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Editorial

Changes: Seasons and Names

Dusty Columbia Embury, Editor
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I am pleased to share that the CCC-DPHMD Executive Board, after consideration from the membership and board, has voted to support a proposed change to our title from Physical Disabilities, Education, and Related Services (PDERS) to Research, Advocacy, and Practice: for complex and chronic conditions (*RAPCC*), *A journal for physical, health, and multiple disabilities*. With this change we hope to better reflect the diversity of our audience, the populations we serve, and our mission as a division of the Council for Exceptional Children with a focus on advocating for “quality education for all individuals with physical disabilities, multiple disabilities, and special health care needs served in schools, hospitals, or home settings.”

The name change reflects our journal’s aim to share promising practices and advocacy in addition to high-quality research with the potential impact the lives of individuals with complex disabilities, conditions, and chronic health care needs. Our journal, like our division, has a rich history of supporting practice, advocacy, and scholarship for individuals who need significant supports to access education, community, home, and family. Research, Advocacy, and Practice for Complex and Chronic Conditions provides a well-respected home for scholarship and my goal as the editor and a member of CCC-DPHMD is to help the journal grow in its role and reach. With our title change, we

are making clear our intention, our audience, and stating that we are THE home for research, advocacy, and practice for those individuals who work and learn and love with individuals with complex disabilities, conditions, and chronic health care needs.



Article

Using a Technology-based Instructional Package to Teach Students with ASD to Construct Sentences

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Abstract: In the current study, we investigated the effects of a technology-based instructional package on accurate sentence construction of three middle school students with autism spectrum disorder and complex communication needs. The autonomous package used constant time delay to teach students to select words to construct sentence frames. We evaluated the effectiveness of the package using a single case multiple probe research design. Data indicated that two of the participants increased accurate sentence construction.

Keywords: echnology, autism spectrum disorder, written expression, sentence construction

Introduction

Effective communication skills are essential for success across a range of environments (Graham & Harris, 2013). Each day, individuals wield multiple forms of communication (e.g., speech, gestures, writing) to access powerful reinforcers, acquire new information, and establish and maintain a variety of personal and professional relationships. Those with stronger communication skills are more likely to solve interpersonal problems (Erozkan, 2013) and report higher levels of relationship satisfaction (Eğeci & Gençöz, 2006). Further, data indicate communicative competence is related to increased positive outcomes in both school and the workplace (Conrad & Newberry, 2011; Graham et al., 2013).

Written communication plays an especially critical role in the experiences of learners as they matriculate through public and private school systems (Troia, 2009). In elementary grades, young writers are required to develop their skills in essential processes and conventions for generating a range of narratives (Graham & Harris, 2015). Upon entering middle school and for the rest of their school careers, students are expected to apply these basic writing skills to demonstrate their acquisition of skills across all academic areas (Graham et al., 2013; Ray et al., 2016). In the last decade, there has been increased emphasis by policy makers on students' writing performance, as 41 states adopted Common Core State Standards setting clear standards for students' writing achievement at kindergarten through 12th grade.

Writing skills also are required in the workplace. Often, individuals must write to access (e.g., complete application requirements) and maintain employment (e.g., monitor performance, produce written reports, communicate with coworkers; National Commission on Writing, 2004; Pennington & Delano, 2014). In 2004, the National Commission on Writing issued a report citing that at least 66% of salaried employees and 20-33% of hourly employees write as part of their job. It was reported that over half of company leaders take writing skills into consideration when hiring. These data suggest that those with weaker writing skills are at a disadvantage for obtaining employment.

Finally, written expression is commonly used by young people to interact with their peers. For example, the National Commission on Writing report on Writing, Technology and Teens (2008) indicated that 85% of teenagers used electronic communication (e.g., texting, email, social media) at least occasionally and 94% of teens used the internet or email. Further, data suggest that engagement in these digital interactions are steadily on the rise (Wartella et al., 2016). Those without the writing skills sufficient to participate in these interactions may find themselves increasingly isolated.

Unfortunately, students with autism spectrum disorder (ASD) are often faced with barriers to acquiring skills in written expression (Dockrell et al., 2014; Pennington & Delano, 2014; Purrazzella & Mechling, 2013). Students with ASD often struggle with handwriting, spelling, and the structure of writing (Finnegan & Accardo, 2017). Additionally, individuals with ASD and complex communication needs (CCN) often present with difficulties in the

use of vocal speech and the development of fine motor skills (Lloyd et al., 2013; Ming et al., 2007). As a result, many rely on augmentative and alternative communication (AAC) to interact with others and demonstrate their understanding in educational settings. Often, AAC takes the form of written expression, as students select combinations of words or pictures to generate a message that is then read by a communicative partner (Mirenda, 2019; Pennington & Carpenter, 2019). The development of a strong writing repertoire for these students with CCN may result in improved communicative interactions and thus, better quality of life outcomes (Simpson, 2019).

There is limited research on teaching written expression to students with ASD and CCN. Pennington and Delano (2012) conducted a review of intervention studies, between the years 1994 and 2011, that focused on writing instruction for students with ASD. Fifteen studies met their inclusion criteria and only seven studies addressed writing skills beyond spelling (e.g., story construction, sentence construction, use of adjectives). Further, many of the investigations involved participants without CCN who primarily used speech to communicate. The researchers suggested there was insufficient support for any practice to be deemed as an evidence-based writing practice for learners with ASD, but that computer-assisted instruction, modeling, and feedback were common elements of effective writing interventions.

Recently, researchers have conducted several studies to demonstrate the effectiveness of intervention on the sentence writing skills of students with ASD and CCN. Sentence writing skills are critical as sentences serve as the building blocks of more extended narratives. Pennington and colleagues (2018) used a multiple probe across behaviors research design to evaluate the effectiveness of an intervention package that included sentence frames and a prompting hierarchy to teach sentence construction to three students, ages 7-12, with intellectual disability and ASD. During intervention, a teacher displayed a picture and directed students to write a sentence using a particular structure or frame (i.e., I want a _____, I see a _____, The _____ is _____). One student used manual handwriting and two students selected words from a digital word bank to generate sentences. The teacher then implemented a prompting hierarchy to teach students to construct or write targeted sentences. Results indicated a functional relation between the intervention package and correct sentence formation across all three participants and that all three generalized their newly acquired writing behaviors to untrained stimuli.

Similarly, Pennington and Rockhold (2018) evaluated the effects of an intervention package (i.e., response prompts, technology, sentence frames) on the correct sentence construction of three elementary-aged students with ASD and CCN. The researchers employed a multiple probe across participants research design. During intervention sessions, a teacher directed students to write a sentence about a picture and used response prompting (i.e., system of least prompts) to facilitate correct responding. Unlike Pennington et al. (2018), the teacher presented different sentence structures as models during each session. Again, data indicated the intervention was effective across all three

participants. Additionally, the students generalized the use of the sentence frames to untrained pictures.

Finally, Pennington et al. (2018) taught two middle school students with ASD and CCN to write different sentences about a single picture. They used a multiple probe across behaviors research design to evaluate the effectiveness of the writing package. During intervention, they used constant time delay to teach students to describe a picture using a targeted sentence frame (i.e., The [subject] is [adjective], The [subject] [(verb)], The [subject] feels [adverb]). Data suggest the package was effective for both participants and that participants generalized the use of sentence frames to journal writing activities. Maintenance data were variable across sentence types and participants.

While these research findings indicate that students with ASD and CCN can acquire critical sentence writing skills, they also indicate potential barriers to intervention in the typical classroom setting. Across all three studies, teachers sat next to students and provided response prompts in a one-to-one instructional arrangement. This poses a challenge as teachers may not have sufficient staff to provide one-to-one instruction and supervise the remaining students in the classroom. In addition, all of the research teams trained teachers to use response prompting strategies using modeling, rehearsal, and feedback. In many districts, teachers may not have training in response prompting strategies or skilled staff to provide training and technical support.

One solution to these potential barriers is to use instructional technology that can provide instruction, response prompting, and feedback in the absence of a human instructor. Recently, researchers have demonstrated the effectiveness of closed loop instructional technology in writing skills to students with more severe disabilities. Mims and colleagues (2018) used a multiple probe across participants research design to evaluate the effectiveness of a digital instruction package in improving the comprehension and vocabulary skills of four middle school students with intellectual and developmental disabilities. The intervention package delivered instruction via an iPad app and included response prompting strategies (i.e., constant time delay, system of least prompts). During intervention, the app read a story aloud, provided vocabulary instruction using constant time delay, previewed the chapter, asked students to make a prediction, and asked comprehension questions. Students' responses to comprehension questions were taught using the system of least prompts. Data indicated the intervention was effective to varying degrees across all four participants.

Most recently, Pennington and colleagues (2019) taught eight students with extensive support needs, ages 8 through 21, to construct sentences about a single picture using a closed loop instructional package (i.e., GoWrite prototype). They used a multiple probe across participants research design to evaluate the effectiveness of the intervention package. During intervention, GoWrite presented a picture and a word bank and used constant time delay to prompt sentence construction. In addition, the app provided feedback for correct responding and presented coins that could be exchanged for

access to video games and purchases for accessories for their digital avatar. Results indicated that the app was effective in increasing sentence construction responses for all participants.

To date, there are limited data on the effectiveness of these technologies in teaching writing to learners with ASD. This dearth of information precludes an understanding of the effects of these software packages on learners with ASD, especially those with CCN. In Pennington et al.'s (2019) investigation, one participant with ASD and CCN failed to construct a single sentence. The authors noted that he may have had difficulty attending to relevant stimuli and thus failed to learn to name instructional stimuli when paired with words during instruction. The purpose of this study is to conduct a replication of Pennington et al.'s (2019) study to further investigate the effects of a technology-based instructional app on learners with ASD and CCN. Specifically, we asked the following research questions.

1. Is there a functional relation between the use of a technology-based instructional app and accurate sentences constructed by three middle school students with ASD?
2. What are the effects of the use of a technology-based instructional app on generalized vocal and handwritten responses?

Method

Participants

We recruited participants through contact with a teacher in a suburban school district within close proximity to a large university in the Southeastern United States. The teacher identified students that met the following inclusion criteria: (a) receives special education services education under the eligibility category of autism, (b) demonstrates significant challenges in expressive and receptive communication, and (c) currently does not generate written sentences. The teacher identified three students for participation and obtained consent from each student's guardian. Further, we obtained assent from each participant.

All three participants received all academic instruction in a self-contained special education classroom for students with ASD. Jerry was a 12-year-old White male with ASD. Jerry was in the 6th grade and participated in the state alternate end of year assessment. He emitted several single words and short phrases that were often unrecognizable to unfamiliar listeners. He also used a speech-generating device to communicate with others. Jerry was unable to produce manual handwritten symbols and used a stamp to record his name on assignments. The teacher reported that he had a basic sight word reading vocabulary.

Beth was a 14-year-old White female with ASD. Beth was in 8th grade and participated in the state alternate end of year assessment. Beth emitted one syllable approximations of words and relied primarily on a speech-generating device to interact with others. She

could write her name and recognizable letters on a paper when asked to write, but she did not write complete words or sentences. The teacher reported that she could read text at approximately the third-grade level independently.

Adrian was a 12-year-old Hispanic sixth-grade male with ASD. Adrian was in 6th grade and participated in the state alternate end of year assessment. Adrian communicated vocally using short phrases and sentences. Although Adrian primarily communicated in English at school, Spanish was spoken in the home. When asked to write, Adrian became easily frustrated but would attempt to write words on paper. He did not write in complete sentences. The teacher reported that he had a basic sight word reading vocabulary.

Setting

We conducted the investigation in a middle school in a suburban school district that served 33,000 students. Of those 33,000 students, 3,773 (9%) received special education services, and 391 received special education services with an education eligibility of ASD. Nearly half (42%) of students across the district qualified for free and reduced-price lunch.

We conducted all intervention sessions in the special education classroom and the attached break room. One teacher and two paraprofessionals provided services to 10 students in the classroom. The room had designated areas for independent work, whole class instruction, and small group work. The attached break room had bean bag chairs, a carpet, yoga balls, magazines, and a SmartBoard[®]. It was used primarily during non-academic time for students to have a break from academic work.

Materials

Students used a technology-based instructional app (i.e., GoWrite prototype) installed on an iPad during all sessions. Prior to collecting baseline data, the teacher assisted students in creating a personalized avatar. The special education teacher guided students through a series of avatar design screens (see Figure 2) and directed students to make choices related to gender, hair color, skin color, and shirt color.



Figure 2. GoWrite avatar design

During all sessions, the student's avatar was present in the top left corner and the digital instructor (e.g., Robin the robot) was present on the left side of the screen (see Figure 3). A picture representing one of five targeted stimuli (i.e., ball, bus, ball, car, bird) was presented in the center of the screen. We selected these stimuli, as they were common in the students' natural environment. Nine buttons containing single written words were presented below the picture. Robin the robot's mouth moved as spoken directions and feedback were presented to the user. The students touched words in order to construct a sentence. The app read the words aloud when the student touched the word. These features were consistent throughout intervention and baseline. Finally, the app displayed digital coins as the student emitted correct selections. Upon completion of an activity, students were directed to a "shop" menu where they could select to purchase accessories for their avatar or play video games.



Figure 3. Example GoWrite Lesson

Dependent Variable and Response Measurement

Across all conditions, the app collected data on the percentage of correct sentence formation. A sentence was recorded as correct if it matched the targeted sentence format (i.e., I see the [noun]) and accurately described the picture. The app calculated percent by dividing the number of correct sentences written by the number of opportunities (i.e., 5 trials) and multiplying by 100. We did not calculate dependent variable reliability as the computer software collected data on students' response. Informal observations suggested that data collection features of the software performed as designed.

Experimental Design

We used a single case multiple probe across participants design (Horner & Baer, 1978) to evaluate the effectiveness of the technology-based package. We randomly assigned participants to the order in which intervention sessions would be introduced. After a stable baseline pattern of responding was established with at least five data points, we introduced intervention to the first participant (i.e., Jerry). Once an increasing trend was observed for at least 3 sessions with a participant during the intervention condition, we introduced intervention to the next participant. Intervention was terminated when the participant accurately constructed 80% or more of sentences across three consecutive sessions.

Procedures

Screening

Prior to intervention, we presented students with the app and assessed their ability to make selections from a word-based array. First, we opened the app and directed each student to create an avatar. After the student created an avatar, the teacher selected the sentence frame of focus (i.e., I see) and the assessment toggle, which turned off all prompting and feedback features. The research team observed as the student attempted to select words. All students were able to independently select words on the App. Additionally, we assessed students' ability to identify the pictures that would be presented during instruction. We presented an array of three pictured stimuli from the app, presented the directive "Touch the _____," and waited for the student to respond. All students identified at least 80% of pictured stimuli.

Baseline

For each participant, we conducted at least five baseline probe sessions with five trials each. During each trial, the teacher opened the app and selected the student's avatar. The teacher then selected the assessment toggle and the targeted sentence frame (i.e., I see). The app presented a word-based array on the screen and directed the student to write a sentence about a pictured stimulus. If the student did not start writing within 8 s, we terminated the trial. If the participant started writing, they were permitted to write until they indicated completion or failed to make a word selection within 8 s. Upon completion of a trial, the teacher only provided general praise for the attempt (e.g., "Good working!").

Intervention

During intervention sessions, the teacher opened the app and selected the student's avatar. The teacher then selected the lesson tab and the targeted sentence frame of focus (i.e., I see) and directed students to start the app. The app implemented constant time delay procedures (Wolery et al., 1992). During the first two days of intervention, *Gowrite* presented five 0 s delay trials and five constant delay trials. During 0 s delay trials, the app presented a pictured stimulus with the correct sentence displayed below it, a spoken request to write a sentence, and immediate response prompts (i.e., highlighted word within the model sentence and highlighted word within bank) to facilitate student responding. During these trials, other options with the exception of the correct word were shaded and inaccessible. During constant delay trials, the app presented a picture, a word bank, the directive "Write a sentence," and waited 8 seconds for the student to respond. If the student selected the correct word, their avatar read the word aloud and a coin appeared in the student's coin bank with an auditory "ping." An 8-second response interval then started for selection of the next word. If the student did not respond or made an error, the app highlighted the correct word and delivered the cue "Select this word." Upon selection of the highlighted word, the avatar read the word, but no coin appeared in the student's bank. At the completion of each sentence, the avatar read the entire sentence aloud as each word in the sentence was highlighted. On the third day, the app presented a single 0 s delay trial and five constant delay trials until the student met criterion. Upon completion of each lesson, the teacher provided general verbal praise for working on the app (e.g., "Good Work!") and directed the student to the store on the app. Once the student accessed the store, the student could decide to use his/her coins to buy a game or accessory for the avatar or to save the coins.

Generalization

We collected generalization probes throughout baseline and intervention for all participants. For Jerry, Adrian, and Beth, we assessed response generalization to pictured stimuli (i.e., vocal behavior, manual handwriting). During generalization sessions for Jerry and Adrian, the teacher presented three pictures from the *GoWrite* app, one at a time, and presented the request "Tell me about the picture." A member of the research team was present for all generalization sessions and transcribed the vocalizations on a paper log. Five and four generalization sessions were conducted with Jerry and Adrian respectively. During generalization probes for Beth, the teacher presented three pictures from the *GoWrite* app, one at a time, and asked Beth to "write about the picture." A member of the research team was present for all generalization sessions with Beth and collected the writing samples at the conclusion of the generalization session. Four generalization sessions were conducted with Beth.

Procedural Fidelity

A member of the research team, not the special education teacher, collected procedural fidelity using a 6-step checklist. The checklist steps included (a) open *GoWrite* app; (b) select assessment or lesson for correct sentence frame; (c) provide directive for student

to work on sentences; (d) omit any guidance that may direct student towards correct response; (e) once the student is finished writing, deliver general praise; (f) if student does not select shop independently, prompt him/her to access it. Procedural fidelity data were collected for 50%, 45.5%, and 50% of baseline sessions for Jerry, Beth, and Adrian, respectively. Procedural fidelity data were collected for 26.7%, 37.5%, and 75% of intervention sessions for Jerry, Beth, and Adrian respectively. Procedural fidelity was calculated by dividing the number of steps completed by the total number of steps and multiplying by 100. The overall mean for procedural fidelity for baseline was 100%. The mean procedural fidelity for intervention was 92.5% (range 80%-100%) for Jerry, 100% for Beth, and 100% for Adrian.

Results

This section contains our findings based on the data collected throughout the study. First, we analyzed the data for changes in level, trend, variability, and immediacy of effect, which is standard in single case research (Ledford & Gast, 2018). Then, to supplement the visual analysis, we calculated Tau-U for each participant (Vannest & Ninci, 2015). Tau-U is reliable single case research effect size calculation that controls for trends in baseline and is appropriate for smaller data sets (Vannest & Ninci, 2015).

Jerry

During baseline sessions, Jerry did not construct a single sentence. Following the introduction of intervention, Jerry did not construct a complete sentence for the first 26 sessions. During the 16th intervention session, we implemented a change to the intervention procedure. If Jerry emitted an error on the first word of a sentence (i.e., I), the teacher provided a visual model (i.e., on an index card) of the complete sentence. The teacher implemented this supplemental procedure for 10 sessions, and no change was observed in Jerry's responding. As a result, we implemented a second change. Following the presentation of the model card, the teacher pointed to the word on the model, waited for Jerry to select that word, and then following Jerry's selection of the word, she pointed to the next word. Following this second change, Jerry increased the number of correct selections but did not meet criterion. Further, during generalization probes Jerry did not emit any vocal responses. Tau-U for Jerry was 0.13 ($p=0.62$, 90% CI = [0, 0.56]). This indicates a small effect.

Beth

During baseline sessions, Beth did not construct any complete sentences across 11 sessions. At the onset of intervention, there was an immediate change in level and an increasing trend with minimal variability was established. Beth met mastery criteria (i.e., three consecutive sessions with 80% or greater of accurate sentence construction) in seven sessions ($M=75\%$, range 60%-100%). However, at follow up 6 days later, accuracy dropped to 20%. However, at follow up 12 days and 14 days post intervention, composition of complete sentences returned to 100% accuracy without any further lessons on the app. Unfortunately, these results did not generalize to physical

handwriting. Tau-U for Beth was 1.00 ($p < 0.01$, 90% CI = [0.55, 1.00]). This indicates a large effect.

Adrian

During baseline sessions, Adrian displayed variable levels of accurate sentence formation, with no trend established ($M = 8\%$, range 0%-60%). At the onset of intervention, there was an immediate change in level and an increasing trend with minimal variability was established. Adrian met mastery criteria in four sessions ($M = 80\%$, range 60%-80%). However, at follow up 6 days post intervention, these gains were not maintained (i.e., 20% accurate sentence formation). Additionally, the results did not generalize to vocal responding. Tau-U for Adrian was 0.60 ($p = 0.07$, 90% CI = [0.052, 1.00]). This indicates a medium effect. See figure 1 for student outcome data.

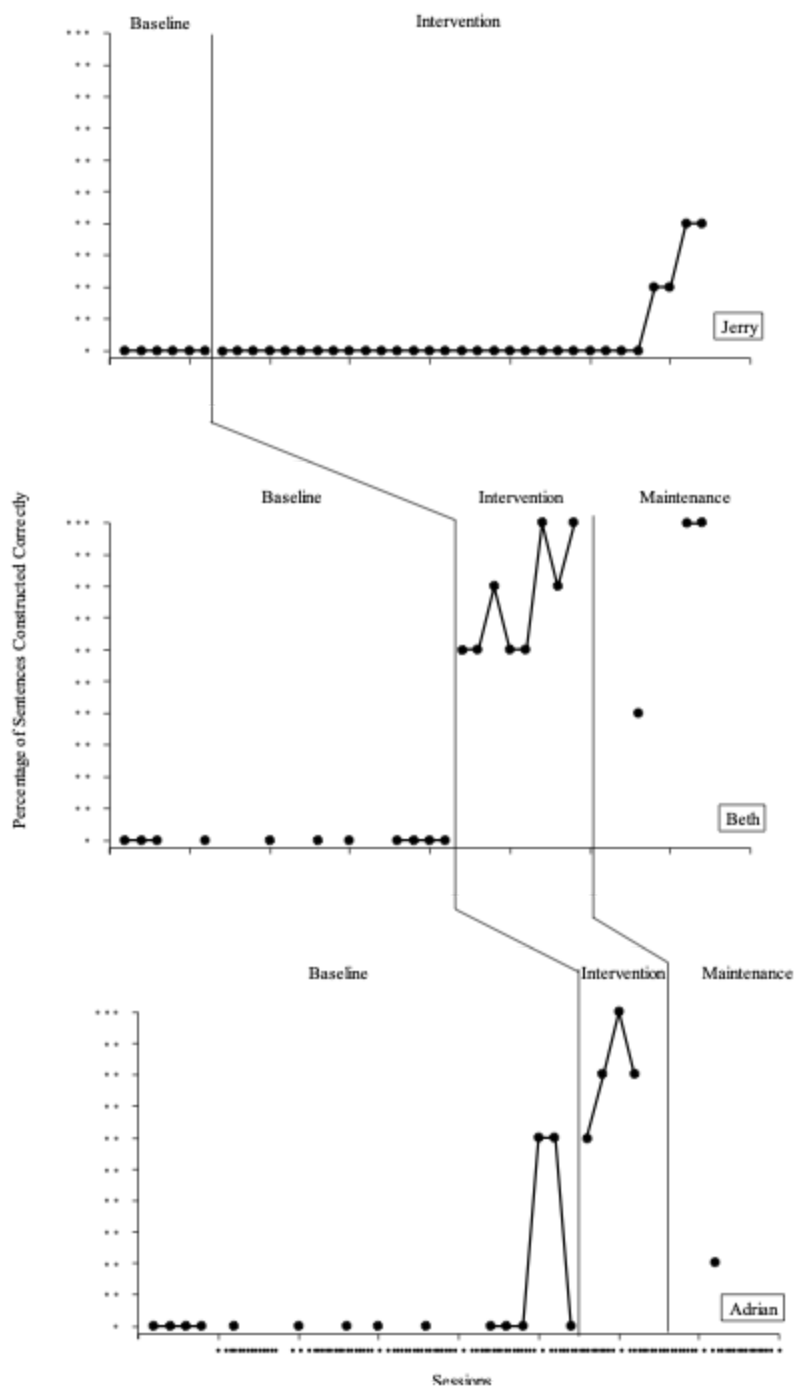


Figure 1. Student outcome data

Discussion

In light of the absence of research-based guidelines and limited resources for teaching written communication to students with ASD and CCN, there is a need to develop and evaluate instructional technologies that incorporate research-based procedures and

require minimal teacher response effort. The purpose of this study was to examine the effects of an autonomous prototype app (i.e., GoWrite) on the sentence construction skills of three middle school students with ASD and CCN. Overall, our findings suggest the app was effective for two of the three students. For the third student, we implemented supplemental instructional procedures that produced an increase in sentence construction responses.

Unfortunately, only one of the students that met criterion maintained responding following the withdrawal of intervention. A second student, Adrian, produced one sentence on a single maintenance probe. This may have been due to his limited time in receipt of intervention. He only received four days of intervention before meeting criterion. It is also notable that he only scored 100% accuracy during one intervention session. It is likely that increased opportunities to practice sentence construction at higher levels of accuracy would have produced greater maintenance. Further, other classroom variables may have impacted performance after intervention was terminated. For example, Pennington and colleagues (2019) noted that students made errors because classroom distractions often precluded them from responding within the app's pre-programmed response interval.

Finally, no student demonstrated changes in vocal or written responding as a result of intervention. This again may have been due in part to the brief duration of intervention conditions. It also may have been related to the students' limited vocal imitation and motor skills. We did not formally assess this presence of these repertoires during screening. Future investigations should include formal assessments of these skills.

Despite these mixed results, we purport that the current investigation demonstrated that apps incorporating research-based instruction designed for independent student use may be a viable approach to improving writing skills of students with ASD and CCN. These results are not surprising in that there is mounting support for the use of technology-based instruction to teach a range of academic skills to students with ASD and other disabilities (Barton et al., 2017). Further, we suggest that this study represents a needed extension of the prior literature as we assessed the effects of the technology-based package on generalized responses and illuminated a need for more research on instructional modifications that may facilitate generalized intervention effects.

Limitations

There are several limitations to this study that should be noted. First, our findings reflect mixed results across participants. This may be due in part to differences in the students' repertoires that were not captured in screening procedures. In future iterations, researchers might consider assessing student performance on a broader set of skills as to further understanding of what prerequisites might be necessary prior to use of these types of apps. Second, we only taught a single sentence frame (i.e., I see the ____). Though the purpose of this study was to evaluate a novel technology, we ultimately

produced a limited new repertoire for the students in the study. Future research should involve teaching more sentence types across a range of purposes. Finally, we only evaluated the effects of our app on three students within a single case design, limiting the generalizability of our findings. There is a need for replication and extension of the current study across additional students and contexts.

Implications for Practice (Outcomes and Benefits)

Our findings from the current investigation present several implications for practitioners. First, the adoption of high-quality technology interventions may be used to support the implementation of evidence-based instruction for all students. Many evidence-based strategies for students with ASD are delivered in one-on-one instructional arrangements (Wong et al., 2015). However, this arrangement is only possible in settings with sufficient staffing resources. The use of technology-based interventions, especially those designed for independent use by students, may serve to ameliorate instructional challenges posed by large student to teacher ratios.

Second, when technology-based interventions incorporate evidence-based strategies, students can benefit from these strategies even if their teachers may be untrained in implementing them. Further, the implementation of these strategies by technology-based systems may result in higher levels of fidelity than when implemented by human teachers (Kodak et al., 2017). Since teachers may implement these interventions directly “out of the box”, they should investigate whether the instructional strategies within technological applications are evidence-based prior to adoption.

Third, teachers might consider using response prompting and sentence frames to increase the complexity of responses by students currently using electronic AAC systems. Research teams have demonstrated the effectiveness of these procedures in increasing the use of sentences in learners with ASD across other response forms (i.e., picture exchange, vocal; Ganz et al., 2012; Hernandez et al., 2007). In addition, in the absence of software delivered instruction, teachers might use sentence models presented on flashcards, in lieu of the software prompts (i.e., highlighting of target words).

Finally, while the instructional apps offer a promising way to deliver high quality instruction in written expression to students with ASD and CCN, some students may still require additional systematic instruction from educators. For example, in the current study, we implemented simultaneous prompting with Jerry. Educators should closely monitor the data and student behavior to determine if additional instruction is needed.

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Article

**A PILOT STUDY OF ADULT DISABILITY SERVICES AND LEGISLATIVE ADVOCACY
AMONG PARENTS OF YOUTH WITH MULTIPLE DISABILITIES**

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Abstract: Although parents of individuals with multiple disabilities have spearheaded legislation for students with disabilities, little is known about their legislative advocacy experiences with respect to adult disability policy and, relatedly, adult disability services. In this pilot study, we examined the perspectives and experiences of nine parents of youth with multiple disabilities with respect to legislative advocacy via two focus groups. Most participants had negative perceptions of their: legislators, adult disability policies, and, relatedly, adult disability services. Many participants suggested changes to increase the flexibility of Medicaid Home and Community Based Services. Directions for future research and practice are discussed.

Keywords: *adult disability policy; multiple disabilities; disability advocacy*

Introduction

For all youth, family involvement is important as they age out of school and into adulthood. For youth with multiple disabilities, family involvement may be especially important as individuals shift from entitlement services in public schools to eligibility-driven adult developmental disabilities services (Hanley-Maxwell, Whitney-Thomas, & Pogoloff, 1995). Further, adults with multiple disabilities (compared to those with less intensive needs) are more likely to experience poor outcomes in the areas of post-secondary education, employment, and independent living (Beadle-Brown et al., 2015; Gray et al., 2013; Neely-Barnes et al., 2008). Positive adult outcomes in community participation, independence, and employment often occur, in large part, due to strong parent advocacy and high expectations (Carter et al., 2011; Rossetti et al., 2016).

Historically, parents of individuals with disabilities have spearheaded legislative changes resulting in improved access to education and related services for individuals with disabilities (Turnbull, Turnbull, & Shogren, 2011). Such advocacy efforts include the passage of the Education for All Handicapped Children Act (now known as the Individuals with Disabilities Education Act) as well as federal and state policies regulating services for adults with disabilities. With respect to transition planning and adult services, person-family interdependent planning may occur—a planning process that includes the individual with a disability and the family (Kim & Turnbull, 2004). Person-family interdependent planning may be necessary as adult disability policies and related services are notoriously difficult to navigate, especially for youth with multiple disabilities (Blacher, Kraemer, & Howell, 2010).

Notably, family involvement continues to be important not only for parents to enable their own youth with multiple disabilities to access adult disability services but also to create legislative change with respect to adult disability policies. The adult disability system is fragmented due to multiple adult disability policies with varying eligibility criteria, services, points of entry, and bureaucratic norms and procedures (Taylor, Hodapp, Burke, Rabideau, & Waitz-Kudla, 2017). In addition, there are often long waiting lists for adult disability services. For example, there are over 216,000 individuals waiting for Medicaid Home and Community-Based Services (Larson et al., 2018). At the state level, 43 states have waiting lists for Medicaid services (Larson et al., 2018). Additionally, individuals with multiple disabilities typically require support from direct service providers (DSPs). DSPs have been perceived as gatekeepers to positive outcomes for individuals with multiple disabilities (Curtis et al., 2009). In addition, finding and keeping DSPs has been a consistent problem in adult services (Hewitt & Larson, 2007). Thus, family involvement is needed to not only impact change for their own children but also to impact legislative changes to adult disability policies. Given the unique knowledge of families about their offspring with disabilities as well as their perseverance and empowerment, families can impact meaningful federal and state policy changes. The purpose of this pilot study was to explore the perceptions of parents of youth with multiple disabilities toward adult disability policies and legislative change. Notably, we focus on national, state, and

regional policies to reflect the interplay between the policies (e.g., national policy sets the bar for state and regional policies).

First, it is important to characterize the perceptions of families of individuals with multiple disabilities toward federal, state, and regional legislators, especially in the context of adult disability policies. Parents have historically been heralded as individuals who spearheaded national special education policy (Turnbull, Shogren, & Turnbull, 2011). However, little research has examined parent perceptions of and experiences with federal, state, and regional legislators with respect to adult disability policies. The lack of extant research is problematic especially given that individuals spend the majority of their lifetimes in adulthood (versus in school). Given the lack of research about legislator perceptions and adult services, we turn to the limited literature about perceptions toward federal and state legislators regarding special education policy. Such research has often found that parents have little experience with legislators (Trainor, 2010; Wright & Taylor, 2014). Unfortunately, few studies specifically examined the needs of parents of individuals with multiple disabilities—a population which may require numerous supports and, accordingly, may be uniquely impacted by adult disability policies.

In addition to exploring the perceptions of parents toward legislators about adult disability policies, it is also important to explore the perceptions of parents toward adult disability policies at the national, state, and regional levels. Most research has found that parents view federal and state adult disability policies and, correspondingly, services to be overwhelming (e.g., Hanley-Maxwell, Whitney-Thomas, & Pogoloff, 1995; Taylor et al., 2017). However, to our knowledge, little extant research has explored the perceptions of parents of youth with multiple disabilities. The dearth of such research is problematic as youth with multiple disabilities may have higher support needs resulting in needing to access a variety of adult disability services (e.g., Vocational Rehabilitation, Medicaid Home and Community-Based Services, Supplemental Security Income, Medicare) to address their needs. Thus, it is critical to solicit the perspectives of parents of individuals who may navigate multiple adult disability policies to secure appropriate services for their offspring.

It is also important to examine parent suggestions for changes in adult disability policies. Given the importance of person-family interdependent planning for youth with multiple disabilities in programmatic changes (Kim & Turnbull, 2004), it is necessary to hear the voices of parents with respect to impacting national, state, and regional adult disability policy. Little research has directly examined suggestions from parents for adult disability policies. However, in a study about parent suggestions for national special education policy, Burke and Sandman (2014) found that parents suggested expanding, clarifying, or retaining text to ensure youth with disabilities receive an appropriate education. Unfortunately, their study did not include any parents of youth with multiple disabilities. It is possible that parents of youth with multiple disabilities may have different suggestions as well as have suggestions for more than one adult disability policy given that their children may access services via several policies.

As youth with multiple disabilities require adult services to meet their needs, failure to access adult services leads to serious ramifications including worse post-school outcomes and regression of skills (Taylor & Hodapp, 2012; Taylor & Mailick, 2014). Because of the shortcomings of adult disability policies, many parents of individuals with intellectual and developmental disabilities have been calling for legislative change (Burke & Heller, 2016). However, most prior research either does not include parents of youth with multiple disabilities or does not specifically explore the perspectives of parents of youth with multiple disabilities with respect to adult disability policies. For this pilot study, in the context of federal, state, and regional policies, we had three research questions: Among parents of youth with multiple disabilities, how do parents perceive legislators with respect to adult disability policies?; What are parent perceptions toward adult disability policies?; and What are parents' desired changes for adult disability policies? By exploring parent perceptions of legislators and adult disability policies, practitioners can identify areas of need with respect to civic engagement and adult services. Further, it is critical to explore parent suggestions for adult disability policies so policymakers can ensure such laws are effective for individuals with multiple disabilities and their families.

Method

Participants

This study is a subset of a larger study about legislative advocacy and disability policy. Unlike the larger study, this pilot study focuses on parents of children with multiple disabilities and adult disability policy—two under-examined areas of research. In this study, the inclusionary criteria required participants to be: parents of children with multiple disabilities, willing to complete a training about legislative advocacy in a Midwestern state, and be over the age of 18. There were nine participants. All participants were college-educated, White, female, mothers of children with disabilities. Eight participants were married. The offspring of the participants were mostly male (77.78%). On average, the offspring were 16.22 years of age (SD = 4.87, ranging from 7 to 21). All offspring were still receiving services from the school district. Although the focus of the training was on adult services, there was no age limit for the participants. However, with the exception of one participant, all participants had transition-aged youth (i.e., youth between the ages of 14.5 and 22). All offspring had at least two co-morbid diagnoses. Compared to other states, the Midwestern state of the study had a reputation for poor adult services. For example, in the Midwestern state, over 20,000 individuals with disabilities were waiting for Medicaid waiver services. See Table 1 for more information about participants.

Table 1.

Participant Demographics (N = 9)

% (n)

Marital Status

<i>Married</i>	88.89% (8)
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Level of Education

<i>College degree</i>	77.78% (7)
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<i>Graduate degree</i>	22.23% (2)
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Annual Household Income

<i>\$30,000-\$49,999</i>	11.12% (1)
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<i>\$70,000-\$99,999</i>	11.12% (1)
--------------------------	------------

<i>More than \$100,000</i>	77.78% (7)
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*Type of Disability**

<i>Intellectual disability</i>	88.89% (8)
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<i>Autism spectrum disorder</i>	77.78% (7)
---------------------------------	------------

<i>Emotional/behavioral disorder</i>	55.56% (5)
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<i>Health condition</i>	33.34% (3)
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<i>Sensory impairment</i>	22.23% (2)
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Percentage of Time in the General Education Classroom

<i>0-39%</i>	66.67% (6)
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40-79%

11.12% (1)

80% or more

22.23% (2)

**All participants indicated more than one type of disability so percentages do not equal 100%*

Recruitment

Upon hearing about a legislative advocacy training to educate and empower parents of children with disabilities for the next special education reauthorization, a suburban school district contacted the first author. The district personnel inquired whether the training could be adapted to focus on empowerment and legislative advocacy for adult disability policies for individuals with multiple disabilities. The first author met with the district and agreed to tailor and offer the training. Accordingly, the district conducted all of the recruitment for this study. To this end, the district distributed the recruitment flyer to all parents of students with multiple disabilities. All participants received \$20 gift-cards for their participation.

Procedures

First, we received Institutional Review Board approval to begin this study. To register for the study, participants completed a demographic survey online or via hard copy, upon request. After completing the survey, the participants were registered for the training and study. Prior to the training, before receiving any content, participants completed focus groups. After the focus group concluded, the training began. At the end of the training, participants completed videotaped testimonials.

Focus groups. The authors facilitated the focus groups. Each author has had training and experience facilitating focus groups. Further, each author previously worked in the special education field. In addition, three of the authors were also family members of individuals with disabilities. Each author shared their connection to the disability field at the beginning of the focus group to facilitate rapport (O'Toole, 2013). The focus group was approximately one hr; two focus groups were conducted. There were four participants in one focus group and five participants in the other focus group. Each focus group was audio-recorded. Each focus group was transcribed verbatim. The transcripts were used as data.

Field notes and memos. The authors recorded field notes during and after the focus groups. They included descriptive information, such as the date and time, setting, and number of participants in each focus group. Field notes were treated as data along with the transcripts. Researcher memos included reflective information about the focus groups, coding ideas, and emerging themes. The research team held weekly calls to discuss the data, including the researcher memos.

Videotaped Testimonials. At the end of the civic engagement program, participants developed their own three minute testimonials detailing their suggestions for adult disability policies using a “Hook, Line, and Sinker” (Walsh & Kuriansky, 2009) format that was taught during the program. The participants were provided with numerous sample testimonials during the program. In the sample testimonials, the participants identified the: a) hook (i.e., introduction of the person providing the statement and their child/family); b) line (i.e., presentation of a problem); and c) sinker (i.e., suggestion for how to resolve the problem). After reviewing the sample testimonials, the participants were given the “Hook, Line, and Sinker” worksheet and 30-45 min to individually write their own legislative advocacy testimonials. Participants were then videotaped with the choice of reading their testimonial or speaking extemporaneously; most read their testimonials.

Measures

Focus group protocol. The protocol was semi-structured such that participants could freely speak about legislative advocacy and adult services. The focus group protocol was developed based on extant literature about adult services (e.g., Burke & Heller, 2016)b and legislative advocacy (Trainor, 2010; Wright & Taylor, 2014). The focus group was piloted with parents of individuals with different types of disabilities, including parents of youth with multiple disabilities. Only minor changes were made (e.g., changes to the wording, change of the order of questions). See Appendix A for the focus group protocol.

Parent Training

The 6 hour civic engagement program was originally developed by the first author to focus on special education services (Burke & Sandman, 2014). For this study, the civic engagement program was revised to include content about adult services (e.g., Medicaid Home and Community Based Services) as well as prompts to facilitate discussion about potential changes to adult service delivery systems. Specifically, the initial three hours of the training reviewed the current state of adult services. The latter three hours of the training reviewed ways to advocate for systemic change, culminating in the legislative advocacy testimonies. The training did not provide suggestions for ways policies can be changed but rather prompted the participant to identify needed changes and to learn ways to voice their concerns to legislators. The training was provided by the first author—a professor of special education and parent of a child with a disability. The training was conducted in-person, in two, three-hour sessions. All participants attended each session. The training was offered in a group.

Analyses

The focus group transcripts, field notes, and videotaped testimonial transcripts were coded inductively using a multi-stage process to identify participant perspectives. Two of the authors—who had facilitated some of the focus groups and were familiar with them—independently coded each of the focus group transcripts. First, they each read the transcripts to familiarize themselves with the data (Tesch, 1990). Then, independently, they used constant comparative analysis (Creswell, 2013; Glaser & Strauss, 1968) to code the same transcripts. Using a line-by-line approach, they examined each piece of data

and notated each piece with a phrase. Then, to create a codebook, they met to discuss their individual codes; they compared the codes for redundancy and to agree on the same terminology. After developing the codebook, they independently coded the transcripts again. While coding, they also looked for new codes and categories. Again, they met to discuss their coding including resolving any discrepancies and updating the codebook. Regarding the latter, the coders only added some new codes. After confirming the codes, they focused on the broader categories and themes (Braun & Clarke, 2006).

After reviewing the data, we looked for patterns. For example, we looked for patterns in themes with respect to the offspring's age. However, we did not find any patterns. We also looked for patterns with respect to participant experiences with legislators. We did not find any patterns with respect to positive or negative experiences with legislators.

Trustworthiness

We made several efforts to ensure the trustworthiness of the qualitative methods. For example, we completed first level and second level member checks of the data and analysis for both focus groups (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005). Level-one member check summaries were created at the end of each focus group. The first author briefly read the summary, and participants offered no changes. After the categories and themes for the focus group data were identified and finalized, a second level member check was used to help authenticate the analysis. Specifically, after reading the transcripts and notes, a two-page summary of each focus group was developed. Each summary was sent to participants via email to determine the accuracy of the summary; participants were instructed to complete a short online survey with any changes they would make to the summaries. All participants conducted the member check; they did not offer any changes. In addition, we utilized investigator triangulation by incorporating multiple researchers and peer debriefing. Peer debriefing occurred during the regular weekly researcher meetings to: discuss progress, address concerns, and resolve discrepancies during data analysis.

Findings

The findings are reported in relation to the research questions about participants' experiences with legislators, perceptions toward adult developmental disability policies, and desired changes for adult developmental disability policies. To contextualize these findings, it is important to first characterize participants' perceptions towards current school services. Such an understanding may help explain family suggestions for adult disability services and their experiences with legislative advocacy.

Perceptions Toward School Services

Participants were overwhelmingly satisfied with school services. A parent of a child with disabilities, including medical needs, reported "We have been really happy with the school. I think we hit the jackpot. We're from Minnesota. They don't have schools like this." Other participants agreed describing their schools as "perfect", "wonderful", and "a

great fit". When asked why they were satisfied with school services, participants reported that the school met their child's needs and did not require as much advocacy on their part to access needed services (e.g., speech therapy; behavioral supports; individual aides). They characterized the school professionals as "collaborative".

Experiences with Legislators

Participants reported varied experiences with federal, state, and local legislators (hereafter referred to as "legislators" unless otherwise noted) in the context of adult developmental disability services. Participants were asked about their degree of contact within the past twelve months. Seven participants reported some degree of contact with legislators. Specifically, three participants e-mailed their legislators and two participants visited legislators about special education issues. In addition, two participants called their legislators about special education. Notably, all participants also reported engaging in other legislative activities including donating to political campaigns, attending a protest or boycott, and signing petitions about legislative issues. Altogether, most participants reported the legislators were unresponsive to their concerns. However, there were a few participants who reported that legislators were sympathetic to the needs of young adults with disabilities. In addition, in some instances, parent advocacy led to legislative action.

Legislators were unresponsive. Most participants reported that legislators were unresponsive to their concerns. Specifically, a mother of an adult with autism stated:

I met with a group of [state] legislators. Had to be about five years ago and I almost walked out. It was the most frustrating thing I've ever had to deal with. We were a group of parents—they [legislators] wanted to hear about what our concerns were and two of them didn't know what Autism was. I mean, they [legislators] weren't educated on what the disabilities they were dealing within the community were.

Notably, this participant met with legislators both as an individual constituent as well as part of a larger effort with other families from an autism organization. The unresponsiveness of the legislators seemed to relate to their lack of knowledge about disability issues. However, other participants reported that legislators were unresponsive due to their inability to address disability issues because of a lack of funding. Participants reported that given the lack of a state budget, state legislators were unable to respond to their concerns about adult services. For example, a parent of a child with multiple disabilities succinctly stated, "We [individuals with disabilities and their families] are the money takers and they [state legislators] are like 'Well, we will just put them [individuals with disabilities] off. Just keep putting them off.'" Because state legislators were financially strapped, they could not suggest solutions to address the needs of young adults with disabilities. However, participants reported that by investing in individuals with disabilities, communities would benefit financially in the long-run. For example, a parent of a child with multiple disabilities reported:

There are so many situations where they [state legislators] do not connect the dots. They just hear, you're asking for more money and they [state legislators] are

like ‘we are broke so we can’t’ but if you think about what you are describing as lost revenue, the cost to the community, the housing, then you know that...there are wonderful opportunities for employers to hire adults with disabilities who can support their business but also support with some tax incentives for their employment. So, it feels like they [state legislators] are short-sighted.

Legislators were sympathetic. In contrast, some participants reported that legislators were sympathetic to their concerns. For example, a participant recalled her experiences advocating with other families of children with disabilities. She stated, “The legislators that we talk to regularly, they’re really sympathetic. They really care, like I said.” Notably, such sympathy did not necessarily translate to legislative action. However, participants reported that at least they perceived legislators as interested and empathetic to their plight. For example, the parent of a young adult with autism and intellectual disability reported regularly and individually contacting her state legislators about disability issues. Correspondingly, she reported:

They [state legislators] are really sympathetic. They really care like I said. But the reality is that in our state is that sometimes...[state] legislators will just talk about what a bad [fiscal] situation is going on in the state and they want to help. They want to add programs, but they talk about the hard choices they have to make.

Legislators responded with action. In addition, some participants reported that their advocacy influenced legislative decisions. For example, a parent of a youth with multiple disabilities reported that she visited Capitol Hill four times to meet with her federal legislators. Her advocacy was part of a larger effort by a disability non-profit organization. As a result of her efforts, she reported that “...we’ve done some great things at the DOD [Department of Defense] medical research program [resulting in] funding research for her [daughter’s] disorder.” Another parent reported about her experience in another state advocating for medical marijuana for her son. In that state, she met with legislators to talk about the importance of medical marijuana; as a result of her visits, she received medical marijuana “within two weeks after meeting him [a legislator]”. Since moving to a new state, the participant was initiating similar legislative advocacy efforts to pass medical marijuana legislation.

Perceptions Toward Adult Disability Policies

Participants unanimously reported negative perceptions toward adult disability policies. Participants specifically cited the poor quality of adult disability services, the limited availability of adult disability services, insufficient funding for adult disability policies, and inappropriate (i.e., only congregate and institutional settings—no group homes or support living options) placements for adults with disabilities. Further, participants reported that adult disability policies were getting worse—not better. Parents of individuals with multiple disabilities who were aging out of school reported:

Parent A: So, now they [state legislators] are cutting funding so there’s less opportunities... I have a friend whose son is 40 and she is like ‘What is he going to

do? He has been going to a day program for 20 years and now that is being taken away. How is he going to socialize? He wants to work'.

Parent B: So, now they [individuals with multiple disabilities] are doing nothing.

They are sitting at folding tables and chairs eight hours a day with nothing to do.

Parent C: It is very sad.

Parent D: I wonder what states are doing it [adult disability services] well?

Parent A: Almost everybody is doing it [adult disability services] better than us.

This conversation emphasized the limitations of existing adult developmental disability policies that were described to be exacerbated by reduced funding. Participants were concerned about transitioning from largely effective and appropriate school services delivered as entitlements under IDEA to not just the unknown of eligibility resources in the adult system, but what they perceived to be a worsening system.

Desired Changes for Adult Disability Policies

Participants reported five desired changes for adult disability policies. Notably, five participants wanted changes in relation to Medicaid Home and Community Based Services, specifically wanting more flexibility and funding for adult day programs. For example, a mother of an almost 22-year old son with autism and intellectual disability, reported that Medicaid needed to offer more post-school day program options for youth with multiple disabilities. Within the context of Medicaid waivers, she stated,

My biggest concern for him is adult programming for his age range, quality adult programming that continues the learning that he had in school. We don't want him to lose that. We spent so much time to educate him and he is educated but that ends at 22. So, I am asking the state to revisit...quality options for adult programming.

Other parents requested that policymakers increase funding for Medicaid waivers to ensure quality services and housing for their offspring with multiple disabilities. The parent of a teenager with cerebral palsy and an intellectual disability reported that there was only one housing agency in the state that had the capacity to meet her son's medical needs. However, the limited Medicaid funding threatened her son's ability to receive their services. She stated, "My request is that you consider giving agencies the funding they need to [serve kids like my son] and expand the [current] formula which doesn't work for kids like my son."

The second most frequent desired change was for employment. Specifically, two participants reported wanting changes in adult disability policies such that employers are incentivized to hire individuals with disabilities. For example, a mother stated how difficult it has been for her to find a job for her son, a 21-year old with autism and intellectual disability. Specifically, she stated:

I have been trying at the low level to even reach out to my village. My son is migrating out in November and I'm looking for a job for him and I have reached out probably to 80% of the businesses in town. No responses. You know, nobody wants to hire,

get involved. So, I actually reached out to the village and to the mayor's assistant...I have yet to receive a call back.

To address the unemployment issues, participants reported that adult service policies should incentivize employers to hire individuals with disabilities. A mother of a 21-year-old reported, "I would like to see incentives for employers to consider hiring adults with disabilities for competitive employment."

Finally, three themes were less common: legalizing medical marijuana, providing transportation, and increasing respite funding. Only one participant reported each theme. For example, a mother stated that giving her son medical marijuana reduced his aggressive behaviors. She stated:

I had been begging for it [medical marijuana] for sixteen years when all hell broke loose at our house...I gave him [state legislator] a picture of Luke [son] with his eyes swollen, bloody and hence that was the time he went in the hospital with restraints....and it [medical marijuana] has made a big difference...I don't want other families to go through what we had to go through so I am hoping that you will pass a law to allow kids with autism to have medical marijuana.

One participant also indicated their offspring needed transportation support. A mother of transition-aged child with multiple disabilities shared:

I am looking to get some help with not only getting a job but with transportation as I live in an area which is split between two villages and cannot get transportation even find a ride to take him from one area to another even within a three mile radius.

Finally, one parent reported that there should be increased funding for respite provided by adult service policies. A parent of an 8-year-old with multiple disabilities reported, "I would like to see more help in terms of respite for our family and lots of other families out there with kiddos with special needs because it is a very exhausting life that people don't understand unless they experience it. There just never seems to be enough support out there for those of us who need it".

Discussion

In this pilot study, we examined legislative advocacy among parents of youth with multiple disabilities. We had two main findings. First, many participants described largely unsuccessful legislative advocacy experiences and negative perceptions of adult disability policies and services. In contrast to prior research about legislative advocacy and special education (Trainor, 2010; Wright & Taylor, 2014), most of the participants in this study had experiences with their legislators. However, many participants reported that their advocacy did not yield positive effects. Further, consistent with prior research about family perceptions of adult disability services (Taylor et al., 2017), many participants had negative perceptions of adult disability services, including that the options were low quality, limited in choice, and inappropriate (e.g., institutional settings). Notably, while participants were looking ahead to engaging with the adult service delivery system,

these findings align with the experiences of parents of young adults with pervasive support needs who had recently transitioned to the adult service system (Rossetti et al., 2015). In that study, parents reported they were more involved than they anticipated, were unprepared for their roles as advocates in the adult system, and resorted to inappropriate (e.g., specialized) programs and placements to meet safety and other basic needs due to concerns. Altogether, these findings suggest that intervention research may be needed to help parents effectively advocate for legislative change to improve adult disability policies and services.

Second, parents of children with multiple disabilities have important input that should be considered for adult disability policies. Children with multiple disabilities often have complex support needs that require additional consideration by policies and, relatedly, service providers. Consistent with prior research, participants possessed deep knowledge of their children's needs, were aware of which special education and related services were effective, and were advocating for appropriate adult services due to growing concerns about deficiencies in the adult system (Rossetti et al., 2016). Given that transition planning and the movement to adulthood often requires person-family interdependent planning for youth with multiple disabilities (Kim & Turnbull, 2004), it is unsurprising that parents had suggestions for policy. However, it is important to note that their suggestions were not limited to one particular policy. Rather, participants had suggestions for Medicaid, employer incentives (which could relate to the Workforce Investment Opportunity Act), the Lifespan Respite Care Program, and other policies. Although not always explicitly stated, participants had far-reaching and diverse input.

As a pilot study, there are several limitations to this study. First, there was a small, homogeneous sample for this study. Relatedly, participants expressed interest in a civic engagement training and families were satisfied with school services. However, families from racially diverse backgrounds, who are not interested in such a training and/or are dissatisfied with school services may have different perspectives of their legislators and/or adult disability policies. Altogether, these participants do not reflect the national population with respect to demographics, interest in civic engagement trainings, and satisfaction with school services. Research is needed with more diverse samples to more accurately capture parent perceptions toward adult disability services and legislative advocacy. Also, although the focus groups were held before any content of the training was provided, it is possible that the training influenced the videotaped testimonials of the participants. Further, although no differences were noted in relation to the age of the offspring, it could be that parents of older (versus younger) children have different concerns regarding adult services.

Directions for Research

Research is needed to identify ways to increase legislative advocacy and, perhaps relatedly, change parent perceptions of legislators. Regarding the former, it is also critical to understand whether legislative advocacy efforts are a mechanism for systemic change. Prior studies about parent advocacy for special education services suggest that

certain factors may impact advocacy. Such factors include access to information about the law, the quality of the family-professional relationships, and parent expectations (Trainor, 2010; Wang et al., 2004). From this study, it seems that the nature of the child's disability and, accordingly, support needs could influence parent legislative advocacy.

However, there may also be other factors. For example, the success of parent legislative advocacy may vary by whether the advocacy is with a local, state, or federal legislator. Also, the advocacy may differ by the policy being addressed and the person who is initiating the advocacy effort (e.g., the individual parent, an organization, a school-family collaborative effort). Notably, legislative advocacy reported by parents of children with a range of disabilities was facilitated by relationships with legislators (Burke et al., 2020) and relationships with other parents of children with disabilities, especially when they initiated advocacy as a group (Rossetti et al., in press). By identifying which factors may facilitate legislative advocacy for adult services, we can find ways to ensure parents voice their concerns about adult services to their legislators.

Another implication for research is to identify patterns with respect to desired changes for Medicaid Home and Community Based waivers. Indeed, in alignment with this study, research supports embedding flexibility in such waivers (e.g., Perkins, 2010). However, it is unclear what flexibility may mean to individual stakeholders. There may be patterns among individuals with certain characteristics with respect to flexibility. Parents of multiple adult children with disabilities may request flexibility in terms of having multiple respite workers for each child with a disability (Perkins & Haley, 2010). Parents of children with intellectual disabilities and mental health diagnoses may request flexibility to address cognitive abilities and mental health. By exploring patterns in support needs and flexibility in waivers, we can identify for whom such changes may need to be made.

Implications for Practice and Policy

With respect to practice, schools and parent organizations may consider offering trainings to parents to conduct legislative advocacy about adult developmental disability services and policies. Currently, the adult service delivery system is underfunded, fragmented, and difficult to navigate (Taylor et al., 2017; Larson et al., 2018). For example, different agencies provide unique and, sometimes, overlapping services. Further, each program or policy has differing eligibility criteria making them harder for parents to navigate. Change is needed to improve adult services, especially so positive outcomes for adults with multiple disabilities are no longer so reliant on parent involvement (e.g., problem solving, direct support; Rossetti et al., 2016). As with special education, parents can spearhead such change (Turnbull et al., 2011), if provided with support. Thus, schools and parent organizations may offer materials, trainings, and information to facilitate legislative advocacy among families.

In addition, family input is needed when writing and reauthorizing adult disability policies for youth with disabilities. In particular, input is needed from parents of youth with multiple disabilities. As noted from this study, participants reported that most disability

policies do not consider the unique needs of their children with multiple disabilities. It is critical to solicit the input from these families to ensure that disability policies support all individuals with disabilities across the range of functioning.

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Appendix A

Focus Group Protocol

Introduction/Rapport

- Introduce yourself.
- Briefly describe your connection to the field and the project. Specify your connection to family advocacy especially.

Guidelines

I want to thank all of you for coming. I hope that each of you enjoys our discussion. I'm going to go over some ground rules before we start. We hope that this will be a lively discussion among all of us. We ask that you respect the **confidentiality** of the information that is shared here so that everyone can feel open to exchange your opinions, feelings, and beliefs. We also ask that the information discussed here will stay here and not be shared with others outside of the room. **If you need to get up** in the course of the conversation, feel free to do so. This is an informal discussion, so if you need to leave the room for a while, or if you have to get up and get a drink or you need to move around a little bit because you get stiff, feel free to do that. Last, there are **no right or wrong answers** here. We want to hear different points of view, so if your view on a topic differs from the views of others around the table, we need to hear that too. Group members do not have to agree, but everyone should listen respectfully as others share their views.

1. When you think about adult services, what would you change?
2. Do you feel like you can affect change for your own child's services?
 1. How have you (or could you)?
 2. What are the barriers?
3. Do you feel like you can affect change in the adult disability service system (for other children with disabilities)?
 1. How have you (or could you)?
 2. What are the barriers to affecting systemic change?
4. How do you feel when interacting with professionals (i.e., educators, school administrators)?
 1. Do you initiate contact with school professionals? For what reasons?
 - i. If yes, how did you contact them and what was the result of the contact?
 2. Do you feel that they listen to your concerns?
 3. What barriers do you face in contacting school professionals?
5. How do you feel about legislators (people who write and pass laws, usually politicians and elected officials) and adult disability services?

1. Have you ever contacted a legislator? Why?
 - i. If yes, how did you contact them and what was the result of the contact?
2. Do you feel that they listen to your concerns?
3. What barriers do you face in contacting legislators?
6. How do you feel about this advocacy expectation for parents in special education?
 1. How do you feel about the advocacy expectation for your own child?
 2. How do you feel about the advocacy expectation for systemic change?
7. What are your perspectives about adult services and your advocacy roles?
 1. Do you feel like you will be able to affect change?
 2. What do you think the barriers will be?
8. Is there anything else you would like to add?

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