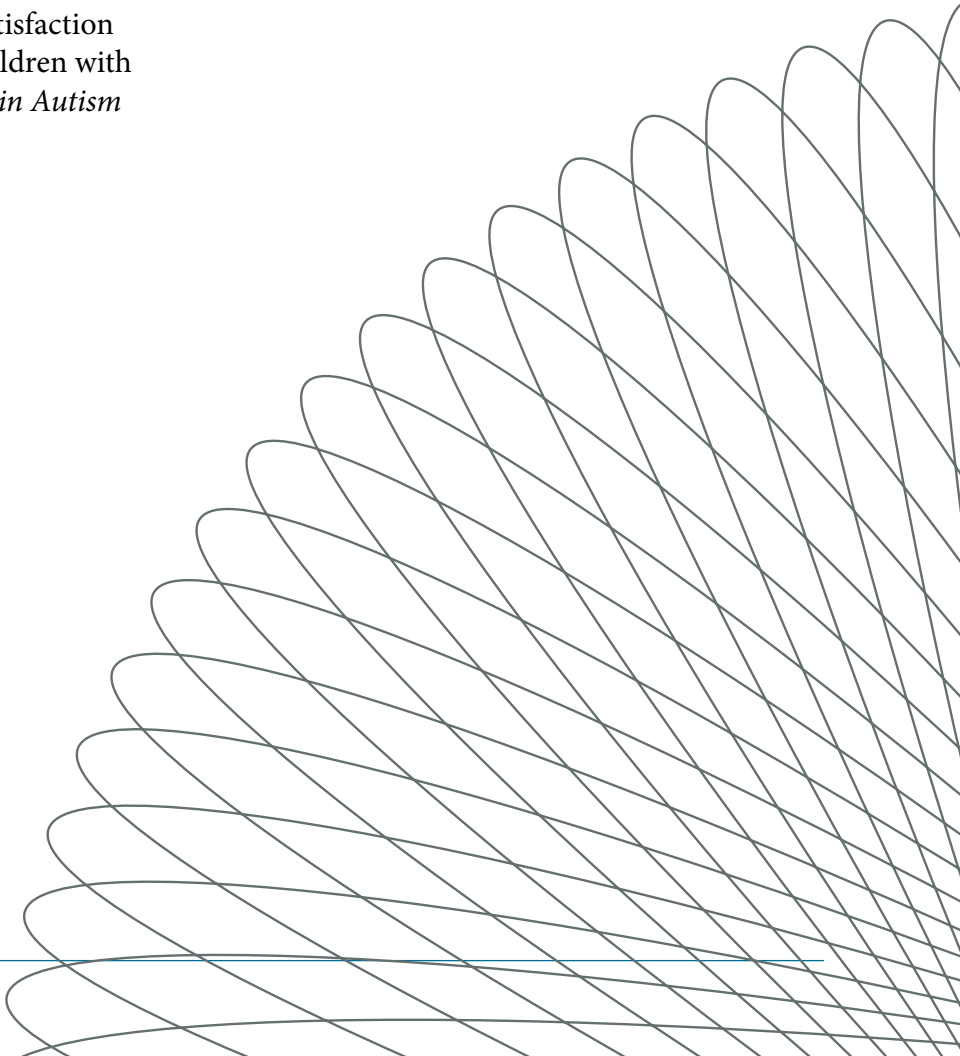
IMPLICATIONS FOR PRACTICE

(by the authors and reviewer)

- A core “diagnostic” team should be co-ordinated prior to, during and post diagnosis.
- This core team should remain consistent to the family and be available prior to, during and post diagnosis, across clinical and home settings, to answer specific questions and guide towards appropriate intervention.
- Individualised programmes for home based “Early Intervention” should be available to all families post diagnosis.
- Resources and support networks should be made available to parents during this time.

Full Reference

Moh, T. A. and Magiati, I. (2012). Factors Associated with Parental Stress and Satisfaction during the Process of Diagnosis of Children with Autism Spectrum Disorders. *Research in Autism Spectrum Disorders*, 6, p. 293-303.



KNOWLEDGE IS POWER: EMPOWERING THE AUTISM COMMUNITY THROUGH PARENT-PROFESSIONAL TRAINING

RESEARCH AIMS

The researchers describe the grant funded Partnerships for Autism through Collaborative Community Choice and Empowerment (Project PACE) which had two goals: (1) to close identified gaps in autism education and training for both parents and professionals, and (2) to coordinate and consolidate community knowledge, resources, and services for autism that otherwise have been fragmented.

RESEARCH METHOD

Twenty seven participants were selected for Project PACE's collaborative training and education. One selection criterion was established for professional participants: they were required to be providing services to individuals with autism in the county where the grant was awarded. Fifteen professionals included individuals who worked in the professional fields of education, speech and language pathology, social work, occupational therapy, mental health, and adult services. Their educational accomplishments ranged from earned master's degrees to earned doctorate degrees. At the start of the program, all professional participants were working with individuals on the Autism Spectrum who ranged in age from preschool through to adulthood. Three of the professional participants self-identified as having disabilities. Two selection criteria were established for the twelve parent participants: (1) residency in the county where the grant was awarded, and (2) status as a parent or guardian of a child or adult with autism. The socioeconomic backgrounds of parents were varied.

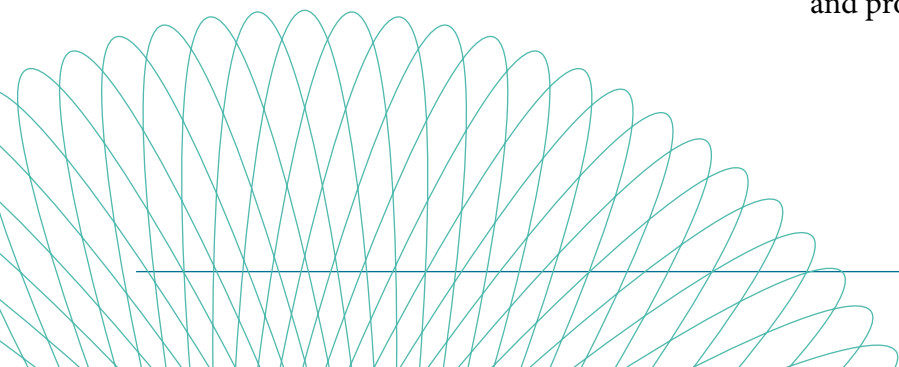
Their educational accomplishments ranged from high school completion to master's degrees. In addition to these eligibility criteria, participants were selected based on referrals from grant administrators, community agencies, and school administrators. Ethnic composition included four parents and three professionals from diverse cultures.

Following the delivery of collaborative education and training workshops, evaluation information was gathered and the 5-point Likert scale was used to measure feedback from the community. Three years later, follow-up information was gathered through phone surveys.

RESEARCH FINDINGS

Project PACE, a one-year funded project, was initiated to build capacity around autism knowledge, resources, and services through parent-professional partnerships in an urban county in northwest Ohio. Project PACE's planning, implementation, and evaluation phases along with "lessons learned" are detailed in the paper.

The researchers found that numerous legislative mandates and numerous professional education organisations support collaborative partnerships among parents and professionals (e.g., general or special education teachers, therapists, social workers, school counsellors, psychologists). The collaborative partnership should evolve into a collaborative triad, with the individual with autism playing a progressively increasing role as growth and maturity allow. In response to prior research findings, the directors of Project PACE created a non-hierarchical collaborative learning community for parents of children with autism and professionals.



Roles and responsibilities were clearly defined and this led to open and effective communication, trust, and shared decision-making. The training model employed combined the best components of train-the-trainer model and parent-professional model. The identified learning community received professional training and in turn, they trained additional groups in the community.

The project was funded for one year, and approximately 300 people attended the three-hour workshops. On a 5-point Likert scale (5 high and 1 low), the overall composite evaluation score for the three workshops was 4.86. Based on these evaluations of the workshops, the groups were successful in providing information that the community valued.

Project PACE trainers continued to provide educational in-services, workshops, and panel discussions on all aspects of autism at other community events, including professional autism conferences at local, regional, and national levels. Follow-up information on training sessions provided by Project PACE participants was gathered through phone surveys in 2009 administered by project directors to Project PACE participants. Project PACE participants were asked to indicate how many formal and informal training sessions they had conducted since their participation in Project PACE. Participants reported a potential impact on more than 4,435 attendees through 209 formal and 336 informal training sessions. Additional information on the outcomes of the participants' involvement in Project PACE trainings are detailed in the research paper.

IMPLICATIONS FOR PRACTICE

(by the authors)

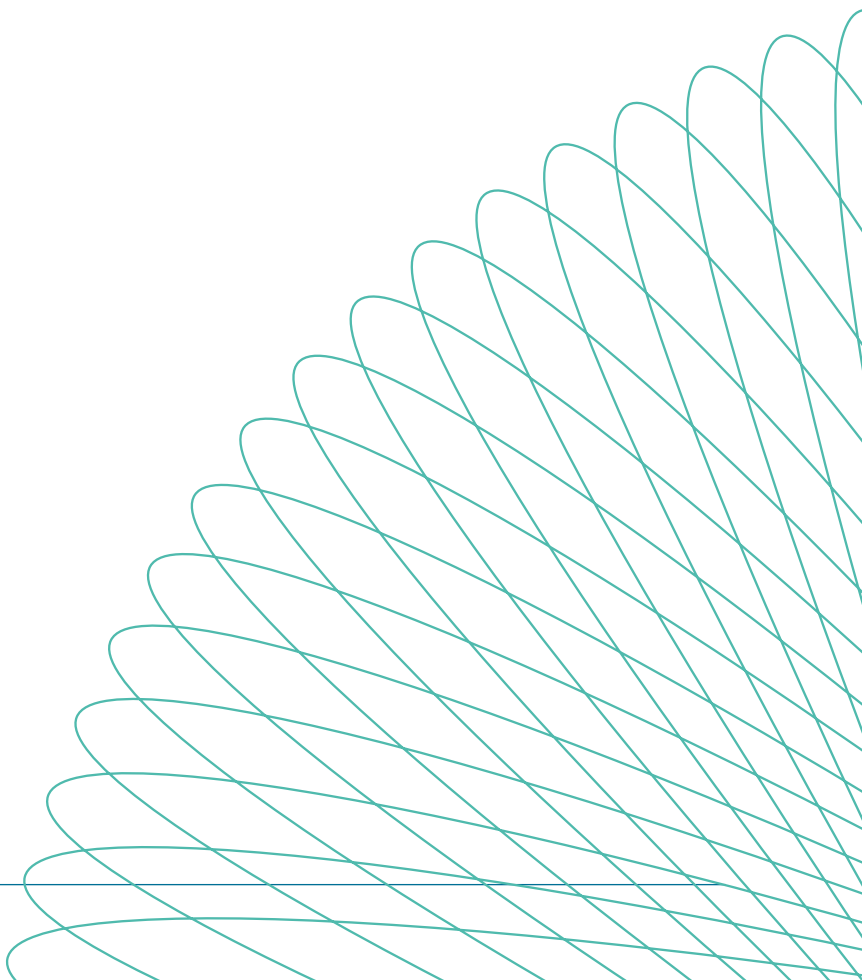
- Collaboration and empowering both parents and professionals with knowledge regarding service options leads to better outcomes for families, their loved one with autism, and the professionals who serve them.
- When parents and professionals partner to meet the needs of the child with autism, the results are often dramatic and can impact positively on their cognitive, social, and emotional development.
- As the child with autism matures, the parent-professional partnership should become a triad, with the individual with autism playing a progressively increasing role.
- The need for professional training and multiple opportunities for parents and professionals to interact together is central to the formation and success of collaborative parent-professional partnerships. Without effective, interactive training and hands-on experience collaborating with each other, parents and professionals may experience ineffective partnerships or significant conflict.
- Clearly defined roles and responsibilities should be established at the beginning of the partnership as this leads to open and effective communication, trust, and shared decision-making.
- Other components that positively influence the effectiveness of parent-professional partnerships include: respecting families' cultural backgrounds and dynamics; developing trust in the relationship; establishing and maintaining parity; sharing decision-making responsibilities among partners; and an elevated level of commitment by both parents and professionals.

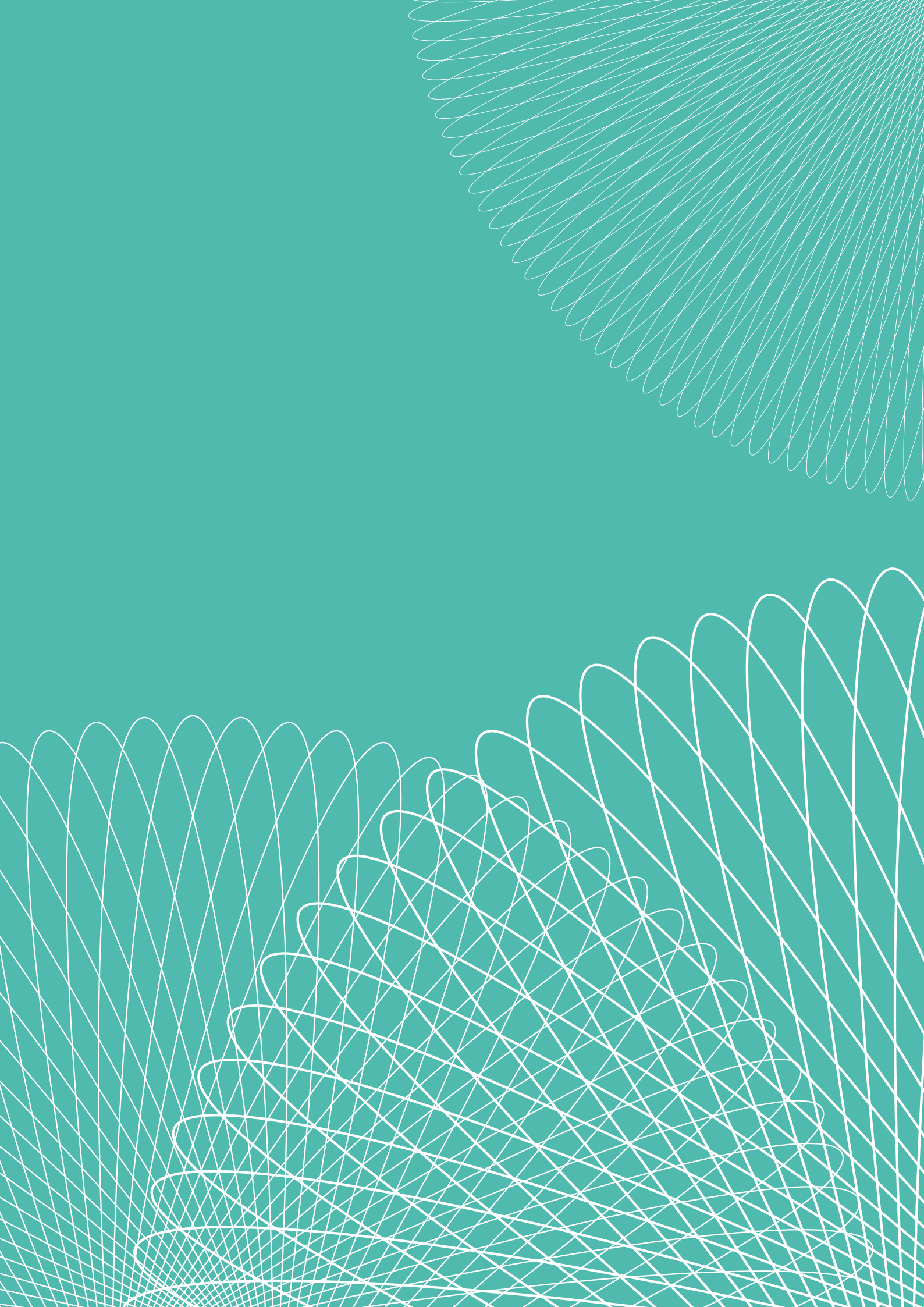
- Teachers with positive dispositions increased parent trust. Also, parents appreciate teachers with research-based information about autism as all too often interventions are not research-based prior to implementation.
- School teams can assist in building parent and professional partnerships by providing workshops and collaborative professional development opportunities.
- When school personnel and community members (parents and professionals) work together to meet identified community needs, the community flourishes. The researchers found this collaborative model project to be appropriate for other identified school/community needs.

With the increased prevalence of autism, the results of this study suggest that Project PACE provides a cost-effective collaborative training model for parents and professionals to develop, maintain, and improve services for individuals with autism.

Full Reference

Murray, M. M., Ackerman-Spain, K., Williams, E. U. and Ryley, A. T. (2011). Knowledge is Power: Empowering the Autism Community through Parent-Professional Training. *The School Community Journal*, 21(1), 19-36. Retrieved from <http://www.schoolcommunitynetwork.org/SCJ.aspx>





COACHING MOTHERS OF CHILDREN WITH AUTISM: A QUALITATIVE STUDY FOR OCCUPATIONAL THERAPY PRACTICE

BACKGROUND

Evidence in research suggests that coaching is a technique that occupational therapists can use to support another person achieving self-created goals. A collaborative partnership between all parties is considered pivotal to achieving the goals which is not based on telling someone how they will reach them. Instead the coach facilitates the participant to assume a solution focused approach to reaching their goals and whilst there are recognised core elements to enabling this process such as: joint planning, observation and taking action, analysing and reviewing, reflecting and feeding back, it does not follow a linear pathway. Emerging research suggests that coaching helps participants increase knowledge, increase their skills set, increase their competence and improves adult learning which in turn can help to reduce stress, increase parental compliance but ultimately increase child participation.

RESEARCH AIMS

The aim of the study was to examine the thought and behavioural processes of parental experience during the coaching process. More specifically, the researchers explored how mothers use their insight from the coaching process when dealing with their children with autism. This research extends previous studies that have provided knowledge of the processes and procedures for coaching. As a result, this study aimed to further develop and aid the refinement of the practices related to coaching.

RESEARCH METHOD

A convenience sample was used to conduct a qualitative study. The sample comprised of ten mothers with children who had autism. Each mother was asked six open ended questions by the researchers which were designed to gain insight into the parental experience of coaching, their understanding of the process and to determine whether parental decisions were affected as result. All parents were known to occupational therapy services and the same therapist that provided intervention asked the research questions.

RESEARCH FINDINGS

Emerging themes were identified, which were consistent with the literature on coaching practices, such as increased parental self-efficacy and feelings of empowerment. The mechanisms that drive these changes are attributed to the quality of the parent/coach relationship and the value placed on this relationship, the analytical approach that the process requires and reflection of the child's level of engagement in day-to-day activities. It is believed that the changes encountered result from parental mindfulness due to understanding the context of the child's experience, which reframes the parent's perception of the challenges the child experiences and thereby enables parents to generate their own solutions in response to them. It was found that the relationship between the coach and parent was central to the success of the outcome and essentially provided an opportunity for both experts, parents and professionals to reflect upon the child's level of engagement. This would seem to be consistent with other OT studies which report similar findings.

IMPLICATIONS FOR PRACTICE

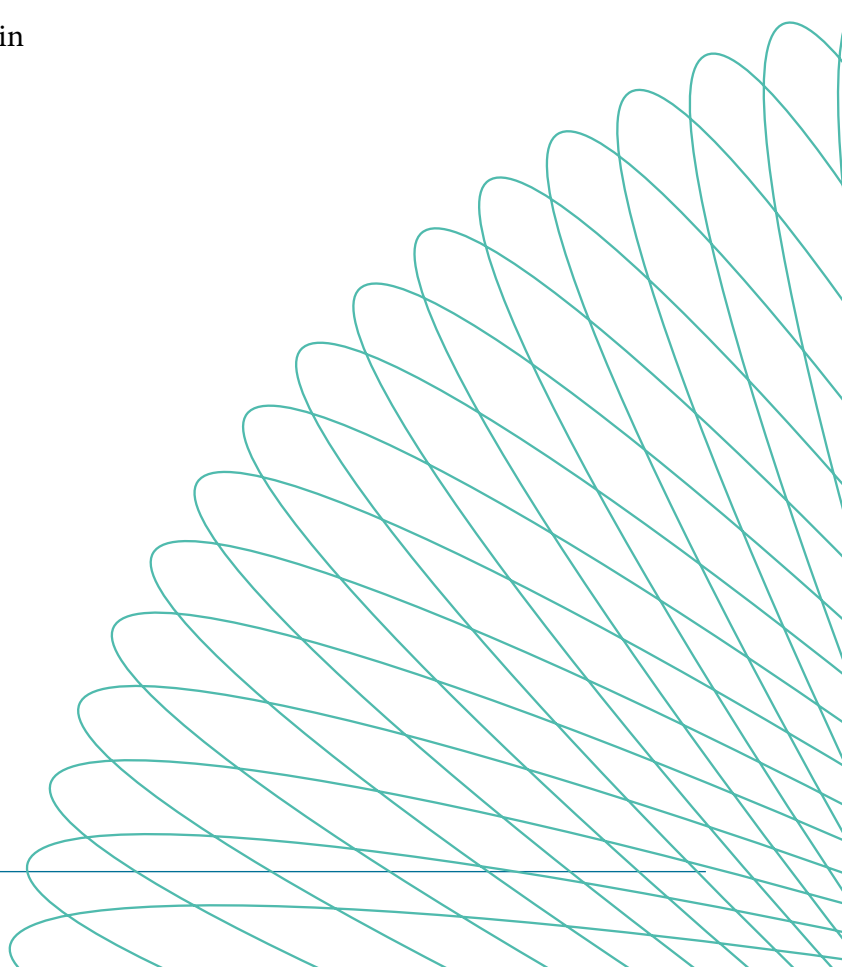
(by the authors and reviewer)

As a practitioner, this study encouraged self-reflection of how support is provided over a period of intervention by professionals.

- It encourages practitioners to step away from the traditional “telling” someone how to do or what to do. Instead, professionals working with families should support them to seek their own solutions.
- In terms of effecting change and empowering parents to continue the model of work after withdrawal of services perhaps coaching may be considered as a therapeutic model of providing such support where changes of performance and engagement are the focus of other interdisciplinary and transdisciplinary teams.
- As well as this, perhaps assessing the effectiveness of employing this model of effecting change after withdrawal of services in the short and long term may also be useful.

Full Reference

Foster, L., Dunn, W. and Mische-Lawson, L. (2013). Coaching Mothers of Children with Autism: A Qualitative Study for Occupational Therapy Practice. *Physical & Occupational Therapy in Pediatrics*, 33(2), p. 253-263.



A STUDY OF PARENT-PROFESSIONAL PARTNERSHIPS SUPPORTING CHILDREN WITH AUTISM: WHAT DO PARENTS AND PROFESSIONALS VALUE?

RESEARCH AIMS

This study explored the issues related to parent-professional partnerships (PPPs) in a Monitoring Support Group (MSG) which provides training to teachers and carers and supports children with autism and their families and professionals.

Four key characteristics of PPPs, as defined by Department for Education and Skills were analysed in the study:

1. Confidence: parent/professional feels their goals have been achieved.
2. Empowerment: parents are “able to fulfil their roles as parents”.
3. Involvement: “the extent to which their wishes, feelings and perspectives have been addressed”.
4. Contact: ability of parents to “contribute their knowledge and understanding of a child to professionals”.

RESEARCH METHOD

Participants in the study were six parents of children with autism who had been involved in the MSG programme for over a year, and six professionals, including educational psychologists, language learning and support services staff and specialist teachers. The children were all under 12 years old and five of the six attended mainstream school.

Interviews were carried out individually with participants using a semi-structured interview. A Likert rating scale was also used to measure parents’ and professionals’ confidence in each other and in the school’s ability to support the child.

RESEARCH FINDINGS

1. Confidence

Parents and professionals reported that schools did not have the adequate knowledge and skills to support children with autism, and parents felt that they had more knowledge than the staff. One professional highlighted the reluctance of secondary schools to be flexible in meeting the needs of pupils with autism. Four of the professionals interviewed did not feel confident in their own knowledge of autism.

2. Empowerment

Two parents provided negative reports on the professional support provided during and after diagnosis, but there was very positive feedback on the support received from other parents. They found it was beneficial to interact with other parents and share supportive ideas.

3. Contact

All parents in the study gave positive feedback on the support received from the PPP and had a sense of trust in their key professional. They found the PPP meetings useful in gaining more information about autism. Professionals were also positive about the support provided by the PPP.

4. Involvement

Parents were concerned about the lack of support for their child’s social skills, and felt that schools did not adequately address inclusion. Parents stated that schools viewed their children as “poorly behaved” instead of seeing the additional support the children required. Parents also felt that their own families and friends did not understand autism and their child’s needs, and this affected the ability to go to family outings and events. This could be divisive in a family, and three of the parents were particularly concerned about the impact on siblings.

The Likert scale showed that parents and professionals had similar levels of confidence in the PPP, in each other and in the schools' ability to meet the needs of the child.

IMPLICATIONS FOR PRACTICE

(by the author)

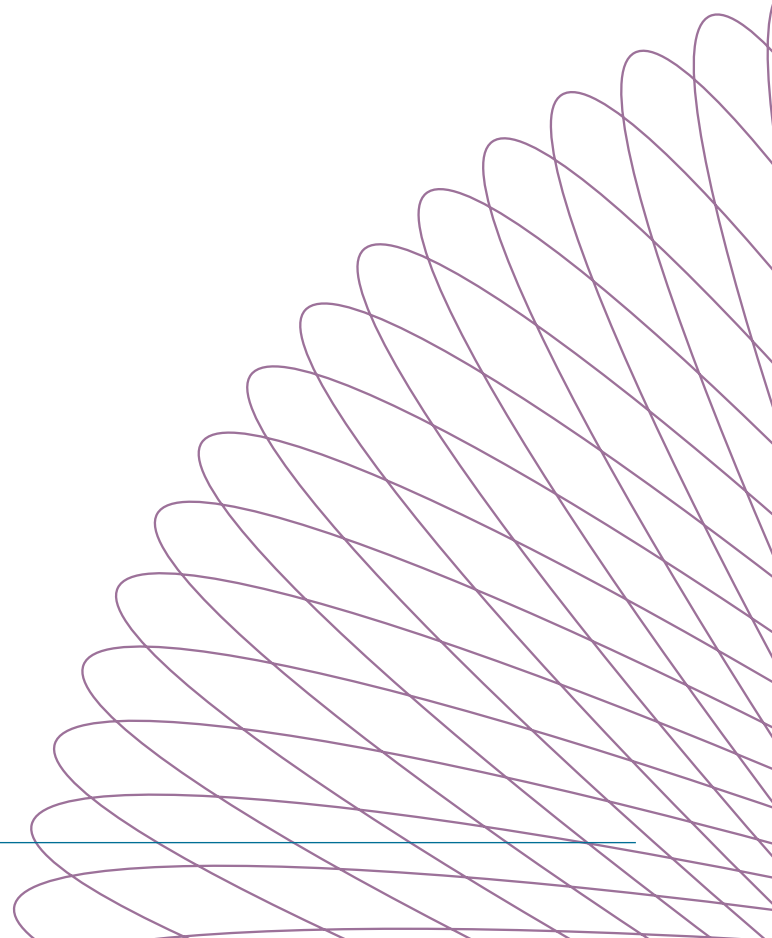
The author recognised the small sample size and acknowledged that there are other studies which have shown good parental satisfaction with schools and diagnostic services.

The main themes which emerged from this study were as follows:

- Contact between parents and professionals is essential in creating confidence, empowerment and involvement. This can be achieved through community-outreach support, forums, meetings and telephone calls.
- Professionals require continuing professional training and development to improve their knowledge and skills in autism and to give them confidence in their ability to support the needs of the children and families.
- Some schools need to become more flexible in order to meet the needs of children with autism and some staff need to increase their knowledge of autism.
- More professional support may be required during and after diagnosis of autism.
- Support from other parents is beneficial, and the opportunity to meet other parents provides reassurance and supportive ideas. Parent groups are therefore a vital resource.
- Professionals need to actively listen to parents and include their views in the process of a PPP.
- Parents need more support from professionals to develop children's social skills, to improve understanding of autism within families and society and to support siblings.

Full reference

Price, A. (2012). A Study of Parent-Professional Partnerships Supporting Children with Autism: What do Parents and Professionals Value? *Good Autism Practice*, 13(1), p. 13-21.



CONCLUSION

The articles reviewed indicate that parental involvement improves outcomes for children and young people. Parents and professionals can learn from each other and this collaboration is a positive and cost effective strategy for schools and other agencies to consider both implementing and improving on.

Simple strategies such as: asking for parental input, improving home and school communication and having specific input in particular areas e.g. IEPs have a significant positive result for both parents, children and teachers.

This level of input needs to be implemented during and post diagnosis and maintained as the child gets older and into adulthood.

Middletown Centre welcomes the views of both parents and professionals. Please email the Centre with your views on and suggestions for the research bulletin on research@middletownautism.com.

YOUR OPINION

The Centre trusts that you have found this Research Bulletin informative. It would be appreciated if you would take a few minutes to provide the Centre with feedback in relation to this bulletin by clicking on the survey link below.

Survey for Parent and Professional Partnerships





CENTRE FOR AUTISM
MIDDLETOWN

The Centre's Research and Information Service welcomes any correspondence including suggestions for future Bulletins to: research@middletownautism.com

Middletown Centre For Autism
35 Church Street, Middletown, Co. Armagh BT60 4HZ
T +44 (0)28 3751 5750 E: research@middletownautism.com W: www.middletownautism.com
J G Cooper: Chief Executive, Registered in Northern Ireland, No. NI063661