

What Works for One

Practice considerations for supporting a child or young person with autism spectrum disorder, drawn from participatory action research

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ABSTRACT

This article is an analysis of the reports submitted to the Ministry of Education by teams and mentors who took part in the autism spectrum disorder participatory action research (ASD PAR) project. The key findings highlight the importance of: individualised support based on a sound knowledge of the child or young person; strategies targeted at the child's environment and the people within it as opposed to addressing perceived within-child challenges; and interventions thoughtfully linked to outcomes and carefully implemented in accordance with the culture and context of the child and the team

Keywords

Action research, autism spectrum disorder, ecological perspective, effective practices, intervention strategies, participatory action research, reflection, student participation.

INTRODUCTION

All students are different and need to be treated that way – what works for one does not always (if ever) work with others. (Local project team D.)

In the reports submitted to the Ministry of Education by the nine teams who took part in the autism spectrum disorder participatory action research (ASD PAR) project¹, each team told their story of how best to support a specific child or small group of children with autism spectrum disorder (ASD). The companion article published in this issue, What We Did, outlines the pemission process for using teams' reports, and the methodology used to analyse them. What We Did also describes the themes that emerged about working and learning as a team, the influence of attitudes, and the process of using participatory action research (PAR). This article focuses on the specific findings about strategies to support children and young people with ASD. The themes are discussed in three sections: child at the centre, the child's world, and putting it into practice. Pseudonyms for children's and adults' names have been used throughout.

CHILD AT THE CENTRE

I have become more aware of how Alex thinks and feels and how he sees the world. I can see the differences between how I see the world and how he does. I have

1 For background to the ASD PAR project and demographic information about the teams involved, see the article With Hindsight in this issue. been able to make small changes over long periods of time, which has resulted in significant changes that make a huge difference for our family. (Local project team A, sub-team 2.)

There are two sub-themes in this section: knowing the whole child, and using the child's interests for motivation and learning.

Knowing the whole child

The importance of truly knowing the individual child or young person was highlighted by all the teams. While many teams were working towards a goal or outcome in a particular area, such as communication, they did not lose sight of the whole child. Teams worked to understand children's and young people's unique profiles, their nuanced way of indicating their preferences and dislikes, their habits and personalities, and their ways of being in different settings. Teams spent time discovering what motivated the child or young person, learnt to appreciate their sensory preferences and imagined how they viewed the world.

We talked about any physical signs Dean might show to indicate he was relaxed in a certain situation. Taking his seatbelt off voluntarily, getting out of the car, and taking off his shoes were all perceived to be signs that he was relaxed. (Local project team H.)

For teaching participants there is now a stronger commitment to begin by assessing their ASD students' prior knowledge, valuing it and using it to inform their future planning and teaching, while always keeping the student and their unique perspectives at the centre. (Local project team G.)

Several teams found that the best way to develop a complete picture of the whole child was for the team to pool what they knew of and observed about the child in different contexts.

The contributions of team members towards assessments are invaluable. Observations of Heidi's social interactions at home, in the classroom and the playground have given comprehensive insights into her capabilities, which may not all be seen in any one setting. (Local project team A, sub-team 3.)

Other teams found that building a relationship with the child or young person was the best way to truly understand their perspective.

Instead of giving staff a plan of how they need to work with students new to them, they are told that they need to get to know the students first and build relationships with them. (Local project team D.)

Teams acknowledged that taking time to look at the world through the eyes of the young person led to a greater understanding of their perspective, and ultimately practices that improved outcomes.

We acknowledged that this was a very successful visit ... The only variable that had changed was the fact that we had taken the time to write Dean two stories to explain what an airport was and why people go to an airport. It made us realise that we cannot take for granted that Dean will understand or perceive places as we do. (Local project team H.)

The student's actual view of the world needs to be understood and not assumed ... All the teachers acknowledged the importance of understanding their students' unique differences in cognition and the value of being able to walk a little way in the shoes of the students with whom they work ... Several teachers realised that their assumptions about the students had led them to miss teaching opportunities in the past. (Local project team G.)

Using the child's interests for motivation and learning

Many teams recognised that an important aspect of understanding what "made their child tick" was learning to understand what interested the child and using these interests to motivate them and enhance their development.

It was fascinating looking at it from her view – keeping our minds open for opportunities to use her interests to progress her learning. Seeing her interests as valid rather than "getting back to the programme". I can see now that just using interests as a motivator may be limiting. (Local project team G.)

New resources I tried to introduce, which I thought might link with Gina's current abilities, often had no interest to her. I found that it was easier to attempt introductions of small extensions to her current interests ... I had to take the lead from Gina. (Local project team A, sub-team 1.)

By taking the child's perspective, appreciating the child's special interests and considering the whole child, teams focused on what the child was able to do, their many skills and what they were good at. This proved an excellent starting place for extending their learning and development.

Hone showed a positive response too in terms of engagement and motivation, and enjoyed being able to use and share his areas of strength and expertise in his school work. (Local project team G.)

THE CHILD'S WORLD: SOME PRINCIPLES FOR EFFECTIVE SUPPORT

We constantly scanned the literature for new ideas and took those we could use. We did not follow new concepts slavishly, but used the ideas in ways that suited our child, our situation and our culture. (Local project team F.)

The following seven sub-themes are discussed within this section: individualising programmes, focus on changing ourselves, adapting activities and the environment, preparing for transition and change, real-life settings, involving peers and siblings, and benefits for all.

Individualising programmes

A clear theme that emerged was that teams developed highly individualised programmes of support. They used their indepth knowledge of the child to individualise every facet of the support provided.

The specific team culture and the context in which teams were working also affected how support was individualised. For some teams, family preferences and aspirations were deemed a particularly important factor in determining directions, goals, approaches and strategies.

Our long-term goal of increasing Esther's willingness to communicate with others in her environment, and thus to open greater possibilities for inclusion, was kept firmly in front of us by the family. On 21/11 her mother wrote: Thank you for the newsletter. The waka ama² participants did so well ... I would like Esther to be involved in waka ama and surf lifesaving mainly because she comes from a very sporty whānau³ and she is so strong'. (Local project team C.)

Focus on changing ourselves

Many teams discovered the benefit of shifting the focus away from changes within the child to changes within themselves. They recognised that improved outcomes for children and young people were determined by the attitudes, interaction styles and behaviours of the people who support them.

The greatest changes documented have been to team members themselves as they have altered the way they interact with Alex. This has in turn had an impact on the way Alex communicates with us. Bridges have been built that have strengthened mutual understanding. (Local project team A, sub-team 2.)

A supportive environment is one that does not just focus on making changes within the student. It focuses on making changes to the practices of the professionals and the environment. (Local project team D.)

Adapting activities and the environment

Much like teams discovering that it was their attitudes and behaviours that required adapting, and not the child's, they also found that making adjustments to the physical setting and how it was arranged and managed, and learning activities and how they were set up and presented, had positive spin-offs for young people.

To encourage the changes in behaviour we wanted, we would have to alter some of the structures and routines of the centre. This was the most difficult step to take. We found that it is not just students who have autism who cling to structure and routine; as a staff we were equally dependent on it for a sense of stability and safety. (Local project team C.)

Outrigger canoe

³ Immediate or extended family.

Preparing for transition and change

The concept of "transition" was acknowledged as encompassing a broad range of experiences; from shifting between activities in the classroom, to making the move from school to the workforce. Many teams reported that experiences involving transition or change, such as altered routines, new situations and novel events, were particularly tenuous for the young people they were supporting, and yet could not be avoided.

The research also highlighted the fact that "transitions" during a child's/family's life are fraught with pitfalls. Unless these times are handled carefully, years of energy and progress can be undone. (Local project team B.)

Many teams found that preparation, pre-planning and support were vital in times of transition and change.

It is also apparent from Maxine's journal (Alex's mother) and from comments by Toni (Alex's teacher) that preparation for transitions is a parallel process to other interventions. Maxine noted that she prepares Alex ahead of time for Riding for the Disabled, going to stay with relations, shopping, or interactions with friends. Toni reported that she is more conscious of impending change in the classroom, and makes sure that she informs Alex when a relief teacher will take the class. Preparation for changes in the bus timetable and for the class camp were discussion points at team meetings. (Local project team A, sub-team 2.)

Real-life settings

Teams discovered that real-life activities, routines and situations, be they in the education setting, at home or in the community, were the ideal location for children and young people to learn and practice new skills.

Meetings in Gina's home doubled as social events, allowing picture exchanges to be used around desired food items, including her drink bottle and vegetable chips, especially following her afternoon sleep, when she was hungry. (Local project team A, sub-team 1.)

A number of teams learned that to ensure children and young people were able to use their knowledge and skills across settings and throughout their day, team members in all environments had to use consistent strategies and supports. However, some teams found it challenging to guarantee this level of consistency.

Using similar strategies to those used in the research on the computer, Dominic has been able to successfully practice some targeted skills, eg, turn-taking in physical education. (Local project team E, sub-team 3.)

When working on developing new skills, teams built on existing effective practice by starting with strategies that had been successful in the past.

We believed that the most effective [approach to] action research was one where the existing systems are used as the basic framework, with additional questioning primarily designed to explore current practices and determine their strengths and/or areas for refinement. (Local project team F.)

Timing for tackling new skills was considered a particularly important factor by some teams, highlighting that it was important to ensure readiness in the child and the team.

Prepare the ground then seize the moments. Where the child initiates, go with the flow. It appeared to us that Elliot thought about and/or watched some activities for a long period of time before he participated. Our challenge was to be ready to support new experiences when he expressed an interest. (Local project team F.)

Involving peers and siblings

Many of the teams identified the invaluable role played by peers and siblings. Some children and young people at the centre of the teams were very motivated to be with and interact with their peers and appeared to respond particularly well to other young people in their environment.

By term's end it was apparent that even if Esther was not responsive to us she was responsive to peers. We also found that we didn't have to institute special procedures to encourage the other girls to respond, as many responded to her naturally as part of their day ... Additionally, she was able to watch the other girls and learn routines from them ... This became very clear during the physical education lessons when, without us guiding her, Esther watched the other girls in the class getting balls and racquets and went up to get her own. By the end of the term, with a little adult prompting, she would put her gear away in the correct place with the other girls at the end of the lesson. (Local project team C.)

Allowing children to learn from peers gradually became more and more significant throughout the process. Elliot gradually became aware of his peers and wanted to interact with them on an increasing number of occasions eg, he wanted to be part of a reading group rather than read on his own. (Local project team F.)

Benefits for all

Most of the local project teams found that the approaches they were using to support an individual child or small group of children had much wider applicability.

Although the project only involved three students, teachers commented that they would use the findings to support other students with ASD in their school. (Local project team E.)

We found that many of the practices we used for Elliot were, in our view, beneficial for all children in the classroom. These were things such as regular routines, visual timetables, clear simple instructions, regular monitoring of the progress, and specific objectives for the child's progress. (Local project team F.)

PUTTING IT INTO PRACTICE: STRATEGIES FOR SUCCESS

A range of specific strategies and approaches were used by the local project teams. Teams did not attribute their successes to the use of a single approach or strategy. A dedication to teaming and the use of PAR meant that strategies were carefully selected, planned, implemented, fine-tuned and adapted.

The strategies used by the teams are described below under the following outcomes:

- · being with others
- communicating
- · regulating self
- · engaging in learning
- making a contribution.

This clustering of strategies emerged as the teams' reports were analysed. Links can be drawn from these outcomes to the strands of *Te Whāriki* (Ministry of Education, 1996) and the key competencies in *The New Zealand Curriculum* (Ministry of Education, 2007).

Being with others

Several teams found that an important aspect of supporting children and young people with ASD to be with others, was ensuring that others were supported to interact effectively with the child. Strategies used by local project teams included:

- With the family's permission, talk to classmates and siblings about the child's unique ways of interacting and communicating and suggest some effective ways to respond to the child.
- With the family's permission, inform the whole staff about the strategies being used to support the child, to ensure these strategies are used in any interaction the child has with teaching staff.

A whole-school approach is vital. All staff must be able to interact appropriately and confidently with Elliot in the playground and in the classroom, if required. If Elliot has a new teacher every year, the myth of "difference being dominant" lessens, and he will form strong relationships with a range of different teachers. (Local project team F.)

Strategies used by teams that involved peers and siblings included:

- Capitalise on the child's positive response to peers by setting up a buddy system in the classroom or playground.
- Consider the buddy systems carefully the best buddy may be an older child, a child with a similar cultural background, or the same child for a long period of time to ensure consistency for the child with ASD and giving them time to develop a good relationship.
- Allow children with ASD to see new tasks or activities first
 modelled by peers or siblings before they are asked to do
 them themselves; and give them the option to "pass" and
 take their turn later.

Communicating

Most of the teams in some way worked towards enhancing children and young people's communication.

Teams that successfully implemented the Picture Exchange Communication System (PECS) reported powerful examples of what happens when young people are provided with a means to initiate interactions and communicate with others in their environment.

Esther was actually better at [using PECS] than we were at working out what she wanted. After several days of showing us a photo of herself and some other students and pointing to one corner of it, only to be praised for recognising herself, one staff member realised that the TV and video were tucked away in the corner [of the photo]. What we had focused on, the people in the foreground, had not attracted Esther at all. She had focused on the small video, half hidden, tucked away in a dark corner. (Local project team C.)

Teams that worked with children and young people with emerging communication skills discovered the benefit of setting up situations in the environment or sabotaging familiar routines in a way that enticed the child to communicate.

A recently established routine between Gina and the other kindergarten teacher, involving Gina's favourite resource, has intensified their social relationship. The teacher began to tease her by tipping the bead/blocks out from the tote tray, or removing the tote tray of beads from her and hiding it somewhere. When Gina looked for and followed her to reclaim it, it was returned, eventually by exchanging it for the appropriate PECS card. This promoted closer attention to the teacher's whereabouts and activities, more eye contact, and close communication to regain the tote tray. (Local project team A, sub-team 1.)

Some teams used Gutstein and Sheely's Relationship Development Intervention Tracking Form (2002) to both assess and monitor their child's communication and socialisation. They found the tool complex but useful, as a means to promote discussion between the team members and to develop a full picture of the child in different settings.

Several teams acknowledged that communication is a two-way process. These teams focused on the adults adapting their communication styles with positive results. They reported that by sharing the responsibility for successful interactions and making changes to how the adults communicated, the children were able to understand and participate in interactions. These "adult change" strategies used by the teams included:

- Make more comments and ask fewer questions.
- · When asking questions, make them specific.
- Wait longer for responses and be comfortable with silence when working together.
- Use fewer words when communicating, for example, one-word instructions.
- Experiment with different tones of voice the child may respond better to some than others.

I have changed the way I approach Alex now, not asking as many questions, as I found this is what I constantly did, and I gave him more time to process the questions and answer. I also found I shied away from giving him responsibility or tasks, which I am now starting to introduce and he is coping really well. (Local project team A, sub-team 2.)

Regulating self

Many teams identified that the world was a confusing and stressful place for the child or young person they were supporting. They also identified that once stressed or dysregulated, children and young people often became unavailable for learning and interacting. Therefore, supporting children and young people to remain well regulated was an important focus.

The following strategies were used by the teams to support children and young people's regulation and to "keep them in the zone" for learning and being with others.

- Observe the child and find out how they show they are getting tired, feeling stressed or becoming overor under-stimulated. Watch for these signs so strategies can be put in place.
- Find out what it is that keeps the child "in the zone", and allow the child to access these activities or supports.
- Consider what it is that stresses the child and attempt to set up environments and experiences in ways that minimise stressors.
- Ensure the child has opportunity for down-time and breaks in their day, both during and after school.
 Respect the child's need for these breaks.
- Plan for down-times. Some children may prefer to have their down-time in a particular place within the home or school, or space within the centre or classroom.
- Integrate physical activities into learning. Some children may find lots of physical activity particularly calming, or may focus better after periods of being active.
- Negotiate or set times for tasks. Some children may find time pressure particularly unnerving – ensure they have enough time and know how much time they have to complete tasks.
- Consider the sensory demands of environments and activities, and the child's own sensory preferences.
 Make modifications to accommodate.
- Alleviate distraction from sounds. Music or headphones support some children to keep focused during activities, as they screen out distracting noises.
- Consider that the child's actions, such as running away, making a lot of noise or leaving work incomplete, might be them telling you that they are dysregulated and just not able to do any more.

The main ways Elliot seems to de-stress are through plenty of physical activity, eg, in the playground at lunchtime with buddies, via sympathetic adults he can talk to if he has concerns, and by ensuring he has adequate "relax time" at home after school. With these strategies, we have experienced very little overload behaviour this year. (Local project team F.)

Some teams found that providing the child with a sense of order, often with the use of visual strategies, was a useful way to support their regulation.

Both Alana and Vincent had a visual timetable containing their programme for the day. This acted as a stress preventer. Visual strategies were also used

when the students did become stressed – by taking the students back to their timetable to remind them of what should be happening. (Local project team D.)

New experiences or changes to routines were identified by several teams as having a dysregulating effect on children. Teams acknowledged the need to prepare children for these changes with a range of strategies.

- Prepare children for changes to school and classroom routines, such as relieving teachers and changes to library days.
- Use a timer as a way of warning a child about how long until an event or activity finishes.
- If a change is avoidable, ask the child how they would like the change managed.

If people don't communicate in a way that the students understand, this can cause stress to them. For example, one day Vincent wasn't told that he couldn't go to work experience because the person there was too busy to take him. It was discussed amongst the staff but not explained to Vincent. When Vincent was told to get his togs for an alternative activity at the swimming pool he became very upset and stressed ... By using visual strategies and Social StoriesTM, giving clear information and giving time to process information, this stress can be reduced. (Local project team D.)

Social Stories™ were used successfully to prepare children for unfamiliar social experiences. Ultimately, this strategy supported children's ability to stay well regulated during these events.

Social Stories[™] are a useful tool to prepare Dean for:

- the sequence of events
- any potentially negative aspects (we learnt to be much more honest about these)
- reassurance that there would always be support or an "out"
- cognitive understanding about the function of places and situations
- either expected or unexpected changes. (Local project team H.)

Once the team had agreed to develop a set of Social Stories™, team meetings were used to gather as much information as possible ... The resource teacher: learning and behaviour and speech-language therapist collaborated to draft the stories, which were then checked with the rest of the team before being shared with the child. Each Social Story™ involved a number of re-writes. The team attempted to ensure that the stories were as accurate as possible, and based on the child's perspective and not on assumptions. (Local project team A, sub-team 2.)

Engaging in learning

Several teams found that children and young people's engagement in learning was affected by the learning environment itself. Teams discovered that it was the role of the educator to adapt the learning environment to suit the child, and not the other way around. Teams employed a

range of strategies that acknowledged how confusing and stressful education settings were for the child or young person they supported. Many of these are listed previously in the "regulating self" section. Other strategies included:

- Consider how group size within classrooms and centres affects a child's learning and interaction.
 Small group work before and following a whole class activity may be beneficial, as it provides prior warning for new topics and creates repeated opportunities for learning.
- Some centre and school activities can cause sensory overload for children and young people; particularly activities that involve close physical contact with many other children, such as attending assembly or sitting with many other children on the mat. Special considerations may be necessary for these times.
- Consider how the child's physical place in the learning environment affects their engagement.
 Working too close to the front of the room, beside a bright window or working in a place removed from their peers could all affect an individual child's engagement in learning.

We moved Esther's desk from a corner, where she had sat since she started at [the school] and where she felt safe and secure, to the main group in the middle of the room. She, and some staff, would occasionally move it back, so eventually we replaced the space with two comfortable lounge chairs. Despite these minor returns to the past, Esther accepted the move well. Soon she went directly to her "new" desk as soon as she arrived at school and worked there happily all day. We noticed that as soon as she was facing the main part of the room, she became far more interested in what we were all doing. She started to seek staff out far more regularly. She started to seek and use classroom equipment for herself ... Eventually we saw the first instances of Esther choosing to involve herself [in] activities with the other girls. (Local project team C.)

Team members are becoming more aware of Heidi's learning style and abilities. Her position in class is monitored by teaching team members, who note that she is less distracted by her surroundings during circle time if sitting on a chair and not on the floor. (Local project team A, sub-team 3.)

Some teams successfully used school-based learning opportunities to support children's understanding about the wider world, such as travelling on a plane or the death of a family pet. Other teams discovered the power of shaping school-based learning around the child's world, by adapting teaching to their preferred ways of learning and incorporating their area of special interest into learning activities.

It was decided to focus on an individualised school programme around the topic of flight, namely planes and airports. Trips and visits would be scheduled as part of our weekly community programme. The experiences gained, any photographs taken and a library of books borrowed around the topic would become the focus of Dean's reading and written language programme. It was

decided to find a toy airport to be used for the purpose of imaginative play around the airport theme. (Local project team H.)

The teacher decided to plan an integrated learning programme around Usha's interest in balloons. She used a clearfile folder, with an activity for each page, instructions and supports for work, which would systematically be replaced by completed student work. (Local project team G.)

Several teams discovered opportunities and constraints afforded by technology. Computers were successfully used by some teams as means of presenting information, as a way of providing children with some down-time, and as a reward.

Making a contribution

Several teams worked towards ensuring the child or young person they supported was given every opportunity to contribute to centre, school, family or community life. Supporting participation in school events, such as sports days and camps, and family events, such as travelling a long distance for a family celebration, required teams to acknowledge how potentially unsettling these events could be for the young person at the centre of their projects. Respecting this and putting considerable effort into preparing for these events reaped positive rewards for the children and young people and those around them.

[We] increased liaison with home in preparation for school camp, and increased preparation time and class discussion prior to camp about what would happen, where they would sleep, what they would eat, the timetable for activities etc. (Local project team A, sub-team 2.)

Many of the specific strategies teams used made sure the child or young person at the centre of their project had the opportunities and the necessary support to be successful. To ensure that children and young people made a successful contribution, teams adapted tasks and activities in the following ways:

- Show the child how to do a task or activity before asking that they try it – talk about what you are doing as you do it and give the child a chance to observe.
- Allow the child to try new tasks or activities several times before you expect success.
- Allow the child opportunities to "rehearse" a task, activity or conversation before expecting them to carry it out in a group.
- Provide the child with visual cues that show the steps of a task or activity that can be referred to as they do it.
- Carry out a task or activity simultaneously alongside the child with the same resources as they are doing it.
- Reduce the number of variables in an activity or the demands the task place on the child, for example, in a choosing task, reduce the number of choices being offered.
- Break new tasks or activities into small steps and work on just one small step at a time.

A psychologist developed a series of commonsense sequential programmes that gradually ensured Elliot met small, incremental expectations. For example, coming outside for physical education lessons, and then slowly participating for longer periods of time during the lesson. The psychologist's programme involved clear, simple expectations with specific, consistent consequences and meaningful rewards. (Local project team F.)

Some teams found that at times they offered too much support and were careful to ensure that adult prompting was gradually phased out as the child became proficient at a task or activity. They discovered that having high expectations of the child and providing an opportunity to achieve were the best ways to encourage the child to successfully make a contribution. Encouraging, and then acknowledging, a child or young person's success was also important.

CONCLUSION

The importance of holding the individual and their uniqueness at the centre of the support provided emerged as the prominent theme about supporting a child or young person with ASD. Teams were in agreement that individualised programmes were essential and could only be arrived at from a place of deep understanding about the child or young person, their blend of strengths and preferences and their views of the world. This finding supports the "no one approach for people with ASD" principle endorsed elsewhere (eg, National Research Council, 2001).

A distinctly ecological approach was evident in the teams' work. Children and young people were always considered in conjunction with the environments in which they lived and learned, and the communities they were a part of. Consequently, difficulties that children faced were not seen by teams to be within-child issues, but matters of concern for how the environment was set up and for how those within that environment interacted with the young person. This explains why many of the "interventions" used by teams were not levelled at change within the child, but focused on the child's world by adapting the environment, the task and the interaction style of adults and other children. This approach works from a social philosophy of disability and was found by teams to greatly enhance effective support.

The outcomes for children and young people that teams chose to work towards were generally not skill-based nor bound to certain tasks or contexts. They focused on goals that would support a child's participation, and the child's enjoyment of life and learning, in home, school, centre and community contexts. The specific strategies and approaches employed by teams as they worked towards outcomes were carefully selected, planned, implemented and adapted. This process was supported by the teams' commitment to collaboration and the reflective practice that underpinned their use of PAR.

The combined work of the teams revealed the complex relationships that exist between the outcomes being sought for young people and the paths taken by the teams to get there. Similar kinds of strategies were used to support a

range of learning or social outcomes, with teams discovering that supporting development in one area often led to positive changes in other areas. Teams did not attribute their successes to the use of a single approach or strategy. An individualised combination of strategies, targeted at the child's world, and thoughtfully implemented in the context by the team around the child, were what teams agreed worked for them.

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