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Journal of Speech, Language, and Hearing Research

A letter to editor regarding Bambara et al. (2021) "Using Peer Supports to Encourage Adolescents with Autism Spectrum Disorder to Show Interest in Their Conversation Partners"

--Manuscript Draft--

Manuscript Number:	JSLHR-22-00028R1
Full Title:	A letter to editor regarding Bambara et al. (2021) "Using Peer Supports to Encourage Adolescents with Autism Spectrum Disorder to Show Interest in Their Conversation Partners"
Article Type:	Letter to the Editor
Section/Category:	Language
Corresponding Author:	Nathan Keates University of Kent Canterbury, Kent UNITED KINGDOM
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Keywords:	double empathy problem; communication; Autism
Manuscript Classifications:	Autism; Communication; Social communication
Abstract:	<p>Purpose The purpose of this letter is to address interpretations regarding Bambara et al. (2021) study and help resolve potential for further missteps within this line of research.</p> <p>Conclusion There is clear value in teaching skills that are wanted by autistic people. The primary issue within the paper is that it does not acknowledge the double empathy problem and is constructed based on only a neurotypical system of interpretation or communication style. What is being promoted is to address skills autistic participants request.</p>
Response to Reviewers:	<p>Dear Prof Stephen M. Camarata,</p> <p>Thank you for offering the opportunity to submit a revised draft of my manuscript titled: 'A letter to editor regarding Bambara et al. (2021) "Using Peer Supports to Encourage Adolescents with Autism Spectrum Disorder to Show Interest in Their Conversation Partners"' to Journal of Speech, Language, and Hearing Research. I appreciate the time and effort that you have dedicated to providing valuable and insightful feedback on the manuscript. We are grateful to the review for the insightful comments on the paper and have highlighted the changes in the manuscript in yellow.</p> <p>Here is a point-by-point response to the reviewers' comments and concerns.</p> <p>Comments from Reviewer 1</p> <p>We have addressed reviewer one's comments point-by-point, and will respond to each comment.</p> <p>The letter raises important issues. However, the frame seems to be primarily on high functioning autistic people. Because of this, the letter should include a short, but more detailed description of how autistic people broadly, who have very diverse communication ability, can be included in the key points you make. Specifically, how autistic people who are nonverbal or minimally verbal can be included in this rubric should be acknowledge and/or addressed. Also, the people in Bambara et al were adolescents, so it is unclear how this is balanced with parent rights and responsibilities. -This is an important point. Thank you for bringing this to my attention. I have addressed this in the manuscript parallel to the rest of the letter. Further detail is available to what has been written – however, I sought to be concise to avoid obscuring the points being made.</p> <p>On the manuscript title page: - Please include the author's full name and affiliations</p>

- Please include the contact information for the Corresponding author
- Please include a Conflict of Interest statement. If there are any relevant conflicts of interest please list them or if none state that there are no conflicts of interest.
- Please include a Funding Statement with the types of funding you received for this work. If funded by a grant, please include the grant number and the name of the recipient of the funding. If no funding was received, please state that you did not receive funding.
- All of the above have been provided on the title page, as well as acknowledgements of further insight pooled from autistic colleagues (added to the manuscript).

Yours Sincerely,

Nathan Keates

19.1.2022

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A letter to editor regarding Bambara et al. (2021) “Using Peer Supports to

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Encourage Adolescents with Autism Spectrum Disorder to Show Interest in

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Their Conversation Partners”

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The authors have no conflicts of interest to declare.

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This study was unfunded.

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21 **Abstract**

22 **Purpose** The purpose of this letter is to address interpretations regarding Bambara et al. (2021)
23 study and help resolve potential for further missteps within this line of research.

24 **Conclusion** There is clear value in teaching skills that are wanted by autistic people. The primary
25 issue within the paper is that it does not acknowledge the double empathy problem and is
26 constructed based on only a neurotypical system of interpretation or communication style. What is
27 being promoted is to address skills autistic participants request.

28 Key words: double empathy problem, communication, autism, skill development, system of
29 interpretation, neuronormativity.

30

31 Introduction

32 Bambara et al.'s (2021) study investigated three autistic participants to help their development of
33 peer-focused conversation with a cue sheet to assist in self-reflection. The paper addresses the
34 development of capabilities the three autistic participants did not have previously well. Enabling the
35 skill development of abilities frequently required in life (such as language and flexibility) can be
36 beneficial (Kapp, 2020). Nonetheless, due to potential literature missed, some key factors have not
37 been considered. For example, as McCracken (2021) argues, the practice of altering autistic
38 communication is essentially asking them to pass as neurotypical (of which it is known causes harm,
39 Cage & Troxell-Whitman, 2019; Halsall et al., 2021; Libsack et al., 2021).

40 Considering the Double Empathy Problem: Autistic Sociality

41 Autistic people tend to have to change to suit other people's communication styles (Williams et al.,
42 2021). Ensuring the social engagement of communication is put upon the autistic person, terming
43 them as 'socially disabled'. This creates social pressure upon them to accommodate the neurotypical
44 communicative need. However, as per Morrison et al. (2020), the perception of atypical autistic
45 sociality is unfounded and there is a need to acknowledge the real-world relational dynamics. Recent
46 studies including those by Crompton et al. (2020) and Morrison et al. (2019) found there are benefits
47 for autistic people to socialising with those with an insider identity, e.g., being autistic. The
48 neurotypical difficulties experienced by the mismatch in neurotype with autistic peers are an
49 important part of the social difficulties (Davis & Crompton, 2021) upon which Bambara et al. (2021)
50 is based. Furthermore, Bambara et al. (2021) indicate how the goal of demonstrating interest in their
51 conversation partners was through verbal means, but other forms such as non-verbal methods exist
52 (e.g., nods, smiles and eye gaze). Jack (2013) discusses that autistic communication does not seem to
53 be constructed as neurotypical human communication. Instead, autistic people may engage in
54 communication through their system of interpretation (contrary to the wider cultural norms, e.g.,
55 eye contact in many western cultures) (Williams et al., 2021). Similarly, such systems of
56 interpretation (i.e., backchanneling, the verbal sounds made to signify the interlocutor is listening)

57 are found to not be used in the homogenous autistic neurotypes interlocutors (Rifai et al., 2021).

58 Albeit that it is commendable that the autistic participants in Bambara et al. (2021) were not forced
59 to adhere to neurotypical backchannelling, the peer focus within the study means the skills are still
60 comparable to the neurotypical peers. Thus, the peers were assigned more power in regard to their
61 position within the research, i.e., improving the autistic participants' conversation skills.

62 DeBrabander et al. (2021) reports that autistic people have rapport with other autistic people due to
63 the *lack of* impediment that any one social encounter has upon a desire for another social exchange.
64 In fact, Crompton et al. (2020) found that neurotypical people self-rate themselves higher than
65 observers and autistic people are more accurately self-rate their rapport. Therefore, this reifies that
66 autistic people do not *need* to learn peer-focused communication when their communication may
67 be accepted elsewhere.

68 Likewise, non-speaking autistic people have a non-normative communication style (Ashby &
69 Causton-Theoharis, 2009; Baggs, 2012; Lehenhagen, 2019). For examples of autistic accounts of
70 being non-speaking, see Higashida et al. (2016) and Baggs (2012). As for autistic people in moments
71 of greater support needs (to avoid the misnomer of high/low binary of 'functioning'; Alvares et al.,
72 2019), a hypothetical triggering event may leave someone to be selectively mute (e.g., Peña, 2019);
73 if those around them empathise and are supportive, there is scope to engage in the communication
74 style necessary in that moment. For an example of positive engagement with non-speaking autistic
75 children, Jaswal et al. (2020) found parents could form an emotionally reciprocal relationship with
76 their child(ren) by considering the forms of connections the child offers (assuming competence and
77 through acceptance).

78 Milton's (2012) double empathy problem relates to these issues through a mismatch of salience. The
79 autistic participants were not understood when using their own communication style and as such
80 were required to comply with and emulate their neurotypical peers.

81 The autistic voice matters

82 As social validity centres on the social importance and acceptability of goals (Foster & Marsh, 1999),
83 in this case, network peers' agreement about whether autistic people succeeded may not hold true
84 social validity for the autistic participants. With ten neurotypical peers and three autistic people, the
85 study reported asking the neurotypical peers whether the autistic participants achieved their target
86 skills. This places the perceived social validity onto the neurotypical participants, rather than the
87 autistic participants. This echoes the concern regarding social validity as given above, and further
88 amplifies a mismatch of salience. Crucially, this is a case of 'oughtism' (Evans, 2019), whereby
89 autistic people ought to be other than themselves. The weight of whose opinion matters is at
90 disparity. Therefore, their opinions are diminished unless they match the views of their network. It
91 remains unclear whether the autistic participants were asked if these skills were desired. There are
92 autistic people that do want to learn 'relevant' social skills to fit in with society or maintain
93 friendships, yet everyone must adapt their communication (to some extent) dependent on who they
94 are talking to (i.e., in relation to Milton's Double Empathy Problem).

95 It is vital to engage autistic people in *their* needs. An ever-increasing amount of work is being
96 conducted acknowledging the need of the autistic voice in research (e.g., Ashworth et al., 2021;
97 Botha, 2021; Pellicano & den Houting, 2021; Waldock, 2019). Therefore, this should be the same
98 within research that is attempting to support and form development opportunities. It is only too
99 common that the autistic experience is devalued (Baggs, 2010). Akin to Arnstein's ladder of citizen
100 control (Arnstein, 1969), autistic people should have a level of power equivalent to citizen's control
101 (Arnstein, 1969) regarding their own autonomy (including desired skills taught), and more broadly,
102 research about autistic people (or preferentially with autistic people).

103 The power imbalance noticeable in Bambara et al. (2021) begs the question about reporting what
104 was wanted by the autistic participants (and not just 'enjoyed'). We need to acknowledge the impact
105 of compliance (see Sandoval-Norton & Shkedy, 2019), the need to change the widely accepted

106 normative idea about what being social means (neuroqueering interpersonal communication theory;
107 Cole, 2021), and autistic people being valid in and of themselves (Yergeau, 2017). There is a growing
108 body of knowledge which demonstrates the importance of gaining a positive identity (which would
109 include autistic system of interpretation) and being accepted by others improves quality of life (Cage
110 et al., 2018; Cooper et al., 2017).

111 Lastly, language used to describe autistic people in the field of autism research has been found to
112 vary across different groups of people (Kenny et al., 2016). Although some autistic people will use or
113 want person-first language, it is important to acknowledge the role of stigma (Bottema-Beutel et al.,
114 2021) and how many autistic people understand being autistic as part of their identity (Sinclair,
115 2013). This is vital to consider, especially when considering power imbalances and the autistic voice
116 within research.

117 **Conclusion**

118 There may be some scope to run skills training that matter to autistic participants. However, social
119 and communication skills must address the double empathy problem and not require autistic people
120 to adhere to a neurotypical system of interpretation. Furthermore, being critical of who is defining
121 what is relevant in regard to power imbalances is a necessary consideration. Lastly, social validity
122 must be both important and acceptable for the primary, key stakeholder(s), i.e., the autistic
123 individuals.

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127

128 **References**

- 129 Alvares, G. A., Bebbington, K., Cleary, D., Evans, K., Glasson, E. J., Maybery, M. T., Pillar, S., Uljarević,
130 M., Varcin, K., Wray, J., & Whitehouse, A. J. O. (2019). The misnomer of 'high functioning autism':
131 Intelligence is an imprecise predictor of functional abilities at diagnosis. *Autism*, 24(1), 221-232.
132 <https://doi.org/10.1177/1362361319852831>
- 133 Arnstein, S. R. (1969). A Ladder of Citizen Participation, *Journal of the American Institute of*
134 *Planners*, 35(4), 216-224. <https://doi.org/10.1080/01944366908977225>
- 135 Ashby, C. E. & Causton-Theoharis, J. N. (2009). Disqualified in the human race: a close reading of the
136 autobiographies of individuals identified as autistic, *International Journal of Inclusive Education*,
137 13(5), 501-516, <https://doi.org/10.1080/13603110801886673>
- 138 Ashworth, M., Crane, L., Steward, R., Bovis, M., & Pellicano, E. (2021). Toward empathetic autism
139 research: Developing an autism-specific research passport. *Autism in Adulthood*,
140 <https://doi.org/10.1089/aut.2020.0026>
- 141 Baggs, A. (2010). Up in the Clouds and Down in the Valley: My Richness and Yours. *Disability Studies*
142 *Quarterly*, 30(1). <https://doi.org/10.18061/dsq.v30i1.1052>
- 143 Baggs, A. (2012). Untitled. In Autistic Self Advocacy Network (eds.). *Loud Hands: autistic people,*
144 *speaking* (pp. 324 – 334). Autistic Press.
- 145 Bambara, L. M., Cole, C. L., Telesford, A., Bauer, K., Bilgili-Karabacak, I., & Thomas, A. (2021). Using
146 Peer Supports to Encourage Adolescents With Autism Spectrum Disorder to Show Interest in Their
147 Conversation Partners. *Journal of Speech, Language, and Hearing Research*. 1-16.
148 https://doi.org/10.1044/2021_JSLHR-21-00150
- 149 Botha, M. (2021). Academic, activist, or advocate? angry, entangled, and emerging: A critical
150 reflection on autism knowledge production. *Frontiers in Psychology*, 12, 4196. Retrieved from
151 <https://www.frontiersin.org/article/10.3389/fpsyg.2021.727542>

152 Bottema-Beutel, K., Kapp, S.K., Lester, J.N., Sasson, N.J., & Hand, B.N. (2021). Avoiding ableist
153 language: Suggestions for autism researchers. *Autism in Adulthood*, 3, 18–29. <https://doi.org/>

154 Cage, E., Di Monaco, J., & Newell, V. (2018). Experiences of Autism Acceptance and Mental Health in
155 Autistic Adults. *Journal of Autism and Developmental Disorders*, 48, 473–484.
156 <https://doi.org/10.1007/s10803-017-3342-7>

157 Cage, E., & Troxell-Whitman, Z. (2019). Understanding the reasons, contexts and costs of
158 camouflaging for autistic adults. *Journal of Autism and Developmental Disorders*, 49(5), 1899-1911.
159 doi:10.1007/s10803-018-03878-x

160 Cole, K. L. (2021). Neuroqueering interpersonal communication theory: listening to autistic object-
161 orientations. *Review of Communication*, 21(3), 187-
162 205. <https://doi.org/10.1080/15358593.2021.1961849>

163 Cooper, K., Smith, L. G. E., & Russell, A. (2017). Social Identity, Self-Esteem, and Mental Health in
164 Autism', *European Journal of Social Psychology*, 47(7), 844-854. <https://doi.org/10.1002/ejsp.2297>

165 Crompton, C. J., Sharp, M., Axbey, H., Fletcher-Watson, S., Flynn, E. G., & Ropar, D. (2020).
166 Neurotype-matching, but not being autistic, influences self and observer ratings of interpersonal
167 rapport. *Frontiers in Psychology*, 11, 2961. Retrieved from
168 <https://www.frontiersin.org/article/10.3389/fpsyg.2020.586171>

169 Davis, R., & Crompton, C. (2021). What do new findings about social interaction in autistic adults
170 mean for neurodevelopmental research? *Perspectives on Psychological Science*.
171 <https://doi.org/10.1177/1745691620958010>

172 DeBrabander, K. M., Morrison, K. E., Jones, D. R., Faso, D. J., Chmielewski, M., & Sasson, N. J. (2019).
173 Do first impressions of autistic adults differ between autistic and nonautistic observers? *Autism in*
174 *Adulthood*. <https://doi.org/10.1089/aut.2019.0018>

175 Evans, M. (2020). Oughtistic narratives in the lives of autistic people and their families. *Ought*, 1(1),
176 62-78.

177 Foster, S. L., & Mash, E. J. (1999). Assessing social validity in clinical treatment research: Issues and
178 procedures. *Journal of Consulting and Clinical Psychology*, 67(3), 308–
179 319. <https://doi.org/10.1037/0022-006X.67.3.308>

180 Halsall, J., Clarke, C., & Crane, L. (2021). “Camouflaging” by adolescent autistic girls who attend both
181 mainstream and specialist resource classes: Perspectives of girls, their mothers and their educators.
182 *Autism*. 13623613211012819. <https://doi.org/10.1177/13623613211012819>

183 Higashida, N., Yoshida, K. A., & Mitchell, D. (2016). *The reason I jump: The inner voice of a thirteen-*
184 *year-old boy with autism*. Random House Publishing Group.

185 Jack, J. (2013). On the limits of human: haggling with Burke’s “definition of man”. In D. Anderson.
186 (ed.), *Burke in the Archives: Using the Past to Transform the Future of Burkean Studies* (pp. 84-98).
187 University of South Carolina Press.

188 Jaswal, V. K., Dinishak, J., Stephan, C., & Akhtar, N. (2020). Experiencing social connection: A
189 qualitative study of mothers of nonspeaking autistic children. *PLoS ONE* 15(11): e0242661.
190 <https://doi.org/10.1371/journal.pone.0242661>

191 Kapp, S. K. (2020). *Autistic community and the neurodiversity movement: Stories from the frontline*.
192 Springer Nature.

193 Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should
194 be used to describe autism? perspectives from the UK autism community. *Autism*, 20(4), 442-462.
195 <https://doi.org/10.1177/1362361315588200>

196 Lehenhagen, C. (2020). Including speaking and nonspeaking autistic voice in research. *Autism in*
197 *Adulthood*, 2(2), 128-131. <https://doi.org/10.1089/aut.2019.0002>

198 Libsack, E. J., Keenan, E. G., Freden, C. E., Mirmina, J., Iskhakov, N., Krishnathasan, D., & Lerner, M. D.
199 (2021). A systematic review of passing as non-autistic in autism spectrum disorder. *Clinical Child and*
200 *Family Psychology Review*, 24(4), 783-812. <https://doi.org/10.1007/s10567-021-00365-1>

201 McCracken, C. (2021). Autistic identity and language learning: Response to Kissine. *Language*, 97(3),
202 e211-e217. <https://doi.org/10.1353/lan.2021.0038>

203 Milton, D. E., (2012). On the ontological status of autism: the 'double empathy problem'. *Disability &*
204 *Society*, 27(6), 883-887. <https://doi.org/10.1080/09687599.2012.710008>

205 Morrison, K. E., DeBrabander, K. M., Jones, D. R., Ackerman, R. A., & Sasson, N. J. (2020). Social
206 cognition, social skill, and social motivation minimally predict social interaction outcomes for autistic
207 and non-autistic adults. *Frontiers in Psychology*, 11, 3282. Retrieved from
208 <https://www.frontiersin.org/article/10.3389/fpsyg.2020.591100>

209 Morrison, K. E., DeBrabander, K. M., Jones, D. R., Faso, D. J., Ackerman, R. A., & Sasson, N. J. (2019).
210 Outcomes of real-world social interaction for autistic adults paired with autistic compared to
211 typically developing partners. *Autism*. <https://doi.org/10.1177/1362361319892701>

212 Pellicano, E., & den Houting, J. (2021). Annual research review: Shifting from 'normal science' to
213 neurodiversity in autism science. *Journal of Child Psychology and Psychiatry*.
214 <https://doi.org/https://doi.org/10.1111/jcpp.13534>

215 Peña, E. V. (Ed.). (2019). *Communication alternatives in autism: Perspectives on typing and spelling*
216 *approaches for the nonspeaking*. Toplight.

217 Rifai, O. M., Fletcher-Watson, S., Jiménez-Sánchez, L., & Crompton, C. J. (2021). Investigating
218 markers of rapport in autistic and nonautistic interactions. *Autism in Adulthood*,
219 <https://doi.org/10.1089/aut.2021.0017>

- 220 Sandoval-Norton, A. H., & Shkedy, G. (2019). How much compliance is too much compliance: Is long-
221 term ABA therapy abuse?, *Cogent*
222 *Psychology*, 6(1). <https://doi.org/10.1080/23311908.2019.1641258>
- 223 Sinclair, J. (2013). Why I dislike “person first” language. *Autonomy, the Critical Journal of Inter-*
224 *Disciplinary Autism Studies*, 1(2), 2-3.
- 225 Waldock, K. E. (2019). Commentary on ‘Thinking Differently? Autism and Quality of Life’. *Tizard*
226 *Learning Disability Review*. 24(2). 77-81
- 227 Williams, G., Wharton, T., & Jagoe, C. (2021). Mutual (Mis)understanding: Reframing Autistic
228 Pragmatic “Impairments” Using Relevance Theory. *Frontiers in Psychology*, 12.
229 <https://doi.org/10.3389/fpsyg.2021.616664>
- 230 Yergeau, M. R. (2017). *Authoring Autism: On Rhetoric and Neurological Queerness*. Duke University
231 Press Books.