

СТРАТЕГИИ РАННЕГО ВМЕШАТЕЛЬСТВА ПРИ РАС С АКТИВНЫМ УЧАСТИЕМ РОДИТЕЛЕЙ И БЕЗ

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Аннотация

Цель нашего исследования состоит в том, чтобы проанализировать и сравнить данные об эффективности программ раннего вмешательства для детей с аутизмом, с участием родителей и без. Было проведено сравнительное исследование, как обучение и участие родителей повышают результаты программы по сравнению с семьями, где родители остаются в стороне и не участвуют в программе раннего вмешательства своего ребенка с РАС (с расстройством аутистического спектра).

Ребенок с РАС характеризуется дефицитом базовых навыков общения и социального взаимодействия, а также ограниченными и повторяющимися моделями поведения. Родители детей с расстройством аутистического спектра часто испытывают сильный стресс из-за серьезности проблемы.

Когда родители впервые сталкиваются с проявляющимися проблемами развития, в процессе постановки диагноза и в начале оказания помощи, их роль становится центральной в удовлетворении потребностей маленьких детей с РАС, включая внедрение и поддержку программы раннего вмешательства.

Исследования показали, что вовлеченность родителей крайне важна в первые годы развития ребенка, и необходимо создать все возможности для их участия. Необходимо организовывать для них тренинги и семинары, защищать их от возможных стрессов, связанных с вмешательством, создавать условия для работы совместно с профессионалами и давать им важные навыки и указания для решения любых трудностей и проблем. Все это дает им возможность повысить качество жизни своего ребенка и своей семьи.

ՎԱՂ ՄԻՋԱՍՏՈՒԹՅԱՆ ՌԱԶՄԱՎԱՐՈՒԹՅՈՒՆՆԵՐԸ ԱՄԽ ՈՒՆԵՑՈՂ ԵՐԵՒԱՆԵՐԻ ԾՆՈՂՆԵՐԻ ԱԿՏԻՎ ՆԵՐԳՐԱՎՍՏԱՄԲ ԿԱՄ ԱՌԱՆՑ ԴՐԱ

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Ամփոփում

Մեր ուսումնասիրության նպատակն է վերլուծել ու համեմատել աուտիզմ ունեցող երեխաների վաղ միջամտության ծրագրերի արդյունավետության վերաբերյալ տվյալները՝ ծնողների ներգրավվածությամբ և առանց դրա: Համեմատական ուսումնասիրություն է իրականացվել այն մասին, թե ինչպես ծնողների վերապատրաստումն ու մասնակցությունը ծրագրին կբարձրացնեն նրա արդյունավետությունն այն ընտանիքների համեմատ, որտեղ ծնողները մնում են լուսանցքում և չեն մասնակցում իրենց երեխայի վաղ միջամտության ծրագրին:

ԱՄԽ ունեցող երեխային բնորոշ են սոցիալական փոխհարաբերությունների ու տեղեկատվության վերամշակման, ինչպես նաև սահմանափակ/կրկնվող վարքի կայուն խնդիրները: Աուտիզմի սպեկտրի խանգարում ունեցող երեխաների ծնողները հաճախ մեծ սթրեսի մեջ են խնդրի լրջության պատճառով:

Երբ ծնողներն առաջին անգամ բախվում են ի հայտ եկած խնդիրներին ախտորոշման ու խնամքի մեկնարկի ընթացքում, նրանց դերը կենտրոնական է դառնում իրենց երեխայի կարիքները հոգալու, վաղ միջամտության ծրագրում ներգրավվելու ու երեխայի առօրյան ճիշտ կազմակերպելու գործում:

Համաձայն մեր հետազոտությունների արդյունքների՝ ծնողների ներգրավվածությունը կարևոր է երեխայի զարգացման սկզբնական տարիների ընթացքում, և պետք է հնարավորություն ստեղծել նրանց մասնակցության համար: Նրանց համար անհրաժեշտ է կազմակերպել թրեյնինգներ ու սեմինարներ, պաշտպանել միջամտության հետ կապված հնարավոր սթրեսներից, պայմաններ ստեղծել մասնագետների հետ համատեղ աշխատելու համար և տալ նրանց կարևոր հմտություններ ու ցուցումներ՝ ցանկացած դժվարություն ու խնդիր լուծելու համար: Այս ամենը նրանց հնարավորություն է տալիս բարելավելու իրենց երեխայի ու ընտանիքի կյանքի որակը:

EARLY INTERVENTION STRATEGIES FOR ASD WITH AND WITHOUT PARENT ACTIVE INVOLVEMENT

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Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder of variable severity characterized by repetitive and characteristic patterns of behavior and difficulties with social communication and interaction [1]. A child with ASD is characterized by a deficit in basic communication and social interaction skills and has inappropriate interactions with their parents [2]. They pose serious behavior problems to their parents, which can cause significant pressure, stress, and discomfort, undermining their confidence in their ability as parents and bringing tension into the family [3].

Nowadays, there is growing evidence that ASD can be diagnosed accurately before two years. It is crucial to design and provide age-appropriate and evidence-based therapy for that age group.

Early intervention for autism should start as soon as possible. Significant research studies show that starting therapy at 1-3 years old, when the first issues with development are noticed, is highly effective for improving a child's language ability, social interaction, and play.

With the development of early screening and the ability to diagnose ASD before age 3 in Armenia, the need for systematic, effective and regular interventions for ASD, especially early intervention for ASD toddlers, is essential and would significantly improve the quality of their life.

Considering the state of emergency declared in Armenia and worldwide due to the COVID-19 global pandemic, we were forced to revise and reorganize our work and continue to stay close to children with ASD and their parents, providing ongoing long-distance counseling and training to parents.

- Taking into account the unique features of each child, based on "Individual programs," we have continued to work with parents and their children on a remote platform. During this time, parents have carried out classes with the help of a specialist. The implementation of tasks has been monitored as much as possible through video calls.

- Online monitoring has been carried out to check children's behavior, give instructions on a child's particular behavior, and help parents show a comparatively positive attitude towards the maladaptive behavior of their child. Likewise, strategies have been developed to reduce, change, and prevent a child's maladaptive behavior.

- A set of online training has been organized for parents on complicated topics. As a result, it became possible to help parents conduct correct work with their children.

All outcomes and achievements were recorded and analyzed. Comparative research was done on how parent training and involvement will increase the program outcomes compared with families where parents remain on the sidelines and are not involved in their child's early intervention program.

1. According to our experience and research, parent involvement is a key component of child therapy, and it makes the process more successful; therefore, it is essential to assist parents in understanding the special needs of their child;

2. Provide parents with information about child development;

3. Help them to obtain the necessary skills that will allow them to support the implementation of their child's IEP

When parents don't know how to appropriately deal with the negative or disruptive behaviors of their child with autism, they may reinforce the problematic behavior, which will cause those behaviors to increase and become more intensive in the future.

Methodology, Methods, Research Instruments or Sources Used

This research aims to analyze and compare the effectiveness of intervention programs when parents or family members are trained and actively involved in the program implementation with the cases when parents are not a part of it.

We will consider different early intervention strategies and their effectiveness, the advantages and disadvantages of active parent involvement in the teaching process, and how to control it.

In our study, we will explore how families with deficient levels of engagement have difficulties interacting with their children and how it influences their family and the child.

We will explain and bring up the fact that not evidence-based methods can affect children at early ages and negatively influence their future development.

We will also consider the importance of assessing and creating an age-appropriate program based on the assessment results.

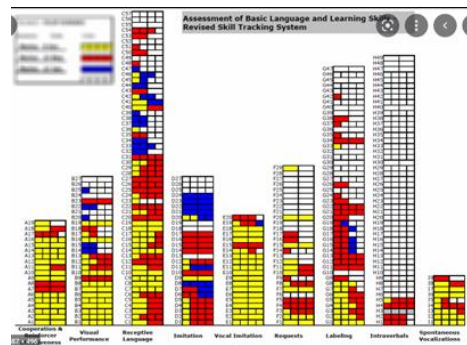
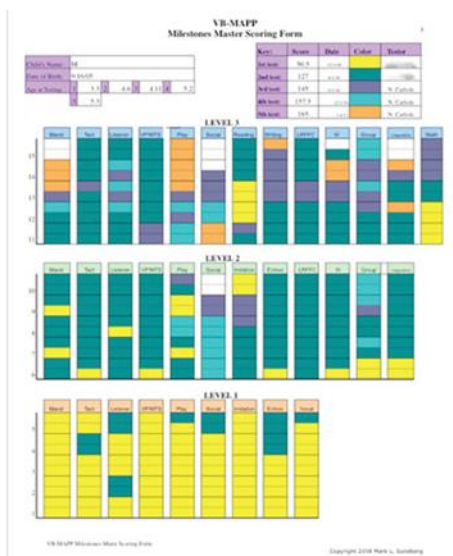
RESEARCH METHODS

The main point of our work is to involve the child's parents and family in the education process and all aspects of the intervention.

Our research study was conducted with 30 children with ASD aged 1-5, from which 15 parents of children have active involvement and were trained by us on implementing an Applied Behaviour Analysis (ABA) program.

In this study, we used questionnaires to understand parents' satisfaction with implementing the program at home, conducted an assessment by VB Mapp [1], and recorded children's progress and reduction of challenging behaviour in their homes or other places.

Progress measures were administered pre- and post-intervention and included a developmental assessment - the Verbal Behavior Milestones Assessment and Placement Program (VB-MAPP); and parent-report questionnaires - the Social Communication Questionnaire (SCQ) and the Assessment of Basic Language and Learning Skills - Revised (The ABLLS-R®).



Social Communication Questionnaire (SCQ) – Lifetime
 PC Answer Sheet
 Michael Rutter, M.D., F.R.S., Anthony Bailey, M.D., Sibel Kazak Berument, Ph.D.,
 Catherine Lord, Ph.D., and Andrew Pickles, Ph.D.

Name of Subject: D.O.B. Interview Date Age:

Gender: F M Name of Respondent: Relation to Subject:

Directions: Thank you for taking the time to complete this questionnaire. Please answer each question by selecting yes or no. A few questions ask about several related types of behavior; please select yes if any of these behaviors were present during the past 3 months. Although you may be uncertain about whether some behaviors were present or not, please answer yes or no to every question on the basis of what you think.

Item	Yes	No
1. Is she/he now able to talk using short phrases or sentences? If no, skip to question 8.	<input type="radio"/>	<input type="radio"/>
2. Can you have a to and fro "conversation" with her/him that involves taking turns or building on what you have said?	<input type="radio"/>	<input type="radio"/>
3. Has she/he ever use odd phrases or say the same thing over and over in almost exactly the same way (either phrases that she/he hears other people use or ones that she/he makes up)?	<input type="radio"/>	<input type="radio"/>

The hierarchy of the program was designed by our team



Passive practice phase

- Observation of how therapists work
- Participation of seminars conducted by us



Active practice phase

- Learning of various techniques based in Applied Behavior Analysis and other Fields
- Teaching parents specific skills to facilitate communication, learning, behavioral and emotional health in their child



Implementation and generalization of learning skills

- Working with their child in the center under our supervision
- Working with their child in home setting /supervision conducted online/
- Generalizing skills in different settings/parks, stores, malls...

In a Passive practice phase we designed the 16-hour training to provide parents with the following knowledge

- understanding of their child's diagnosis and treatment,
- training on ways to better manage behavior and improve skill building in their children,
- assistance with how to access community resources

The seminars were conducted in eight two-hour sessions.

During the Active Practice phase, from the available programs offered for children with ASD, we chose Applied Behavior Analysis (ABA). We trained parents to apply this program at home and in other settings. We also started to teach parents one of the ABA techniques -Discrete Trial Training (DTT). DTT is taught by using a specific task repeatedly until the student has completed the task. DTT makes learning easier for children on the spectrum by breaking down a task into its most basic components.

In the third phase, "Implementation and generalization of learning skills," under our supervision, parents integrated into directly implementing the intervention skills they learned after observing the intervention provided by the therapist. During this phase, the therapy sessions were recorded. Then parents watched videos of themselves interacting with their children to learn how they could improve and learn to spot when and how their child is interacting with them. In the last stage of this phase, parents work with their children at home or in other settings alone. Finally, parents start implementing all these learned skills independently with their children. However, ongoing support from therapists remains available.

Results

The intervention was developed along 12 weeks, in which the control group only received the conventional/usual sessions of the ABA program while the parents of the experimental group participated in training, seminars, working with their child and receiving supervision from certified behavior analysts and experienced staff.

During 12 weeks in person and online supervision was conducted.

Our comparative study between 2 groups with (1st group) and without (2nd group) parent enrollment has the following outcomes:

- There are significant reductions in disruptive behaviors, improvements in the child's functional development, and increases in parenting skills and compliance with parental demands in the control group.
- There are significant improvements in the interaction between a parent and a child, in children's communication initiation, and in play and initiation of communicative gestures in the 1st group.
- There are substantial social and communication skills changes in those children whose parents received training from our team and were actively involved in the program and implemented it at home or other places.
- Parents' knowledge of how to work with their child as a behavior therapist was enlarged
- Children have visual changes in motor, social skills, language development, and academic performance.
- There is a substantial decrease in parent stress and panic after training and starting to work with their child as a therapist.
- Parents of the first group also stressed significant changes in the relationship of their family members.
- The mothers from the control group reported increased use of commands and communication by their child, better engagement, and significant change in the quality of their relationship with the child.

Conclusions, Expected Outcomes or Findings

In conclusion, creating all opportunities for parents to be involved is essential. Therefore, we should organize training sessions and seminars for them, protect them from the possible stresses associated with the intervention and empower them with essential skills and techniques to deal with any difficulties and challenges. All these give them the power to increase their child's and their family's quality of life.

The training of the parents should be carried out using all possible resources, creating manuals, organizing meetings and support groups, video-feedback sessions, remote support or video conferences.

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