

Canterbury Research and Theses Environment

Canterbury Christ Church University's repository of research outputs

http://create.canterbury.ac.uk

Please cite this publication as follows:

Patton, S. and Hutton, E. (2016) Parents' perspectives on a collaborative approach to the application of the Handwriting Without Tears programme with children with Down Syndrome. Australian Occupational Therapy Journal, 63 (4). pp. 266-276. ISSN 0045-0766.

Link to official URL (if available):

http://dx.doi.org/10.1111/1440-1630.12301

This version is made available in accordance with publishers' policies. All material made available by CReaTE is protected by intellectual property law, including copyright law. Any use made of the contents should comply with the relevant law.

Contact: create.library@canterbury.ac.uk



Parents' perspectives on the application of the Handwriting Without Tears® program with children with Down Syndrome

Background

Contemporary Occupational therapy practice emphasises family-centred care collaborative practice with families and other agencies to support childhood occupations. This paper presents parental perspectives on three-way collaboration between teachers, parents and an occupational therapist in the application of the Handwriting Without Tears® programme with children with Down Syndrome.

Methods

Within a larger mixed methods study, 46 parents completed purpose-designed preintervention questionnaires and 44 parents completed post-intervention questionnaires. Additionally, 6 parents attended a post-intervention focus group to gather parental perspectives. Analysis was based on descriptive analysis of numerical data and content analysis of open-ended questions and focus group content.

Findings

Enablers of parent-child engagement identified were the parent-child friendly aspects of HWT®, the continuity of practice by teachers, parental perception of having less pressure to ensure practice at home and the ongoing support and guidance of the occupational therapist. The occupational therapist was reported as essential to encouraging both teacher and parent involvement in implementation of the programme. Barriers to child-parent engagement included fluctuations in child illness, mood, attention and finding time due to commitments to other programmes.

Conclusions

HWT® provided a useful parental teaching method when delivered using a collaborative approach. The three-way collaboration was important to enabling parent-child involvement in implementing the programme at home, as was the inclusion of group intervention. This approach warrants further investigation. Findings have the potential to inform clinical guidelines related to intervention with

children with Down Syndrome and their families and to inform pre and postgraduation education related to collaborative practice with families.

Key Words

Parents, children with Down Syndrome, collaboration, Handwriting Without Tears®

Introduction

Handwriting can be considered a childhood occupation which is performed as part of the school day, in homework assignments and everyday activities within the home/community. As a complex perceptual-motor skill, the process of developing handwriting skills requires much practice to reach competency. Handwriting development can be particularly challenging for children with Down Syndrome (DS) (Trenholm & Mirenda, 2006; Turner & Alborz, 2003) and they typically require additional practice to develop fine motor skills, such as handwriting (Sacks & Buckley, 2003). Therefore, collaboration between parents, teachers and occupational therapists is required to ensure additional practice opportunities when implementing intervention to promote the occupation of handwriting with children with DS.

Despite there being a plethora of occupational therapy literature to be found on the topic of handwriting, no studies were found investigating parental perspectives on teacher-parent-occupational therapist collaboration in handwriting interventions in general or in relation to handwriting interventions involving specific interventions for children with DS. Additionally, there is a dearth of literature on parental perspectives of home programs addressing handwriting.

Children with DS typically present with difficulties in handwriting abilities according to teacher/parent report (Trenholm & Mirenda, 2006; Turner & Alborz,

2003). Empirical studies, although limited in number would also indicate difficulties with handwriting legibility (e.g. Bird, Cleave, White, Pike & Helmkay, 2008). Other potential challenges to children with DS that may impact on their ability to engage in learning a complex skill such as handwriting include; poor auditory memory, language difficulties including understanding verbal instructions, poor short term memory, poor task perseverance and poor attention to task (All Party Parliamentary Group on Down Syndrome (APPGDS), 2012; see Daunhauer & Fidler for review). Teaching approaches advocated for children with DS include; use of hands on materials, opportunities for repeated practice, use of visual and kinaesthetic materials (APPGDS, 2012; Wolpert, 2001). HWT® is a handwriting curriculum that incorporates hands on multi-sensory materials and fun activities, uses a step-by-step approach to teaching letter formation and provides lots of opportunities for repeated practice. The structure and content of the program could potentially help address learning needs for children with DS. While positive findings are reported in robust studies with typically developing children (e.g., Roberts et al., 2014), evidence with children with special educational needs (SEN) is lacking and hampered by small sample sizes although improvements are reported (e.g. Owens, 2004).

The active involvement of parents and children with disabilities in occupational goal setting and intervention is integral to contemporary occupational therapy process models (e.g. Occupational Therapy Intervention Process Model, Fisher, 2009), is considered best practice and important to effective outcomes (Dunn,2011). Additionally, parental involvement in their child's education, along with parental collaboration with teachers and allied health professionals to address SEN, is emphasized in national and international education policy (e.g. Individuals with Disability Education Improvement Act: IDEA, 2004; Children and Families Act,

2014; Education of Persons with Special Educational Needs: EPSEN Act, 2004). Within an Irish context, collaborating with parents and teachers to meet SEN is challenging as occupational therapists are not school based and are employed by the Department of Health with ongoing issues regarding lack of adequate therapist resources to address SEN (NCSE, 2013). A variety of terms have been used to describe collaborative approaches with families. However, the key aspects of these include; the unit of intervention is the family and the child; shared decision making and goal setting; equal partnership and services consider family needs (Hanna & Rodger, 2002). Common collaborative service delivery approaches with parents and children include home programs; parental education and direct intervention, either individual or group.

Facilitators of the abilities of parents to adhere to home programs provided by occupational therapists include; the children's responses to the program, how effective the parents perceived it to be and how applying the program merged with family routines (Segal & Beyer, 2006, Cantu, 2003; Jaffe et al., 2010). In a recent study by Novak (2011), parents of children with cerebral palsy reported benefits using partnership home programs, which consisted of establishing a therapist/parent collaborative relationship, involvement of parents and children in goal setting, tailoring intervention to fit with family routines, ongoing support and re-evaluation. A key element in motivating parents to persist was therapist ongoing support. The desire for support from occupational therapists as well as wanting 'individualised and flexible interventions' (p.8) has also been reported (Hessell, 2004). Reported barriers to parental involvement centred on finding time to implement the program identifying balancing the demands of therapy and everyday life as key difficulties (Wiart, Ray, Darrah & Magill-Evans 2010). In relation to parent education, parents report

expectations of gaining information from occupational therapists (Hessell, 2004) and they value therapists' technical expertise (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004). Coaching and support in home program implementation is reported as important to home program effectiveness (Novak & Berry, 2014).

In summary, the active involvement of parents in intervention with children with disabilities is considered important to effective outcomes and advocated as best practice in occupational therapy. Therefore, the gathering of data on parental perspectives is essential to inform practice. Parental perspectives on specific occupational therapy intervention approaches for supporting handwriting development in children with DS are lacking. This paper presents parents' perspectives on a collaborative intervention approach involving children with DS, their teachers, parents and an occupational therapist (first author) in the application of (HWT®),

The specific research questions addressed:

- 1. What are the perspectives of the parents on the application of the HWT® program?
- 2. What factors impact on the practical implementation of the HWT® program?

Given the sparse literature available on this subject, the findings are highly contemporary and relevant to current occupational therapy practice and future research.

Methods

Context of Study

The findings presented here were attained within the specific context of the application of the HWT® program with children with DS using a three-way

collaborative approach involving parents and teachers of the children and an experienced occupational therapist (first author). The first author is an experienced children's occupational therapist having worked 12 years in community settings. The principles of family-centred care were applied in the collaborative approach adopted. The approach included: parent/teacher education in the use of HWT®, joint collaborative goal setting, child/parent participation in group intervention (7 sessions) and provision of ongoing support during implementation of programmes at home and school (eight months). Refer to table 1 for details. [Insert Table 1 here]

The findings presented here were gathered as part of a larger mixed methods doctoral study (Patton 2011). Mixed methods were used to gather parent perspectives, this included a purpose designed questionnaire completed by parents post intervention and a post intervention parent focus group.

Participants

Data was collected in 2006–2007. Purposive sampling was used, with 46 parents and their children participating in the study. In collaboration with Down Syndrome Ireland (DSI), a voluntary parents organisation, study information was sent to parents of children with DS aged 5 to 10 years 11 months within three counties in the Republic of Ireland from their database. A cover letter and parent and teacher information leaflets were provided by the first author to DSI, who sent the information to parents identified from the database. Inclusion criteria included that all children had a diagnosis of DS, attended mainstream schools, and were perceived to have handwriting difficulties by parents and teachers. Both parents of each child were invited to participate. Ethical approval was obtained from DSI research committee and Trinity College Dublin, (conforming to the provisions of Declaration of Helsinki).

Informed voluntary consent was obtained from the parents at the start of the study. To address anonymity, codes were assigned to individual participants and placed on questionnaires prior to their issue. Participant codes were also used when analysing and reporting focus group data.

Instrumentation

Questionnaire sections to specifically identify parental perspectives on the usefulness of the content and structure of HWT ® practical issues impacting implementation and limitation of HWT® were developed. The development process involved detailed analysis of the content and structure of HWT® and findings from content analysis of field notes. The first author recorded field notes in a research log following each direct (e.g. during training sessions) and indirect (e.g. telephone conversation) interaction with parents and children. Issues raised by parents, for example, child illness impacting on implementation, were then included in questionnaires to identify their frequency. Refer to Appendix II for sample questions from the questionnaire. Best practice questionnaire design was applied including use of open and closed questions, 5 point Likert scales and provision of adequate space to encourage participant response (Polgar & Thomas, 2000). To facilitate honest expression of positive and negative opinions, the questionnaire design included a section of potential limitations of the using the HWT® and space to provide comments was given in all sections of the questionnaire. All questionnaires were reviewed by 2 academic staff. The pilot questionnaire was piloted with 3 parents selected by stratified random purposive sampling to represent children at different prewriting/handwriting ability levels. Face and content validity was addressed during the process of questionnaire development by the iterative process of reviewing literature, use of themes identified in content analysis of field notes, seeking feedback on content from 2 academic experts and requesting written and verbal feedback from parents during piloting. Construct validity was addressed by an iterative process of literature review and recording of field notes from parent interactions during intervention to reflect relevant dimensions of research questions. The analysis of field notes recorded during intervention and the tracking of reasoning for individual question inclusion and scoring structure of questions during development of the instrument was recorded in detail in the research log. Questionnaire reliability was not addressed.

The first author devised a semi-structured format of focus questions. Focus group questions were designed to further investigate parental perspectives on the use of HWT® and to investigate the collaborative approach. Questions were reviewed by two academic staff members. Refer to Appendix I for questions. [Insert Appendix I here]

Data collection and Analysis

Questionnaires

Questionnaires with cover letters and stamped addressed envelopes were posted to parents at the end of intervention. Forty-four parents completed and returned the post-intervention questionnaires (97%, n=46). Descriptive statistics (frequencies and percentages) were used to analyse questionnaire data along with content analysis of open-ended question responses.

Focus Groups

Sampling for focus group was by stratified random sampling whereby 8 parents of children at different levels of prewriting/handwriting ability where selected. The questions were provided to parents prior to the focus group. Six parents attended and

participated in the focus group on the day. The parent focus group was conducted post-intervention by an academic staff member. The focus group was recorded and transcribed verbatim. A content analysis of focus group data was completed and themes independently validated by an academic staff member. Member checking was completed with all participants in agreement with themes identified. This process addressed the issues of credibility and dependability in relation to validity.

Triangulation of data from questionnaires and focus group was completed to identify themes related to the application of HWT®, collaboration and practical issues of implementation.

Results and Discussion

Due to the mixed methods data collection and triangulation of results, this article will present and discuss the findings alongside the findings in this section. Triangulation and analysis of themes revealed two categories: enablers and barriers to active parent-child engagement with the programme. Refer to Table 2 for a summary of themes. Of note is that many of the themes identified below from parent data were also identified by teachers in the larger study (for details see Patton, Hutton & MacCobb, 2015)

Background Information

All parents were of Irish origin, with the exception of one set of parents of African origin. While both parents were invited to be involved, in most cases the mother was the most active in programme implementation and collaboration with the therapist. Fifty per cent of parents (n=46) reported having received no occupational therapy services prior to the study. A majority of those who had received occupational therapy intervention previously reported this as consisting of a short block of weekly intervention (4-6 one hour sessions only). These findings support other teacher/parent

report of difficulties accessing occupational therapy services for assessment and support for children with DS in an Irish context (Egan and Doherty, 2009).

Enablers of parent-child engagement:

Parent-Child friendly aspects of HWT®.

A number of features of the content and structure of HWT® supported parent-child engagement with the program. In the questionnaires, over 85% of parents (n=44) identified the variety of manipulative materials in HWT® as "very useful" or "useful" for teaching their child. Parents reported that the manipulative materials facilitated child interest (n=7) and enjoyment of participation (n=6). Over 85% of parents (n=44) who used the various writing materials also reported that they found them "very useful" or "useful" for teaching their child. For details of parent perspectives of the usefulness of specific activities using manipulative materials and writing materials refer to Table 3. [Insert table 3 here]

A majority of parents reported most aspects of the structure of HWT® "very useful" or "useful" for teaching their child, in particular, the step-by-step approach to letter formation and the language used. Refer to Table 4 for details. [Insert Table 4 here] These themes also emerged in the post-intervention focus group:

"Participant C: even if they couldn't write they could put say the wooden pieces together or they could put the strips onto the magnetic board— there are three things before they actually put the pencil on the page — she loved that - the routine of doing the three different things..."

"Participant C: And I found the terminology that was used was very goodso it was very specific -you knew that you had to go straight down and then
around or whatever so you were given the down and the up.."

Participant C: Yes it was very consistent – she knew what you were saying – you are going to do a "c" for example – do your "c" as in do your curve, a small curve or a big one or whatever it was and it was a very consistent terminology that was used"

Parents in the focus group also reported how the child perceiving the program as fun and therefore being willing to engage in the program as helpful.

"Participant E: He has been finding it interesting – today it's part of play for him...."

"Participant F:so we started the programme, he loved it and it was great fun and even though he was being taught to write – he just thought it was great fun and he took to it great...."

Similarly, Segal and Beyer (2006) had reported the child's responses as a significant factor, reported by parents, in influencing their ability to continue with home programs. Parents in the focus group identified that the program content being at the right level with tasks broken down for the children was helpful to their ability to implement HWT®. Also, the fact that HWT® was easy to implement in short periods of time and the manageable amount of program homework were important to parent ability to implement it.

"Participant E: I don't know if other people feel this way but there is always the feeling of guilt that you are not doing enough — I always feel that constantly and now in the corner is the blackboard and you can say — do a straight line there and do a whatever — do a small curve and I feel better about

it and he is delighted too... Yes it's kind of learning on the go – you can pick it up and drop it easily- it's very easy to use it anywhere really" [Focus Group] Studies have discussed the need for home programs to be integrated with the daily routines (Cantu, 2003) and that this will not occur if home programs are 'too burdensome' (Segal & Beyer, 2006, p.508). This links to other findings by Hessell (2004), who concludes that parents wanted 'individualized and flexible interventions' from occupational therapy interventions. Similarly, parents have reported wanting manageable active involvement in therapy that did not demand too much time and energy (Egilson, 2011). Interestingly, two parents in the focus group commented on feelings of guilt about the amount of time spent on extra work to develop child skills. This suggests that therapists recommending home programs should consider emotional resources/issues of parents, an issue highlighted by contemporary authors (Jaffe & Cosper, 2015). In the questionnaires, all parents (n=42) who responded reported that they would continue to HWT® with their child in the future and 43 (98%, n=44) reported that using HWT® had increased their understanding of how to teach prewriting/handwriting skill to their child.

Collaborative approach.

Collaboration with teachers: Continuity and 'Taking the pressure off'.

All parents (n=44) reported that the involvement of the teacher was relevant to their ability to implement HWT® with their child. Qualitative comments from the questionnaires indicated that this was important to ensure consistency in approach (n=7), provide follow up on the program (n=7) and to the success of using the program (n=6). Participants in the post-intervention focus group reported that the involvement of the teacher was essential:

"Participant C: I don't think it would have worked without that three-way thing...."

They reported how teacher involvement ensured continuity of work on the program.

This was a support to parents as:

"Participant B: ... because he is after doing it in school so we didn't have to put so much emphasis on getting this done and getting that done at home – whereas if he wasn't in the humour you would say – right - you did this today in school and he would be doing it again tomorrow...

Participant A: I think it was great that the schools participated in it too – it took the pressure off us, feeling you had to do it as part of homework.

All participants: Yes it did" [Focus Group]

This suggests that the teacher involvement was very important in supporting parents as well as enabling HWT® to be carried out in home and school contexts. The integration of programs into family routines is considered a key element in supporting parent's abilities to adhere to home programs (Cantu, 2003; Segal and Beyer, 2006). The fact that the program was part of homework meant that it was potentially integrated immediately into a family routine. This, along with teacher involvement, created flexibility within the implementation which appears to have eased emotional demands on the parents.

Collaboration with therapist: Ongoing support and guidance.

The themes of support and practical guidance emerged as the benefits of collaboration with the therapist in the focus group. The therapist role in supporting the parents was important in facilitating parent involvement and in empowering parents.

'Participant C: I also feel that you start out with great intentions...And if you let it slip at all it can slip for a couple of days or a week or whatever during the holidays — or whatever it might be and you need to know that you are going to have someone there — even if its just to say -come on!...you just need that there — or even to ask you — have you done this or you have that to do? You just need that there, no matter what it is' [Focus Group]

This highlights the fact that direct contact with the therapist was essential to facilitating continuity of parent involvement. This is consistent with previous research where professional encouragement and ongoing therapist support during implementation of home programs has been identified as helpful by parents (Fox et al., 2002; Hurley & Lynch, 2008; Novak, 2011). In relation to practical guidance, the parents valued the practical advice, such as specific ideas on improving pencil grip. Support and practical guidance have been reported as expectations that parents have of what occupational therapists can provide along with parents valuing the provision of specific information and technical expertise when working with therapists (Blue-Banning et al., 2004; Hessell, 2004). Interestingly, parents also reported that therapist involvement was essential to facilitating the teacher involvement. This highlights the importance of the occupational therapy role in coordinating collaboration with teachers and parents and acting as advocate for child and parent.

Collaboration with therapist: Group intervention.

Parent perspectives articulated in the focus group suggested that the direct intervention offered by the occupational therapist during group sessions was beneficial to the parent and child. Parents identified the group tasks being at the child's level as beneficial. The group provided a setting where the children could have a sense of achievement, build confidence and develop skills.

"Participant F: They were delighted with themselves. I think it was a confidence builder for them...and if they didn't get it right the first or second time they would know after that- I have it done now- I have done it..." [Focus Group]

Parents also valued the group sessions as a forum where the children could work alongside other children which provided practice opportunities and was motivational for the child. These findings concur with parent perspectives on group intervention outcomes reported previously to include; facilitating self esteem, having positive effects on motivation, and promoting social participation and wellbeing (Camden, Tetreault, & Swaine, 2012). One disadvantage of the group sessions identified by one parent was that it could encourage modelling of unwanted behaviour by the child. Parental report suggests that the use of occupational therapy group intervention was beneficial to supporting active child engagement and participation and can therefore be considered an important part of intervention for supporting the occupation of prewriting/handwriting development in school-aged children with DS.

Overall, the findings indicate that the elements included in the approach were valuable to supporting the parents and child's engagement with intervention. In particular, the three-way collaboration was considered essential to the success of implementation and the occupational therapy coordination of this was seen as essential by the parents. Yet, substantial therapist time and expertise are required to support the elements of the collaborative approach used in this study (which involved parent/teacher education, collaborative goal setting, ongoing support, and coordination as well as group intervention with child and parents). Authors have acknowledged the amount of time required to negotiate collaborative goals and advocated for the need for the creation of a work culture, proper resource allocation

and supportive working environment to enable staff to engage in family-centred care (Kolehmainen et al., 2012; Brewer et al., 2014).

This is challenging in an Irish context where occupational therapists are not typically employed by Department of Education, there is a lack of interagency infrastructure to support occupational therapist/teacher collaborative work practices and there are ongoing issues regarding lack of adequate therapist resources to meet needs of children with SEN (NCSE, 2013). Additionally, a lack of training in initial education has been identified in particular in relation to early intervention and family-centred care where therapists report low levels of competence in US study (Campell, Chiarello, Wilcox and Milbourne, 2009). Contemporary authors are advocating for the need for continuing professional development post graduation on collaborative goal setting and facilitating a collaborative process (e.g. Brewer et al., 2014).

Barriers to parent/child engagement

In the questionnaire, 35 parents (81%, n=43) indicated that time available was a relevant factor in their ability to implement HWT®, with 20 parents (45%, n=44) indicating that the programme being time consuming to use was a limitation.

"Sometimes it was a struggle to get work carried out [using HWT®] - just due to general family commitments and having to work with other siblings...day to day life..." [Questionnaire]

Parents reported finding it difficult to fit in the program along with other homework (n=9) and the child's involvement in a number of other programs (n=18) also limited their ability to implement HWT®. Having to meet demands of other family commitments and other siblings' needs were also identified as relevant. This difficulty

with balancing the demands of therapy with everyday life was also identified by parents in recent research (Wiart et al., 2010). This highlights the importance in clinical practice of co-ordinating with other service providers to negotiate timing of delivery of intervention so as not to create additional burdens on families. This would be especially important with children with complex needs, such as DS, who often require input from a number of allied health professions. Additionally, over a third of parents (n=44) identified child illness as a barrier and over 90% of parents (n=43) identified both fluctuations in attention span and mood of child as factors impacting negatively on their ability to implement the program. These findings concur with previous findings of poor attention span, lack of perseverance at tasks, cognitively avoidant behaviours in children with DS (Daunhauer & Fidler, 2011). Child tiredness was also commented on as a barrier by parents in the questionnaires (n=10) and the focus group.

"Participant F: ...but some days he would come home and he was too tired to do three sets of homework even though it was only three bits" [Focus Group]

Implications for Practice and Research

While the findings cannot determine how effective HWT® was at improving handwriting, they provide a useful insight into parent's perspectives of using the programme. The findings suggest that HWT® was a useful teaching method for parents and that the structure and content of HWT® facilitated active parent-child engagement in handwriting intervention. Also, the findings suggest that the three-way collaborative approach involving teachers, parents and an occupational therapists working together was a key factor in enabling parents to sustain involvement and

engage their child in implementing HWT®. This suggests key roles for occupational therapists in empowering parents and coordinating the involvement of parents and teachers in supporting the occupation of handwriting at home and school environments. The findings could inform clinical practice guidelines for occupational therapists working with children with DS and their families. Further research is needed to explore in more depth the dynamics that underpin teacher-parent- therapist collaboration during intervention for handwriting and the application of HWT® with children with SEN.

Barriers to active child and parent engagement, including specific issues for children with DS and time limitations, are important factors for therapists in practice to consider when planning intervention. In particular, these findings suggest that further investigation into understanding the emotional demands on families when implementing home programs and strategies to empower families is warranted. An example could be integrating aspects of HWT® into other routines besides homework, such as playtime with siblings and other home writing activities (e.g. signing a birthday card) to help empower families' involvement in intervention. The need to include siblings and facilitate parents to recognise the value of child involvement in routines relating to writing in the home have been highlighted as areas that need to be addressed to develop more occupation based practice (Gerde, Foster & Skibbe, 2014; Jaffe & Cosper, 2015). Finally, given the need for professional education in relation to collaboration and working with families identified in recent commentaries (e.g. Brewer et al., 2014) the findings can inform and pre- and post-graduation education in relation to working with families and children with DS.

Limitations

Findings are limited in their generalisability as the data collected was in relation to an intervention applied using purposive sampling within a specific context and sample size was small. No standardised questionnaire was available and the questionnaire used was purpose-designed by the first author. The researcher and therapist roles in the study were performed by the first author. This potentially increased bias as this relationship with parents may have caused their reluctance to express honest opinions. The researcher took the following measures to mitigate the impact of this. The focus group was conducted by an independent academic member of staff and member checking completed. Also, questionnaires were coded and posted to parents for completion to reduce the direct contact with the researcher/therapist during completion. These measures may have assisted expression of positive and negative opinions by parents.

Conclusion

The parents reported that the content and structure of HWT® facilitated their implementation (e.g. easy to implement, step by step approach) and child engagement (e.g. variety of manipulative materials facilitated interest and enjoyment). Barriers to engagement in implementation reported included; finding time among other family demands, involvement in other programs and issues with child health, child attention span and mood. Two key aspects of the collaborative approach were identified by parents. Firstly, the continuity of practice achieved by teacher involvement eased implementation demands on parents. Secondly, the importance of the ongoing support, guidance and coordination of the three-way collaboration of parent, teacher therapists by the occupational therapist was highlighted. The findings provide information to inform clinical practice, future research and pre- and post- graduation education for occupational therapists in the under-researched area of intervention to

support the development of prewriting/handwriting skills in school-aged children with DS.

Acknowledgements:

The authors wish to acknowledge the kind participation of families and teachers involved in this study. Acknowledgement is given to Dr Siobhan Mac Cobb, Trinity College Dublin, Ireland, for her supervision during doctorate completion. Additionally, the initial assistance of Down Syndrome Ireland (DSI) in recruitment of participants and financial support given by DSI and Froebel College of Education, Dublin, is gratefully acknowledged.

References:

All Party Parliamentary Group on Down Syndrome (APPGDS) 2012. Down Syndrome: good practice guidelines for education. APPGDS, Retrieved 23 January 2015 from http://www.ucl.ac.uk/educational

psychology/newsletter/resources/APPGDS_guidelines.pdf

for collaboration. Exceptional Children, 70(2), 167-184.

Blue-Banning, M., Summers, J. A., Frankland, H. C., Nelson, L. L., & Beegle, G. (2004). Dimensions of family and professional partnerships: Constructive guidelines

Bird, E., Cleave, White, D., Pike, H., & Helmkay, A. (2008). Written and oral narratives of children and adolescents with Down Syndrome. Journal of Speech, Language, and Hearing Research, 51(2), 436-450.

Brewer, K; Pollock, N & Virginia Wright, F. (2014). Addressing the challenges of collaborative goal setting with children and their families. Physical and Occupational Therapy in Pediatrics, 34 (2): 138-152.

Camden, C., Tetreault, S., & Swaine, B. (2012). Increasing the use of group interventions in a pediatric rehabilitation program: Perceptions of administrators, therapists, and parents. Physical & Occupational Therapy in Pediatrics, 32(2), 120-135.

Campell, P. H., Chiarelo, L., Wilcox, M. J., & Milbourne, S. (2009). Preparing therapists as effective practitioners in early intervention. Infants and Young Children, 22(1), 21-31.

Cantu, C. (2003). Occupational Therapy at home: Helping parents follow through with home programs. The Exceptional Parent, 33(12), 28-30.

Children & Families Act 2014: Part 3 children & young people in England with SEN or Disability. Retrieved 23 January 2015, from

http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted.

Cohn, E. S. (2001). Parent perspectives of occupational therapy using a sensory integrative approach. The American Journal of Occupational Therapy, 55(3), 285-294.

Daunhauer, L. A., & Fidler, J. F. (2011). The Down Syndrome Behavioral phenotype: Implications for practice and research in occupational therapy. Occupational Therapy in Health Care, 25 (1), 7-25. doi:10.3109/07380577.2010.535601

Department of Education and Science (DES). (2004). Education of Persons with Special Educational Needs Act. Dublin, Ireland: The Stationary Office.

Doherty, U., & Egan, M. (2009). Report on educational provision for pupils with Down Syndrome in mainstream primary schools in Limerick city and county.

Limerick, Ireland: Curriculum Development Unit.

Dunn, W. (2011) Best practice occupational therapy for children and families in community settings, (2nd ed). Thorofare, NJ: Slack Inc.

Egilson, S. T. (2011). Parent perspectives of therapy services for their children with physical disabilities. Scandinavian Journal of Caring Science, 25, 277-284.

Fox, L., Vaughn, B. J., Wyatte, M. I., et al. (2002). 'We can't expect other people to understand': Family perspectives on problem behaviours. Exceptional Children, 1-450.

Gerde, H.K., Foster, T.D., & Skibbe, L.E. (2014). Beyond the pencil: Expanding the occupational therapist's role in helping young children to develop writing skills. The Open Journal of Occupational Therapy, 2(1), 1-19.

Hanna, K., & Rodger, S. (2002). Towards family-centred practice in paediatric occupational therapy: A review of the literature on parent-therapist collaboration.

Australian Occupational Therapy Journal, 49, 14-24.

Hessell, S. (2004). 'Entering the unknown?' Identifying potential expectations of paediatric occupational therapy held by families. New Zealand Journal of Occupational Therapy, 51(2), 5-10.

Hurley, N & Lynch, H. (2008). The use of home programs in children's occupational therapy: Bad habits or good practice? The Irish Journal of Occupational Therapy, 36, 3, 12-21.

IDEA. (2004). Individuals with Disabilities Education Act of 2004: Pub. L. 108-466.

Jaffe, L., & Cosper, S. (2015). Working with families. . In J. Case-Smith & J. O'Brien (Eds.), Occupational therapy for children and adolescents, (7th ed. pp.129-162). St. Louis, Mo: Elsevier Mosby Inc.

Jaffe, L., Humphry, R., & Case-Smith, J. (2010). Working with families. In J. Case-Smith & J. O'Brien (Eds.), Occupational therapy for children, (6th ed). St. Louis, Mo: Elsevier Mosby Inc.

Kolehmainen, N., MacLennan, G. Ternent, L., Duncan, E. A. S., Duncan, E. M., Ryan, S. B., et al. (2012). Using shared goal setting to improve access and equity: A mixed methods study of good goals intervention in children's occupational therapy. Implementation Science, 7, 76.

National Council for Special Education (NCSE). (2013). Supporting students with Special Educational Needs in schools. NCSE policy advice paper no.4. Retrieved 22 January 2015 from

http://ncse.ie/wpcontent/uploads/2014/09/Supporting_14_05_13_web.pdf.

Novak, I. (2011). Parent experience of implementing effective home programs.

Physical & Occupational Therapy in Pediatrics, 31(2), 198-213.

Olsen, J. (2003). Handwriting Without Tears (9th ed.). Potomac, MD: Author.

Polgar, S. & Thomas, S. A. (2000). Introduction to research in the Health Sciences (4th Ed.). London: Churchill Livingstone.

Roberts. G. I., Derkach-Ferguson, A. F., Siever, J. E., & Rose, M. S. (2014). An examination of the effectiveness of Handwriting Without Tears® instruction.

Canadian Journal of Occupational Therapy, 81 (2) 102-113.

doi:10.1177/0008417414527065

Sacks, B. & Buckley, S. (2003) 'What do we know about the movement abilities of children with Down syndrome?'. Down Syndrome News and update, 2 (4), 131-41. Segal, R., & Beyer, C. (2006). Integration and application of a home treatment program: A study of parents and occupational therapists. American Journal of Occupational Therapy, 60(5), 500-510.

Trenholm, B., & Mirenda, P. (2006). Home and community literacy experiences of individuals with Down syndrome. Down Syndrome Research and Practice, 10(1), 30-40.

Turner, S., & Alborz, A. (2003). Academic attainments of children with Down's syndrome: A longitudinal study. British Journal of Educational Psychology, 73(4), 563-583.

Wiart, L; Ray, L; Darrah, J; Magill-Evans, J. (2010). Parents' perspectives on occupational therapy and physical therapy goals for children with cerebral palsy. Disability and Rehabilitation, 32(3), 248-258.

Wolpert, G. (2001). What general educators have to say about successfully including students with Down Syndrome in their classes. Journal of Research in Childhood Education, 16(1), 28-38.

Appendix: Sample questions post-intervention parent questionnaire

Section 1: How you used the programme with your child

Q.1. The following table lists the contents of the programme. You are asked which you used and how useful it was in teaching your child prewriting/handwriting skills. Please tick the relevant boxes.

Content of programme	Very useful	Useful	Somewhat	Not at all
If used, please tick relevant box			useful	useful
a. Action songs				
Used □ Not used □ Not applicable □				
b. Language used to teach letter formation				
Used □ Not used □ Not applicable □				
c. Making mat man				
Used □ Not used □ Not applicable □				
d. Drawing lines/ shapes				
Used \Box Not used \Box Not applicable \Box				
e. Making letters using wooden pieces				
Used \Box Not used \Box Not applicable \Box				
f. Making letters using capital letter cards				
Used \Box Not used \Box Not applicable \Box				
g. Making letters using magnetic board				
Used □ Not used □ Not applicable □				
h. Making letters using play dough				
Used \Box Not used \Box Not applicable \Box				
i. Making letters using chalkboard				
Used \Box Not used \Box Not applicable \Box				
j. Completing worksheets in workbook				
Used \Box Not used \Box Not applicable \Box				
k. Forming letters using box outline				
Used \Box Not used \Box Not applicable \Box				
l. Writing name using box outline				
Used \Box Not used \Box Not applicable \Box				
m. Writing letters using grey box paper				
Used \Box Not used \Box Not applicable \Box				
n. Writing using double lined copy/ paper				
Used \Box Not used \Box Not applicable \Box				

Q.2. How useful were the following aspects of the programme to your teaching of prewriting/handwriting with your child? Please tick appropriate box and provide a comment below. For any that do not apply to, please write 'Does not apply' in the comments section.

	Aspects of programme
	a. Variety of manipulative materials
Comments	Very useful □ Useful □ Somewhat useful □ Not at all useful □
Comments	
b. Language used	in programme to help letter formation and/or positioning letters between line
Comments	Very useful □ Useful □ Somewhat useful □ Not at all useful □
Comments	
_	
	c. Step by step approach to teaching letter formation
a	Very useful $\ \square$ Useful $\ \square$ Somewhat useful $\ \square$ Not at all useful $\ \square$
Comments	
	d. Teaching order of letters
	Very useful $\ \square$ Useful $\ \square$ Somewhat useful $\ \square$ Not at all useful $\ \square$
Comments	
influenced	following is a list of external factors that may or may not have I your ability to use the programme with your child. Please tick as to your situation and provide additional information in comments
Factors that	influenced use of programme
	s level of health.
Relevant	Not relevant □
Comments	
b. The amoun	nt of time available for individual work using the programme with the
child.	
Relevant	Not relevant □
Comments	
c The variety	
c. The variety	y of materials contained in the programme
Relevant \square	y of materials contained in the programme Not relevant

d. Involvement of teacher in carrying	out the programme		
Relevant \square Not relevant \square	out the programme		
Comments			
Comments			
e. Other external factors, please speci	fy		
	nd their interest in prewriting/handwriting ing statements, please tick the answer which		
best describes your ch			
a My child anions using the hands	on materials in the programme		
a. My child enjoys using the hands Strongly Agree □ Agree □ U	Juncertain ☐ Disagree ☐ Strongly disagree ☐		
the programme.	of prewriting/ writing activities since starting Uncertain □ Disagree □ Strongly disagree □		
c. My childs' mood at the time of the completed using the programme.	he session has a significant impact on work		
	☐ Uncertain ☐ Disagree ☐ Strongly		
disagree disagree	□ Uncertain □ Disagree □ Strongly		
d. My childs' attention span at the time of the session has a significant impact on			
work completed using the programme. Strongly Agree □ Agree □ Uncertain □ Disagree □ Strongly disagree □			
Section 5: Overall views of the programme			
O 10. The following table lists rescribe factors which were horse limited			
Q.10. The following table lists possible factors which may have <u>limited</u> your			
ability to use the programme. For each statement, please tick whether it was a			
limitation or not and give details in the comments section.			
r • •4 4•	G		
Limitation	Comments		
a. Having to learn about a new			
programme			
Limitation \Box Not a limitation \Box			

b. Different approach to teaching handwriting Limitation □ Not a limitation □	
c. Other children in class following another prewriting/handwriting scheme Limitation Not a limitation	
d. Emphasis on teaching of capitals first in the programme Limitation □ Not a limitation □	
e. Time consuming to use	
Limitation □ Not a limitation □	
f. My child was involved in a number of other programmes, e.g. speech programmes, numecon Limitation Not a limitation	
g. Other, please specify	
8 - 1 - 7 F	

Table 1: Details of collaborative process between occupational therapist/parents and teachers

and teachers			
Pre-intervention	Telephone consultation with parents and teachers to gain		
collaboration	baseline child information.		
Pre-intervention	Pre-intervention child assessment involving measures of		
assessment	child pencil grasp, posture, visual motor integration,		
	handwriting abilities; and parent interview. Parents were		
	present throughout assessment. Assessments occurred at		
	local community centres to facilitate ease of access for		
	parents.		
Pre-intervention	Parent/teacher training in use of HWT® after child		
training	assessment		
Pre-intervention	Individualised child goals were established collaboratively		
Goal setting	between parents, teachers and therapist (face-to-face		
	meetings) and agreed by all.		
Group sessions x 7	Group sessions occurred in local community centres to		
fortnightly	facilitate ease of access for parents.		
	Groups consisted of 2-3 children matched at same		
	developmental handwriting level.		
Parent-child active	Parents were present in the group sessions and observed		
engagement	and actively participated in HWT® activities with their		
	children under the guidance of the therapist.		
Parent/teacher guidance	Therapist demonstrated the techniques used in HWT® to		
	the parents within the group setting and answered any		
	queries as appropriate. Liaison with teachers occurred		
	formally on 2 occasions by telephone and when requested		
	during their implementation of HWT®.		
Goal adjustment	Progress reviewed at start of group and short term goals		
, v	adjusted with parents to suit family routines. Liaison with		
	teachers by telephone/email occurred as required to		
	coordinate review/adjustments to goals.		
Advice	Advice regarding adaptations to improve body posture and		
	pencil grasp was provided as appropriate.		
Ongoing support	Therapist encouraged telephone/email contact by parents		
	and teachers with queries throughout duration of study.		

Table 2: Parent focus group question outline

Question 1	What were the benefits, if any, to you as a parent to being
	involved in carrying out the programme?
Question 2	What were the practical issues for you of carrying out this
	approach?
Question 3	The study involved a collaborative approach between you as a
	parent, your child's teacher and an Occupational Therapist.
	What were the benefits, if any of this approach?
Question 4	Did you find it beneficial to attend the occupational therapy
	group sessions with your child?

Table 3: Enablers/barriers of parent-child engagement with $HWT \mathbin{\rlap/} {}^{\tiny \textcircled{\tiny \$}}$

Enablers	Data Source
Parent-friendly aspects of HWT®	
Variety of materials	Q/FG
 Step by step approach 	Q/FG
Content at right level	FG
Child willing to engage with programme	FG
Easy to implement	
Child-friendly aspects of HWT®	
• Fun	Q/FG
 Fosters interest 	Q/FG
Simple language	Q/FG
Collaboration with therapist	
 Ongoing support 	FG
Guidance	FG
 Promoting teacher involvement 	Q/FG
Collaboration with teacher	
Key to workability	FG
 Continuity of practice 	FG
 Took pressure off parents 	FG
Group Intervention	
 Tasks at the child's level 	FG
 Children could have a sense of achievement, 	FG
build confidence and develop skills	
 Forum where child could work alongside other 	FG
children, which was motivating	
Barriers	
Finding time/family commitments	Q
 Finding time/child involved in other 	Q
programmes	
Child illness	Q
Fluctuating mood of child	Q/FG
 Fluctuating attention span of child 	Q
Child tiredness	Q/FG

Note: Q = Questionnaires, FG = Focus Group

Table 4: Parent perspectives: Usefulness of activities using manipulative and writing materials contained in HWT®

Manipulative Materials	How many used item n (%)	Very useful – Useful n (%)	Somewhat – Not at all useful n (%)
Making letters with wooden pieces	43 (98)	37 (86)	5 (12)
Making letters using chalkboard	42 (95)	37 (88)	3 (7)
Making mat man with wooden pieces	37 (84)	35 (95)	1 (3)
Action songs	34 (77)	26 (76)	8 (24)
Making letters using magnetic board	35 (80)	29 (83)	5 (14)
Making letters using capital letter cards	26 (59)	19 (73)	4 (15)
Making letters using play dough	21 (48)	17 (81)	4 (19)
Writing Materials			
Completing worksheets in workbook	41 (93)	37 (90)	1 (2)
Drawing lines/shapes	37 (84)	32 (86)	4 (11)
Forming letters using box outline	32 (73)	28 (87.5)	3 (9)
Writing name using box outline	26 (59)	23 (88)	2 (8)
Writing letters using grey block paper	22 (50)	19 (86)	1 (5)
Writing letters using double lined paper	20 (45)	18 (90)	1 (5)

Note: Not all items were applicable to all children, dependant on program level

Table 5: Parent perspectives: Usefulness of structure of HWT® for teaching

Table 3. Farcht perspectives.	Very useful - useful		
	very userur - userur	Somewhat – not at all	
		useful	
	n (%)	n (%)	
Language Used	38 (95.00)	2 (5)	
n = 40			
Step by step approach	42 (100)	0 (0)	
n=42			
Teaching order of letters	26 (74.29)	9 (25.71)	
n=35			
Teaching Shapes	27 (79.41)	7 (20.59)	
n=34			
Boxes/grey block structure	30 (93.75)	2 (6.25)	
n=32			
Double line structure	15 (93.75)	1 (6.25)	
n=16			
Teacher guide layout	37 (90.24)	4 (9.76)	
n=41			
Child workbook layout	33 (80.49)	8 (19.51)	
n=41			

Note: Not all items were applicable to all children, dependant on program level