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This is the thirty-fifth Research Bulletin produced by Middletown Centre for Autism, providing summaries of ten articles from 2018 to 2021.

The Bulletin commences with an interview from Fiona Ferris, Deputy Chief Executive Officer at AsIAm. Fiona has worked with AsIAm since 2017, initially in the role of Early Years Specialist, but assumed the role of Deputy CEO in 2019 and oversees the Training Department within AsIAm. Fiona delivers talks both nationally and internationally about autism, neurodiversity and disability, while contributing her own experiences as an autistic adult and a parent to a child on the spectrum. In her talks, Fiona aims to give practical, relatable knowledge and strategies to assist others in supporting the autistic community to meet their own individual potential and fully participate in their communities. Fiona’s expertise covers a broad range of issues including autism and women, neurodiversity, disability rights, employment, accessibility and education. Outside work, Fiona is an artist and is also completing an Honours Degree in Law.

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
FIONA FERRIS

1. How can community inclusion be best described?
I believe community inclusion is best described as when there is an opportunity within a community for all its members to live, work, contribute and participate without barriers or obstacles to do so. In an inclusive community each person has their individual needs and differences not only accommodated, but celebrated and valued.

2. What does community inclusion mean for autistic children and young people?
Many autistic children and their families experience barriers to inclusion within their community that makes them unable to participate and enjoy the full benefits and offerings that others in their community do. This can lead to social isolation and exclusion for many families. Community inclusion would describe a situation when these barriers do not exist.

3. What challenges do autistic students experience that restricts their inclusion within the community?
The main barriers restricting inclusion for autistic students within the community are communication differences, the sensory environment, lack of predictability and control and the judgement and attitude of others.

4. How can we promote and/or best facilitate community inclusion for autistic children and young people?
In AsIAm’s experience the main reason these barriers for inclusion still exist is due to a lack of understanding of autism and neurodiversity. Through promotion of increased understanding, using education and awareness campaigns that will inform people what the barriers are and what they can do to help, many of these barriers can be addressed and eventually removed.

5. Why is community inclusion important for autistic students?
Community inclusion is something that everyone should be able to benefit from and enjoy. Under the Universal Declaration of Human Rights everyone has the right to participate within the cultural life of the community. The reason this is so important to focus on in terms of autistic people is because of the increased barriers they face to have their human rights met.

6. How can we best support employability among young autistic people within the community?
Unemployment and underemployment are still huge areas of concern within the autistic community, again due to a lack of understanding of autism. Creating and allowing for work experience and placement opportunities within education will help autistic students see what careers they are best suited for; however, there is a large amount of work to be done in the employment space itself to increase understanding and accommodations for autistic people in the workplace.

7. How can families be best supported in relation to community inclusion?
One of the key difficulties families face within the community is social isolation due to the barriers for inclusion they experience. Ensuring that families of autistic children or adults are not excluded or forgotten about when planning community events or social engagement opportunities is essential, as is making sure that these opportunities are inclusive and accessible for all.

8. Are there any fundamental differences between inclusion and integration for autistic children and young people?
Integration is to ensure that everyone has a seat at the table where the discussion is taking place. Inclusion is to ensure that everyone has an opportunity for their voice to be heard.

9. Can the need for individualisation of approach impede the school or community’s ability to provide inclusive practice?
I believe the opposite to be the case. It is only when we take an approach of individualisation that we can truly achieve inclusive practice. All children and students should have their strengths and needs addressed in a holistic, individualised way in order to develop a plan for them to meet their own individual potential. If we do not take an individualised approach, we are not truly achieving inclusion. It is the difference between equality and equity.
BACKGROUND
There continues to be stigma surrounding autism and its acceptance within the wider community. Public attitudes mean that many autistic individuals still experience discrimination because of their diagnosis. A common result is that parents of autistic children experience high levels of parenting strain as well as internalised feelings of stigma. Research suggests that increasing public knowledge about autism can lead to more positive perceptions of the condition; redressing the bias that many autistic children and their families experience in their daily lives. This research paper evaluates the online initiative Sesame Street and Autism: See Amazing in All Children (See Amazing), which was developed by Sesame Workshop as a strategy to increase understanding and acceptance of autism on a community level.

RESEARCH AIM
The aim of this research was to evaluate the impact of the See Amazing initiative across the United States in order to assess a) the acceptability of the materials b) their potential to promote increased understanding and acceptance of autism, and c) whether they promote a more positive attitude towards autism.

RESEARCH METHODS
Surveys were administered online to parents of autistic children and parents of non-autistic children aged up to six years. Participants were provided with a link to the online survey, screened in relation to their suitability and directed to the appropriate baseline survey based on whether or not they were a parent of an autistic child. Both surveys collected measures on knowledge and acceptance of autism as well as parenting matters (parental competence, strain and confidence) and community inclusion; while the parents of autistic children answered additional questions about stigma. Once they had completed the survey parents were asked to spend 1.5–2 hours browsing the materials on the See Amazing website. After one week a follow-up survey was sent to participants that included the same measures as at baseline, but now asked questions on the extent of their satisfaction with the website. The parents of autistic children were also asked to complete a one-month follow-up survey to determine if any additional benefits emerged over time.

RESEARCH FINDINGS
The researchers found that following exposure to the See Amazing website:
(1) parents of both autistic and non-autistic children found the content useful and engaging, and would either use it themselves or recommend it to others.
(2) engagement with the materials led to significant increases in knowledge and acceptance levels among parents of non-autistic children.
(3) parents of autistic children reported positive change in terms of community inclusion, a decrease in parenting strain and improved feelings of parenting competence.

Full Reference
EXPERIENCES PARTICIPATING IN COMMUNITY PHYSICAL ACTIVITY BY FAMILIES WITH A CHILD ON THE AUTISM SPECTRUM: A PHENOMENOLOGICAL INQUIRY

BACKGROUND

This study used thirteen semi-structured interviews to try and understand issues and barriers affecting participation in gross motor activities. The interviews were conducted with families of an autistic child, and investigated the families’ experiences and views on participation.

RESEARCH AIM

The aim of this study was to explore the parental experiences of the autistic child taking part in community gross motor activities and to understand the factors affecting involvement in these activities.

RESEARCH METHODS

Ethical approval was sought and received from Chico, California State University Institutional Review Board. This phenomenological study used semi-structured interviews to collect data from thirteen families with a child on the autism spectrum to understand their experiences as a family attempting to access physical activity opportunities. Eight of the families had an autistic child in their teens and five families had an autistic child under the age of ten. Eleven families had more than one child in the family, and while each family had only one child diagnosed with autism, no siblings were at risk for autism. Purposive sampling was used to recruit parents from like geographic regions that had similar experiences of raising an autistic child. All parents were over the age of thirty, came from a wide range of education and employment backgrounds and were mostly Caucasian with a few being Hispanic or mixed race.

Articles Reviewed

Twenty-nine papers were reviewed. The researchers looked at previous research in relation to the levels of engagement of members of the autistic community in physical activities. Literature identifies the health benefits of physical activity and demonstrates that exercise is an evidence-based practice for those with autism. Limited studies have investigated whether the benefits of gross motor activities apply to those with a diagnosis of autism or if obstacles might exist to limit the autistic population’s access to gross motor activities. Robust evidence can be found on the significance of gross motor activities in neurotypical populations, but limited studies have highlighted the barriers for autistic people. Evidence indicated that most autistic participants enjoyed gross motor activities and that autistic teenagers spend more inactive time and less active time in gross motor activity than their neurotypical peers. Nevertheless, they often stated that they were too busy to do gross motor activities and that it was boring, dangerous, too hot or too cold to partake in these activities. The outcomes of these results are supporting factors in the development of appropriate gross motor activity programmes among individuals on the autism spectrum. More evidence is required to understand the challenges and barriers for autistic individuals, especially because of the great discrepancy between individuals on the autism spectrum.

It is important to note the influence of family members when considering the barriers to autistic children engaging in gross motor activities as children with autism are dependent on these individuals for support when participating in these activities. This was also highlighted in previous studies that recognised several difficulties for autistic children, such as lack of motivation, limited attention, understanding, motor skills and social skills. Family activity can be influenced by the sensory processing needs of the child and has been shown to increase as children gain more independence. Opportunities for gross motor activities are important because when obstacles are reduced, gross motor activities provide chances to build stronger connections to family and to the broader community. Family activities can also aid the development of gross motor abilities, which are linked to functional living skills. Overall satisfaction and competence when participating in activities are important for an individual’s mental health.

RESEARCH FINDINGS

Families who had an autistic child shared their experiences of gross motor activities in the community. This research paper identified the following four themes:

1. Safety outside the home

Safety in the community was the primary concern for all the families in the current study and was defined as any time the family described an incident, situation or environment they perceived as unsafe for their child. Learning new skills in public, concerns of children running away, safety around using playground equipment, stress in relation to the child wandering or having to over plan activities were identified as special challenges for the autistic child’s family. These concerns were consistent across all the families regardless of the age or severity level of the autistic child.

2. Lack of acceptance

Lack of acceptance, isolation and judgement were highlighted by families in this research study. They longed for acceptance and understanding but they described their experiences of feeling judged by members in the community who do not have an autistic child. Due to this perceived judgement families would often avoid busy public places; opting instead to go there at quiet times for fear of being judged if their child had a behaviour event or became deregulated.
3. Behaviour affecting family participation

Behaviour rooted in the autistic child’s inability to cope in social situations, difficulty with change and uncertainty and sensory processing issues were highlighted as the main causes of discomfort to the family and all those involved. This affected family participation and influenced the types of activities that their family could participate in.

4. Limited opportunity for activity

Restricted opportunity for gross motor activity was described as the following: any experience that does not fit the child’s needs and/or the family itself being challenged to take part in the activity or causing the child to opt out. Even though the families in the present study understood the importance of being physically active and were motivated to do this in a community setting, they reported many challenges in engaging in gross motor activities.

**IMPLICATIONS FOR PRACTICE**

(by the author)

This research study examined the factors that impact participation in community gross motor activities for families that have an autistic child. Several limitations to this study should be identified: small sample sizes limit the generalisability of the findings to other populations; only one main interview was conducted for each family, which could have affected the type of information gathered by the researchers; multiple data points would also avoid the burden of a long single interview and would allow researchers to check for corroborative or contradictory information gained from previous responses. Future studies should examine the experiences of families on the autism spectrum in more urban areas and compare this experience to their more rural counterparts. Also, preferences for activities can vary by culture, region, or both, and although the experiences of the families in this study might be true for their area, families in other parts of the country and the world are likely to have different experiences with the autistic community.

(by the reviewer)

Further research is needed to examine detailed information from families. Future researchers might find it advantageous to conduct multiple interviews over several sessions.

Autism awareness training should be widely available in community settings and improve social connections by encouraging parents to become active members of community groups, policy making and planning bodies. Autism-specific activities, accessible for the child and the family, would increase awareness and support the autistic child’s engagement in gross motor activities.

**Full Reference**


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**AUTISM IN AUSTRALIA: COMMUNITY KNOWLEDGE AND AUTISTIC PEOPLE’S EXPERIENCES**

**BACKGROUND**

Historically the definition of Autism Spectrum Condition (ASC) has focused on a deficit-based model. The emerging concept of neurodiversity moves away from this deficit-based approach towards a focus on neurological differences. In the neurodiversity model the strengths associated with autism are recognised, and disability is viewed as resulting from environmental failures to accommodate the needs of the autistic person. With research studies and media coverage reporting the increase in prevalence and incidence rates of autism over the past two decades, public awareness of autism has increased; however, the general population’s understanding of the needs of autistic people and the prevalence rates of autism remains low. This research paper seeks to understand the experiences of autistic individuals in Australia and also to understand community knowledge and attitudes towards autism.

**RESEARCH AIMS**

This study looked to explore the lived experiences of autistic people and their families and also the understanding of autism in the wider community. The research aims were:

a. to investigate community attitudes towards autism across Australia.

b. to examine the experiences of autistic people and their families in the state of Victoria.

**RESEARCH METHODS**

Two separate studies were carried out. In Study 1 a group of 2,424 (primarily non-autistic) Australian adults aged eighteen years and older were recruited through a mixed-mode approach that consisted of telephone and online surveys. The focus of Study 1 was to measure understanding of autism and levels of belief in facts and myths through five key areas of knowledge: Awareness, Prevalence, Causation, Outcomes and Impact. In Study 2 a group of 1,353 autistic adults aged eighteen years or over and/or a family member/carer of an autistic person were recruited to participate in an online survey. The focus of this study was to explore the experiences of autistic people, what is important to them and what they want the wider public to know about how autism affects them.
RESEARCH FINDINGS

Table 1
The data from non-autistic participants in Study 1 showed the following understanding.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Most %</th>
<th>Some %</th>
<th>Few%</th>
<th>None%</th>
<th>Unsure%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulties in social situations</td>
<td>18.0</td>
<td>34.6</td>
<td>39.3</td>
<td>7.1</td>
<td>1.0</td>
</tr>
<tr>
<td>Meltdowns</td>
<td>14.0</td>
<td>29.8</td>
<td>44.8</td>
<td>9.9</td>
<td>1.5</td>
</tr>
<tr>
<td>Stimming (e.g. waving hands)</td>
<td>10.5</td>
<td>28.5</td>
<td>45.5</td>
<td>12.2</td>
<td>2.3</td>
</tr>
<tr>
<td>Anxiety about unexpected changes</td>
<td>5.8</td>
<td>23.5</td>
<td>56.1</td>
<td>13.1</td>
<td>1.5</td>
</tr>
<tr>
<td>Making noise</td>
<td>5.1</td>
<td>25.3</td>
<td>52.4</td>
<td>14.8</td>
<td>2.4</td>
</tr>
<tr>
<td>Literal interpretation of language</td>
<td>4.4</td>
<td>17.3</td>
<td>59.1</td>
<td>17.0</td>
<td>2.2</td>
</tr>
<tr>
<td>Sensory sensitivity</td>
<td>3.6</td>
<td>20.7</td>
<td>57.7</td>
<td>16.2</td>
<td>1.1</td>
</tr>
<tr>
<td>Using language that seems odd</td>
<td>4.4</td>
<td>20.0</td>
<td>58.4</td>
<td>15.0</td>
<td>2.2</td>
</tr>
<tr>
<td>Wandering/absconding</td>
<td>4.1</td>
<td>23.7</td>
<td>52.8</td>
<td>15.6</td>
<td>3.8</td>
</tr>
<tr>
<td>Needing extra time</td>
<td>3.6</td>
<td>14.9</td>
<td>62.1</td>
<td>18.0</td>
<td>1.4</td>
</tr>
</tbody>
</table>

IMPLICATIONS FOR PRACTICE
(by the authors)

- The instruments in this study were devised in consultation with autistic people and family members/carers and highlight the importance of working with the autistic community.
- Increased awareness is needed around the prevalence of autism in girls and around the differences in presentation between males and females.
- Education is needed to reduce misperceptions around autism as these myths are potentially harmful to the autistic population and their families.
- Increased support is needed for older children transitioning to adulthood and for autistic adults.
- Study 2 had the following limitations: the response rate was low (9.4%) and obtained from a single source, therefore any generalisation should be undertaken with caution. Additionally, the sample was predominately female and predominately family members caring for autistic children, who are likely to be more knowledgeable about autism and better able to obtain resources and information than autistic adults or those caring for them, so the needs, concerns and negative experiences of this population may be underestimated.
- More research that incorporates the perspectives of autistic people and the wider community is needed, and this research should underpin the development of interventions with, rather than about, autistic people.

Full Reference
AUTISM IN BLACK, ASIAN AND MINORITY ETHNIC COMMUNITIES: A REPORT ON THE FIRST AUTISM VOICE UK SYMPOSIUM

BACKGROUND
Little is known about the way autism is interpreted and accepted among ethnic minority communities in the United Kingdom (UK). This report summarised a symposium on autism in the UK Black, Asian and Minority Ethnic community in 2018, organised by Autism Voice UK, Participatory Autism Research Collective (PARC) and the Critical Autism/Disabilities Studies Research Group (CADS) at London South Bank University (LSBU).

RESEARCH AIMS
The objectives of the symposium were to highlight different perspectives about autism in ethnic minority communities, to promote inclusion and to preserve the cultural dignity of the community in supporting autistic members. This report summarised the symposium and reported the viewpoints of the participants attending the symposium.

RESEARCH METHODS
Of the sixty-five delegates attending the symposium, twenty-nine participants completed and returned anonymous evaluation forms about the symposium. These included a range of open-ended questions designed to enable participants to express their ideas and share their knowledge and understanding of the topics under discussion and their wider concerns. In addition, the whiteboards were used to capture comments from the day. Four speakers presented on the symposium’s two themes:

• Theme one covered diverse approaches to autism within the ethnic minority community (cultural, religious and ethnic).
• Theme two focused on paving the way to future approaches.

The twenty-nine participants were then divided into groups to discuss the themes from a practical and operational perspective. The groups generated action points that were recorded on the whiteboard. The evaluation covered what participants found useful, what was missing, ideas for future events, suggestions for improvements and offers for future contributions. Thematic analysis of the evaluations and group discussions was conducted.

RESEARCH FINDINGS
The main themes generated from the evaluations included:

• Culture, religion and ethnicity: cultural, ethnic and religious sensitivities were important to participants, who felt that these were often ignored by non-ethnic minority professionals.
• Autism knowledge and understanding: the need for collaboration to improve autism awareness within the community and understanding by professionals of the intersectionality between autism and identity in ethnic minority families was prioritised.
• Stigma: issues around feelings of stigma were common, but delegates felt that these were not well understood beyond people identifying as Black, Asian and Minority Ethnic.

IMPLICATIONS FOR PRACTICE (by the authors)
As a result of the evaluations and discussions held at the symposium, an action plan was created. The action plan highlighted raising public awareness through community engagement, improving access to information for parents and culturally aware autism education for professionals and ethnic minority communities.

This study highlights the importance of:

• the need for autism stakeholders working within the ethnic minority community to establish good partnerships to raise autism awareness.
• the need for professionals to improve their understanding of cultural values of the different populations within the ethnic minority community.
• schools to help bridge the gap between local support services and families from ethnic minority communities, to enhance positive acceptance and recognition and access to appropriate services, and to reduce stigma.

Full Reference
TARGETING IEP SOCIAL GOALS FOR CHILDREN WITH AUTISM IN AN INCLUSIVE SUMMER CAMP

BACKGROUND
Most children with autism face challenges in the development of social skills, despite a desire to form friendships. Goals that target the development of social skills are essential for children with autism as they improve long-term outcomes, such as improving mental well-being, participation in leisure activities, academic achievement and employment opportunities.

Several research studies have found that peer-mediated interventions in inclusive settings are effective in improving socialisation and language development. Research has also indicated that paraprofessionals can be trained in the facilitation of social interactions between children with autism and their peers. There is concern, however, that regression in skill development can occur during school summer holidays when there is less opportunity for interaction. Some studies have examined the effectiveness of intervention facilitated by paraprofessionals taking place during summer camps, but no research to date has addressed the possibility of incorporating IEP goals for social skills into these summer camps.

RESEARCH AIMS
The current study aimed to answer three research questions:
1. Would students with ASD make progress on IEP social goals during an inclusive two-week summer camp with interventions being implemented by a paraprofessional?
2. Would gains in social goals maintain until the following school year and generalise to the child’s natural settings (i.e. home and school)?
3. Would any collateral gains be evidenced following the implementation of an intensive social intervention during an inclusive summer camp?

RESEARCH METHODS
Three boys and one girl, aged 7–14 years, were included in the study. All had a diagnosis of autism and received special education public school services. The paper provides detailed descriptions of each child:

Participant 1: The main areas of concern in relation to his social skills were refusal to play group games, disrupting games and becoming upset during games. He had no goals in his IEP that targeted social skills and was not receiving any specific intervention to facilitate social interactions.

Participant 2: The main areas of concern in relation to his social skills were lack of initiation of interactions and delayed echolalia. He had one IEP target related to social skills, which was to improve eye contact.

Participant 3: The main areas of concern in relation to her social skills were lack of interaction with peers and difficulties in waiting and turn taking. She had some verbal language but used alternative and augmentative communication systems in school. She had one IEP target relevant to social skills, which was to improve her ability to take turns when playing with a peer or adult.

Participant 4: The main areas of concern in relation to his social skills were lack of interaction with peers and limited responses to questions asked by adults. He had two IEP targets specifically on the development of social skills, which were to improve eye contact and infer what another person is thinking, and to tell three details about a recent experience.

A concurrent multiple baseline design was used to collect data across home and school settings. During the two-week summer camp data was collected several times each week and then follow-up data was collected at home and school 1–3 months after the summer camp. Probe data were recorded for ten minutes in vivo or via iPhone recordings.

The summer camp was inclusive and held on a university campus. Participants were separated into different age groups, with 10–15 children per two staff members. Each day ran from 9 a.m. to 3 p.m., and activities included swimming, dance, art and gymnastics. The children with ASD were allocated a one-to-one paraprofessional who was an undergraduate studying psychology and who had undertaken a course in ASD. They were supervised by experienced graduate students.

Intervention during the two-week summer camp incorporated individualised positive behavioural support (PBS) strategies that included:
- priming – introducing the child to the activity and explaining the rules.
- peer mediation – typically developing peers were selected to support the participants with autism by helping them to engage in interactions, take turns, etc.
- self-management – the participants were taught to record their own achievement or absence of the targeted social behaviours.

Intervention procedures for each participant
Participant 1: His IEP goal focused on engagement in non-preferred activities with peers. He was primed for activities and taught to record his achievements on a self-management sheet.

Participant 2: His target was to improve eye contact, and this was facilitated through peer mediation and self-management techniques. He used a clicker to record every instance of eye contact.
Participant 3: Her IEP goal was to improve turn taking, and this was encouraged through peer mediation techniques.

Participant 4: His IEP goal was to give three details about a past experience to a conversational partner. Priming consisted of reminding him of this goal. Peer mediation was used in a question and answer game in which peers asked questions to encourage him to give details. Self-management consisted of the participant independently ticking a sheet each time he verbally shared a detail with peers.

All four participants received individualised tangible rewards when they achieved targets.

The specific details on data collection methods (scoring and recording) are provided in the paper, and the measures taken to ensure fidelity and reliability are also explained.

**RESEARCH FINDINGS**

All four participants made improvements in their IEP social targets, and they all maintained this progress at follow-up across school and/or community settings. The four participants also made collateral gains in initiating interactions and in engaging with peers.

**IMPLICATIONS FOR PRACTICE (by the authors)**

- Children with autism can achieve IEP social targets more quickly in inclusive settings than in non-inclusive settings.
- Unstructured settings, such as a summer camp, can still foster positive social outcomes if carefully designed social instruction methods are used.
- Supervised paraprofessionals can successfully support the attainment of social targets.
- PBS strategies are effective for a wide age range of children.
- Systematic social interventions at summer camps may be beneficial for children with autism and help to prevent regression in skill development.
- Summer camps offer a valuable opportunity for social interactions with peers, and these social skills can be generalised to other settings months after the summer camp has ended.
- The intensive intervention provided at summer camps may be an important factor in the development of social skills. Children were able to apply the learned skills to new peers and in novel settings after the summer camp.

**Full Reference**


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**APPROACHES TO INCLUSION AND SOCIAL PARTICIPATION IN SCHOOL FOR ADOLESCENTS WITH AUTISM SPECTRUM CONDITIONS (ASC) – A SYSTEMATIC RESEARCH REVIEW**

**BACKGROUND**

This article is based on a systematic research review which identified approaches towards inclusive education for adolescents with autism without an intellectual disability (ID). The study included a review of the definitions of inclusion, whose perspectives are taken into account, approaches and their implications from a range of research articles.

**RESEARCH AIM**

The aim of the study is to identify, describe and analyse different research approaches to inclusion and social participation for autistic adolescents.

**Table 2**

<table>
<thead>
<tr>
<th>Activity</th>
<th>Inclusion criteria</th>
<th>Exclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Selection</td>
<td>1. Social participation in school and/or society</td>
<td>1. Age group (infants, children in Kindergarten primary or elementary school, preschool, or adults &gt; 20 years old)</td>
</tr>
<tr>
<td></td>
<td>2. Inclusion in school and/or society</td>
<td>2. Intellectual disabilities</td>
</tr>
<tr>
<td></td>
<td>3. Age group (high school and secondary school, adolescents &gt; 11 years old, young adults &lt; 21 years old and student group in mainstream school, general education settings, no specifically defined age group</td>
<td>3. Diagnosis other than ASC</td>
</tr>
<tr>
<td></td>
<td>4. Articles mainly focused on communicative or behavioural development (i.e., medical or clinical studies) or only in non-educational contexts</td>
<td></td>
</tr>
<tr>
<td></td>
<td>5. Systematic research reviews without a specific focus on inclusion</td>
<td></td>
</tr>
<tr>
<td></td>
<td>6. Book reviews</td>
<td></td>
</tr>
</tbody>
</table>

**RESEARCH METHOD**

In keeping with the research aim, inclusion and exclusion criteria were applied to a database search of journal articles. This was to ensure inclusion of research studies that were specific to autism, social participation and inclusion in education and focused on post-primary students with ID. Research abstracts were reviewed and sorted using the inclusion and exclusion criteria set out below.
After sorting the articles using the selection process, eighty-five articles were reduced to a final sample of fifteen articles to be included in the final review. These articles were examined, analysed and categorised using a thematic analysis process. Articles were categorised into four research areas: articles dealing with topics such as social anxiety; best practice for inclusion and participation; the role of the teacher; and autistic individuals' own perspectives regarding inclusion or participation.

**RESEARCH FINDINGS**

Nine of the articles defined inclusion as 'being socially accepted in the context and socially participating in the group and in the school'. The remaining six defined inclusion as 'being physically placed in mainstream classes, leading to social participation'. Overall, the articles highlighted physical placement in mainstream classes supporting social participation as well as being socially accepted in the wider school context. One of the key factors for successful inclusion and social participation of autistic students is a united whole-school approach towards inclusion.

In total, fifteen articles focused on three perspectives to inclusion and social participation in education: the students', the teachers' and the parents' perspectives.

The research approaches to inclusion and their implications for practice were categorised into four themes.

**First research approach: social/academic inclusion and participation – level of anxiety**

One study examined the relationship between depressive symptoms and psychosocial constructs such as insight into autism symptoms, rumination, desire for social interaction and satisfaction with social support. Their findings suggested that rumination by a young person on their own autism-related difficulties may be linked to a greater risk of depression and declining participation in social activities after high school.

Another study explored social anxiety among individuals with autism and reported a correlation between adolescents with less severe autism and high social anxiety with less social engagement. Results also indicated that severe social anxiety was only weakly correlated with 'feeling lonely', suggesting that those with less severe autism symptoms did not seek few social interactions.

A further study explored how unstructured and structured social participation changed from before to after high school. They defined unstructured as spending time with friends or co-workers and structured as attending social events at a place of work or socialising with sports teams. Results suggested no average change in participation after high school other than some individual variability. For those individuals participation in structured social activities was reduced after high school. Young people with more structured participation in high school were more likely to experience increases in unstructured social participation afterwards. In addition, a high level of internalising symptoms for autistic adolescents during high school predicted increased social isolation after leaving high school.

Overall, anxiety appears to affect adolescents' ability to participate and engage in social activities.

**Second research approach: methods and/or development of best practice for inclusion and social and academic participation for individuals with autism in school and society**

One study evaluated social interactions for autistic students who use augmentative and alternative communication (AAC). Results suggest students mostly interacted with educational professionals and played a passive role within interaction. Additionally, students with AAC devices relied on non-verbal cues such as facial expressions and gestures within interactions.

One study's results that evaluated social interaction by reviewing different interventions suggested peer-mediated interventions (PMI) showed potential. Furthermore, another study suggested within this paper highlighted that specially designed coaching strategies and programmes in sports education were critical for fostering socialisation and developing social skills.

**Third research approach: teachers' perspectives, approaches and training**

A study reported that teachers aimed for autistic students to develop socially, make friends and interact with peers. Additionally, teachers were adamant about supporting typically developing students to behave in a more accepting way towards students with disabilities.

Fourth research approach: autistic individuals' own perspective/view on their social and academic participation in school and society.

A study that explored autistic adolescents' perspective of anxiety induced by pressure from taking part in social activities found that those with more severe autism symptoms were more likely to experience greater interest and enjoyment in leisure than those with less severe autism. Adolescents with higher social anxiety reported higher levels of in-the-moment anxiety while engaging in social activities compared to those with lower levels of social anxiety.

Also, teachers assumed students with disabilities were not the responsibility of the general education system. Researchers reported that teachers generally professed a lack of knowledge about educating students with severe disabilities.

Previous students reported that teachers indicated positive attitudes towards inclusion and those with modern views on integration were more likely to report high levels of inclusion within their school; however, regardless of these positive attitudes towards inclusion of autistic students, teachers expressed concern about potential problems associated with integrating autistic students.
BACKGROUND

Many autistic students leave secondary school without the skills, experiences and supports necessary for work. Data from the United States National Longitudinal Transition Study-2 found that the vast majority of autistic high school students (85%) did not have an after-school or summer job during the previous year, and after leaving high school only about half were employed outside the family home. Two possible explanations are: 1) relative to neurotypical peers, autistic students require more time to develop the skills needed in the workplace, and 2) autistic students need more time to adjust to the new environment.

Authors identified a caveat in research focused on vocational preparation for this population. They found that previous literature reviews focused on job tasks and specific job instruction rather than on pre-employment skills and the social communication skills needed for engagement with co-workers and customers. Cumulatively, these studies reveal that pre-employment training needs to support autistic students to develop skills in relation to the task/work, social communication and adaptive behaviours as not having these skills are a barrier for autistic students.

RESEARCH AIMS

To extend understanding of the vocational support needs of secondary school–aged autistic students, this paper reviewed anonymised evaluations of a pre-vocational programme called CommunityWorks Canada® across three years.

The aim of CommunityWorks Canada® is to develop and reinforce socially appropriate interaction and workplace specific skills. It is a government-funded thirty-hour pre-employment programme delivered each week after school for twelve weeks to autistic students aged 15–21 years old. The autistic students work in partnership with neurotypical volunteer peer mentors in public, private and not-for-profit community businesses that are potential areas of interest for future employment for the autistic student.

RESEARCH METHODS

Data was collected from programme evaluations at seven sites in five provinces in Canada between April 2015 and March 2018. The evaluations consisted of pre- and post-programme standardised questionnaires, satisfaction surveys and qualitative interviews that explored stakeholders’ (autistic students, parents, neurotypical peer mentors and employers) perceptions of the programme and its impact. Comparative analysis of pre- and post-programme scores was conducted using quantitative data management software (SPSS).

The following standardised tools were used:

<table>
<thead>
<tr>
<th>Pre-CommunityWorks Canada®</th>
<th>Post-CommunityWorks Canada®</th>
</tr>
</thead>
<tbody>
<tr>
<td>Peabody Picture Vocabulary Test–4 (PPVT-4)</td>
<td>Work Readiness Inventory (WRI)</td>
</tr>
<tr>
<td>Waisman Activities of Daily Living (W-ADL)</td>
<td>Social Skills Improvement System (SSIS)</td>
</tr>
<tr>
<td>Social Responsiveness Scale–2 (SRS-2)</td>
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IMPLICATIONS FOR PRACTICE

This systematic review highlights several key implications for future practice:

- Whole-school inclusion requires all staff to have a clear and shared understanding of the aims and expectations of inclusion within their school. This must also be supported by senior management.

- Further understanding of the ways in which social activities may influence the internalisation of symptoms is important. They are amenable to intervention and could potentially improve mental health.

- Strategies for managing anxiety and research approaches to improving social skills are among some of the measures available to young people. Direct interventions such as social-skill training designed especially for the individual may have a positive effect.

- Social interaction opportunities should be carefully planned rather than hoped for. Additionally, students with AAC should have ongoing access to appropriate AAC systems so they can be active communicators.

- Generic training for all school staff about students may not always be appropriate. Teachers reported a preference for informed, targeted training for groups working directly with autistic students.

Full Reference

At conclusion of the programme surveys were distributed to autistic students, parents, peer mentors and community partners/employers to determine overall satisfaction with the programme. Additionally, the programme evaluators interviewed a subsample of eight autistic students, nine parents and seven peer mentors. NVivo data management and analysis software was used to code the interviews and to generate themes.

**RESEARCH FINDINGS**

All participant groups reported skill development in the areas of work preparedness and social skills.

There was a significant decrease in all scores on the WRI, indicating fewer work-readiness concerns. Also, survey results from autistic participants and their parents indicated growth in work-readiness skills.

Post programme over 70% of autistic participants indicated they were more prepared to find a job, and 71% agreed or strongly agreed that they developed job-related skills and abilities, learned the importance of teamwork in the workplace, how to interact at work and the importance of trustworthiness and the need to be reliable in the workplace. Involvement in the programme enabled autistic students the opportunity to explore different types of jobs and job tasks. It also boosted autistic students’ self-confidence in relation to getting a job, coping with employment, working with others, self-advocacy, understanding and managing emotions, undertaking roles and completing tasks. Developing these skills are perceived to be integral to ultimately finding a job.

Over 80% of parents agreed or strongly agreed that their autistic youth had gained an understanding of necessary job skills, and almost half indicated improved understanding of career fit.

Although no significant changes in overall social skills were reported on the SSIS, autistic participants and parents indicated positive changes. Seventy-one per cent of autistic students agreed or strongly agreed that their communication and social skills as well as understanding of social cues had improved as a result of engagement in the CommunityWorks Canada® programme, and over 50% of parents indicated that there was noticeable gain in their adolescent’s communication and social skills.

Community partners/employers and peer mentors identified gains in personal knowledge and attitudes about autism. They reported appreciation for what they generally described as a frequent strong work ethic among autistic participants. They also reported that their involvement in the programme enhanced their knowledge about autism while simultaneously decreasing worries and negative stereotypes associated with working with autistic individuals.

All neurotypical peer mentors agreed or strongly agreed that participation in the CommunityWorks Canada® programme had positively affected them by deepening their understanding of autism. Other identified gains included an increase in social connections, with subsequent improvement in social efficacy and mastery. These gains increased personal confidence as well as perceived connections with autistic peers.

Follow-up phone calls with autistic participants and/or their parents were attempted at three, six and twelve months post-programme to inquire about post-secondary education and volunteering or paid employment. A significant difference was found only for employment rate: the employment rate for autistic participants increased to approximately 20%; however, most of the participants (83%) worked less than twenty hours per week, and all were in entry-level positions (e.g., food delivery, dish washer and yard maintenance) with the vast majority (89%) earning minimum wage.

**IMPLICATIONS FOR PRACTICE**

(by authors)

Autistic students experience more challenges compared to their neurotypical peers with regard to work readiness and employment. This is in keeping with research that recommends pre-employment activities in secondary school.

The programme provided initial exposure to work experience and a way of overcoming being unemployed as well as a pathway to employment.

Qualitative and survey data identified social communication skill gain. These gains were not captured on the SSIS. This amplifies the need for sensitivity when using evaluative instruments to assess progress for autistic youths and preparing and building employment-oriented social skills.

Parental expectations for their autistic youth’s vocational future, including increased independence and integration within the community, benefited from the young autistic person participating in this programme.

Neurotypical peer mentors and community partners benefit from participation in work-readiness programmes. This is helpful in creating more diverse acceptance in workplaces and communities.

School-based activities focused on nurturing work exposure and the development of skills are needed for the workplace. These processes are integral to future employment for autistic students.

Full Reference

COMMUNITY LED CO-DESIGN OF A SOCIAL NETWORKING PLATFORM WITH ADOLESCENTS WITH AUTISM SPECTRUM DISORDER

BACKGROUND
Autistic adolescents face challenges in forming positive friendships. Although social networking sites can provide a platform for autistic people to communicate and socialise with their family and friends, many autistic people and their parents/carers may avoid such sites due to the potential risk of inappropriate content and cyberbullying. A local community such as a support group may provide a familiar and regulated social networking site for autistic individuals.

This paper presents the results of a study that involved the development of a social networking platform based on the needs of a small group of autistic adolescents and their parents/carers. The paper further examines what potential benefits such a system could provide and discusses the role of autistic adolescents as participants in the co-design process and how other stakeholders, such as community support groups and/or parents, play a critical role in supporting the co-design process.

RESEARCH AIM
The aim of this study was to investigate how autistic adolescents can be involved as co-designers in building a community social networking site (InterestMe) through an iterative software design process over an extended period of time.

RESEARCH METHODS
The study implemented the key principles of shared outcomes and community immersion from Participatory Action Research (PAR) as overarching principles. Six participants (five boys and one girl) were all members of an autism support group and were aged 14–16 years old. Only one participant had prior experience in game design. To be eligible to take part in this study participants were required to have been diagnosed with Asperger’s or ASD without language or intellectual impairment. Participants were recruited through channels such as Facebook and a monthly newsletter. Five participants were recruited at the start of the study while one participant joined from workshop three onwards. Participation was voluntary and they could withdraw at any time.

The researchers conducted seven co-design workshops with six autistic adolescents over a period of eight months. The team (which consisted of the researcher and participants) exchanged ideas and communicated through group discussions and drawings. Each workshop lasted for two hours and was recorded. All workshop conversations were transcribed and analysed together with other items such as drawings and voting results using thematic analysis. Thematic analysis allowed the researcher to identify emerging concepts and to understand participants’ concerns. At the beginning of every workshop the results were shared with the participants. A member-checking method was employed, which permitted participants to amend any misinterpretations of the data points documented across the study and the results.

A community immersion approach was adopted. The researcher joined the support group ten months prior to the first workshop. The researcher participated in monthly committee meetings and social and fundraising events organised by the group. Attendees of the autism support group’s activities included autistic members and their parents/carers. The researcher developed a computer club for the autism support group with the support of an executive committee. The computer club acted as a facility for autistic adolescents who were interested in technology to socialise and exchange ideas through monthly meetups. The researcher planned and organised the monthly computer club meetings, which involved liaising with parents on registrations and providing mentorship for the club members. The computer club ran for eight months prior to the first co-design workshop. This immersion approach in the research environment provided the researcher with key insights that were invaluable in the research study and enabled the participants to become familiar with the researcher and study prior to it commencing. Everyone involved in the study, i.e. the autism support group, participants, caregivers and the researcher, was able to establish and understand the shared goals and potential outcomes of the study.

RESEARCH FINDINGS
In this study the community-led social platform aimed to provide a safe and localised environment for the autism group members to socialise and interact online. Within this study participants felt safe to comment and post on the community social networking.

The findings from the study suggest that:
(1) participants demonstrated self-advocacy skills through an iterative co-design process.
(2) a safe and familiar environment encourages active participation from autistic adolescents as co-designers.
(3) parents, community groups and fellow participants play a pivotal role in engaging autistic adolescents on a social network.

IMPLICATIONS FOR PRACTICE
(by the authors)
The authors highlighted that although there is an increasing call to adopt a user-centred design approach in software, many software designers face challenges in adopting these approaches when designing for groups with special needs.

Both community immersion and co-design approaches require significant time investment and skills of the researcher/designer to carry out the activities. Organisations may not have the resources to invest in long hours of community immersion prior to the design phase. In addition, organisations may not have trained designers who could adapt co-design methods to suit the capabilities and needs of autistic people. Organisations developing software for autistic people can consider partnering with existing community groups, such as support groups or schools, in co-designing the software. Co-design methods and principles can be shared with personnel from the community groups and they will conduct the co-design workshops with the target users. Extensive community immersion would not be required in this approach.

A person with attention deficit hyperactivity disorder (ADHD) may have different needs and wants in relation to technologies and their personal situation may inspire a different genre of designs.

Full Reference
INCLUDING STUDENTS WITH AUTISM IN SCHOOLS: A WHOLE SCHOOL APPROACH TO IMPROVE OUTCOMES FOR STUDENTS WITH AUTISM

BACKGROUND
With the increasing number of autistic students and their families now choosing mainstream education, alongside the recommendation of the Salamanca Statement (1994), education professionals are striving to deal with the challenge of meeting the specific needs of each student, including autistic students, within their educational setting. As this specific challenge is not addressed in teacher training preparations, teachers feel that they need a greater level of support and training to ensure that they fulfill their vocation, provide child-centred pedagogy, and thus educate children in a safe and inclusive setting. Therefore the need to formulate a whole-school approach where ‘each school should be a community accountable for the success or failure of every student’ (Salamanca Statement, 37, means that the school principal, class teachers, family and the entire student body have been identified and the following evidence-based suggestions offered.

RESEARCH AIMS
This research aims to design a model of intervention based on the identification of effective and evidence-based practices that will deliver inclusive programmes and interventions to meet the needs of not only the autistic students in a mainstream school but the entire school body, made up of professionals, parents and all students. They based the characteristics of the model of intervention on previous research, which highlighted a range of considerations: family involvement, accessibility of adequate resources, staff knowledge and awareness of autism, the diversity of strengths and needs of autistic students and the need for differentiation of practice with appreciation of the impact of the environment.

RESEARCH METHODS
After extensive research into current best practice on inclusive education and relevant modes of inclusion for all students, including autistic students, the researchers derived an inclusive model that focused on the design, implementation and evaluation of the school-wide autism competency approach (SAC). This model addresses specific processes, with a guiding leadership team at the helm, and four distinct stages:

1. Exploration Stage
2. Installation Stage
3. Initial Implementation Stage
4. Full Implementation Stage

Recognition is given to the benefits of external supports.

This model of intervention has only been trialled in three schools, and at present the outcomes are unpublished and unreported. Such an approach is broken down into the three key areas: leadership, competency and organisation and is designed to empower school communities to formulate an evolving, progressive pathway that marries the needs of all involved.

RESEARCH FINDINGS
SAC recommends the identification and formation of a strong leadership team that guides, implements and evaluates the approach as it is applied to each particular setting:

- A principal actively implements the recommendations and sources the relevant resources required, thus establishing and maintaining a whole-school approach ethos.

- A curriculum specialist teacher, allowing for acknowledgement of the academic content and the practical application of the practices.

- A special education specialist teacher, bringing knowledge of autistic children and evidence-based practices.

- A parent of an autistic child to oversee the identification and appreciation of the strengths, future hopes and needs of the autistic children.

- A parent of a non-autistic child, offering community and whole-school appreciation.

- An autistic student, allowing for lived experiences.

- A non-autistic peer, offering suggestions for inclusion within the peer group.

The first step is to ascertain whether student outcomes have been maximised through an analysis of shared leadership, professional learning, conditions for learning, curriculum and teaching and engagement with families and the community, as each will have a bearing not only on the whole-school inclusive ethos, but also on the autistic child reaching his or her potential and being a fully included member of the school. SAC also recommends identifying key external agencies that may be supportive and developing cooperative links with them.

- Regional supports – supporting with funding and additional expertise.

- Critical friend – an external support who can observe and offer constructive but honest feedback while retaining focus – the inclusion of autistic students.
**Exploration Stage**

- Development of a shared vision – a whole-school approach.
- What are the school community’s priorities?
- Recognition that there is a need to include autistic children in a tiered approach designed to meet the students’ needs at specific times throughout the school year. Tier 1 is whole-school strategies, Tier 2 is classroom strategies and Tier 3 is individual goals and strategies.
- What practices are currently being used within the school?
- Where are the gaps?
- Is external support needed or would dissemination of internal good practice be valuable?
- Are they, as a whole school, meeting their goals?
- Could these goals be differentiated or amended?

Each section is rated as being met, partially met or yet to be developed, then prioritised as to which will be developed first.

**Installation Stage**

This is the action research component to the programme. Can best practice or evidence-based research or practice be successfully implemented within the context of a mainstream school that must deliver the curriculum to the full student body as set out by government policy? This means practically implementing what at times appears to be the theoretical perspective.

- Are the identified strategies workable within the school environment?
- Are the needs of the children being addressed and how practical are the interventions?

Time-sensitive goals are agreed upon and set to meet the targets in the Exploration Stage and determine whether the strategies needed to meet the goals are whole school, class level or individual student level.

**Initial Implementation Stage**

Evaluation at team level as to how the goals are progressing.

- Do they need to be tweaked? Are they easily accomplished by every class teacher?
- Is this an issue that needs to be brought back to the leadership team for further clarification, modification or provision of more suitable resources?
- Are there additional unforeseen barriers that must be addressed?

**Full Implementation Stage**

The embedding of the agreed interventions and strategies as a means of creating an inclusive culture.

**IMPLICATIONS FOR PRACTICE**

(by the authors)

The inclusion of autistic students in a mainstream setting can be incredibly difficult and calls upon the amalgamation of a wide range of evidence-based considerations, including Universal Design for Learning (UDL), Response to Intervention (RTI), Schoolwide Positive Behaviour Support (SWPB) as well as recognition of the diverse needs of autistic students and differentiation of the appropriate interventions at different times throughout the students’ school day, week or year.

This SAC approach calls on the professionalism of each concerned team member to develop and maintain a whole-school ethos of inclusion. Therefore, everyone has a responsibility to:

- recognise the complexity, diversity and individuality of autistic students.
- appreciate how modifications to the environment can have such a positive impact on the learning opportunities for the students.
- understand that a positive learning environment can lead to improved participation and achievement in school and in post-school opportunities.

- realise that autistic students can and will learn and develop in conducive teaching, learning and inclusive environments.

With such diversity it is worth noting that teachers are continually reviewing their pedagogy and sometimes need additional support, learning, time and resources to ensure that they can meet the needs of their students.

Teachers are striving to meet the needs of their students while experiencing stress and anxiety as they try to formulate supportive interventions, but they also need support that they can call upon at different times throughout the school year knowing that their input is valued and valuable to the construction of such an inclusive school environment.

Parental contribution and collaboration are vital to the success of any inclusive school ethos and provision.

The challenges faced are whole-school challenges best addressed by a whole-school response for the betterment of all concerned team members.

**Full Reference**

CONCLUSION

BACKGROUND
For autistic children and young people community inclusion, being able to work, contribute to, participate in and feel safe without barriers can be difficult. This is especially true in relation to social inclusion, education and employability. Often these difficulties stem from a lack of understanding of autism and neurodiversity.

To have true community inclusion, participating, being accepted by others and having the opportunity to be heard is vital. This can be achieved by building awareness among the public as a means of changing attitudes, dispelling myths, improving policies and having adequate support services available.

Key points from the articles included within this Bulletin are provided below, giving practical advice in relation to how best to promote and encourage true community inclusion.

- Increasing understanding of autism (e.g. the presentation of autism between males and females) through education, awareness and/or public health campaigns is a priority. Increased knowledge and understanding will help inform people what the barriers are and what they can do to help. With this knowledge and awareness many barriers, including misconceptions and stigma around autism, can be broken down and removed.
- Collaboration is key. Involving the autistic community in decision-making, planning and the development of activities and programmes is important in improving and valuing their input in the promotion of community inclusion as is considering the cultural, religious and ethnic needs of everyone. This can be achieved, for example, by:
  - schools helping to bridge the gap between local support services and families from ethnic minority communities.
  - summer camps that may also offer valuable opportunities for social interactions, helping autistic children to achieve individual social targets more quickly within an inclusive setting than in non-inclusive settings.
  - whole-school inclusion where all staff have a clear and shared understanding of the aims and expectations of inclusion within their school and can further contribute to promoting community inclusion, especially when this is supported by senior management. This will help to build understanding in the complexity, diversity and individuality of autistic children and young people allowing for their strengths and skills to be built upon.
  - the development of peer intervention initiatives that can have a positive influence on changing attitudes and perceptions towards the autistic community.
  - having training for all school staff that is specific to the autistic students who are being supported.
- Increasing support for older children transitioning to adulthood. For example:
  - to improve their employment prospects, the creation of work experience, placement opportunities and pre-employment activities (developing skills needed for the workplace) at post-primary level will help autistic students to see what careers they are best suited for.
  - employers increasing their understanding of autism and making accommodations for autistic people in the workplace.
  - understanding how social activities may influence the internalisation of symptoms so strategies can be put in place to manage anxiety that can often deter families from participating in community activities.
  - when planning community events and activities or social engagement opportunities, ensure families of autistic children or adults are not forgotten by making sure that opportunities for community inclusion are inclusive, safe and accessible for all.

Ultimately, as highlighted by Fiona Ferris, in an inclusive community each person should have their individual needs and differences not only accommodated but celebrated and valued. This should be borne in mind when supporting autistic students and their families across different environments and the community as a whole.

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.

Research Bulletin Feedback
Community Inclusion
The Centre’s Research and Information Service welcomes any correspondence including suggestions for future Bulletins to: research@middletownautism.com


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